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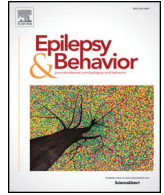
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Experiences and perspectives of stigmatization and discrimination against people with epilepsy in Accra, Ghana

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ABSTRACT

A qualitative research approach was utilized to investigate experiences and perspectives of people with epilepsy (PWE) and key informants. Twenty participants (14 PWE and 6 key informants) were purposively selected as participants for the study and in-depth interviews were conducted. The interviews were audio-recorded, transcribed, and analyzed to identify emerging themes that addressed objectives of the study. The findings indicated that PWE and key informants included in this study perceived epilepsy as a spiritual, curable, and medical condition. Besides, it was found that for fear of being infected by epilepsy, some people stigmatized and discriminated against PWE. Additionally, the study provided evidence that PWE were stigmatized and discriminated against in employment and intimate relationships with the incidence of seizures being the major reason. Furthermore, the study revealed that PWE adopted various strategies (concealment, not responding to demeaning comments made by people, involvement in religious activities, and joining support groups) to manage stigma and discrimination. The findings suggest the need for public education about epilepsy in order to modify people's beliefs and views about the disease. Moreover, the provision of counseling services would help enhance the psychosocial wellbeing of PWE.

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1. Introduction

Epilepsy, a chronic brain disorder, is a public health issue worldwide. While its prevalence and incidence vary between low- and high-income countries, it is a condition that has no geographic, national, or ethnic boundaries [1]. The disease affects about 50 million people globally, and 80% of the affected people live in developing countries [2–4]. Epilepsy is among the dominant neurologic conditions that cause disability and socioeconomic burden [1].

It is a complex disease in view of the fact that different conditions are known to be risk factors as the susceptibility to the disease may be partly genetically determined and could interact with brain maturation and environmental factors [4]. The disease is characterized by persistent derangement of the nervous system due to abrupt excessive disorderly discharge of the aggregate group of neurons from the cerebrum [5]. The excessive discharges result in disruptions of sensation, convulsive movement, or psychic function with or without loss of consciousness [5,10]. It affects all age groups, racial and social class, as well as physical, psychological, and social lives of affected people [5,9].

Given that it is a chronic and debilitating condition, epilepsy impacts not only those affected by the condition, but also their families and caregivers [6]. In many developing countries, including Ghana, the condition

is mostly untreated because of inadequate or unavailable health delivery systems, dearth of trained personnel, shortage of essential drugs, and traditional beliefs and practices that usually do not consider epilepsy as a treatable disease [4]. Thus, many people with epilepsy (PWE) are unable to lead normal lives because they do not receive treatment [7,8]. However, if people are provided with appropriate and timely caring services, the appearance of epilepsy-related complications could be reduced or prevented [9,10]. One of the major factors that normally affects PWE negatively is the social environment [9] as most often, social support is unavailable, and thus, they are likely to be picked on [9,11], particularly through stigmatization and discrimination.

A plethora of studies (e.g., [5,12,13,14]) have demonstrated that illness-related stigma could have adverse effects on the health and wellbeing of affected people, such as PWE. The concept of stigma is often viewed as an attribute that is greatly demeaning and has the potential to result in psychopathology in PWE [15,16]. Given the nature of the disease and its associated label, it has been described as a stigmatizing condition with distinction [14,17,18] because many PWE perceive themselves as defined by their diagnosis [14]. In order to avoid being stigmatized, some PWE, as well as their families are compelled to rebuff the label of epilepsy or try to renegotiate another one [19], and these could have adverse effects on diagnosis, treatment, and drug compliance. Compared with other chronic medical conditions, the impact of epilepsy on the daily and quality of life of PWE is huge since the related stigma generally creates a vulnerability of its own [4].

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Besides, stigma impacts PWE because they have a relative position of subordination based on the fact that their condition is socially devalued [20,21], which could expose them to negative treatment, particularly by people who do not or have inaccurate information about the disease. Many people with stigmatizing health conditions, like epilepsy report feelings of stigma through at least three fundamental stigma routes – enacted stigma, anticipated stigma, and internalized stigma [20,21], which is usually reflected at the micro, meso, and macro levels [20]. Enacted stigma is the extent to which PWE have experienced acts of discrimination due to their condition [19,22]. It is the actual occurrence of discrimination, both formal and informal, against PWE solely on the basis of their diagnosis [23]. Individuals who are stigmatized because of epilepsy usually have higher rates of fear, despair, and decreased life satisfaction [22,24].

Anticipated stigma describes how stigmatized persons envisage that they will experience prejudice and/or discrimination from others in the future [20,21], and this could drive PWE into the shadows [25]. People who experience a high degree of anticipated stigma may have difficulty disclosing their status because of fear of rejection [20,21]. Internalized stigma is the extent to which PWE experience hurting internal struggle with the disease, even without any encounter with stigmatization [23]. As a result, they are likely to sanction harmful beliefs and feelings that are linked to PWE [21,26]. Internalized stigma is frequent and could lead to feelings of shame, concealment of the condition, and a self-fulfilling prediction [23]. In addition, some people without the disease may be stigmatized because of their association with stigmatized persons, and this is referred to as courtesy stigma [15]. Thus, the moral burden attached to epilepsy does not only affect PWE, but also their close associates (e.g., siblings and parents), especially when people perceive the disease as being genetic, which may threaten familial desires and other life chances [23].

Stigma that is associated with chronic diseases is among the challenges to treatment because health-related stigma is a complicated issue that is often based on particular characteristics of the health problem and could also compel affected people, such as PWE to hide the condition [27,28]. Stigmatization usually results in discrimination, and many PWE have been targets of harmful behaviors in various areas of life over many centuries and in several cultures [4,29], as the disease is linked with outdated and sometimes insensitive and preposterous views that tend to be stigmatizing [27]. Historically, epilepsy was viewed as a sacred disease resulting from attack of the body by a god that threw a person on the ground, convulsed him/her, and then quickly restored the person's consciousness [12]. In addition, epilepsy is traditionally perceived as a curse by ancestral spirits or attributed to possession by evil spirits and witchcraft [30]. Also, in some developing countries, it is believed that the disease is communicable and spreads through bodily fluids like urine and saliva that are excreted during convulsion [12]. Furthermore, because of the unpredictability of seizures, and social exclusion emanating from negative attitudes toward them, PWE are often stigmatized [31,32].

Unlike other chronic diseases like hypertension or diabetes, the symptoms and signs of epilepsy are mostly visible, erratic, and difficult to comprehend by many frightened onlookers who may not understand why a person would behave in a strange manner, which makes seizures look like confusion against cultural norms [33,34]. The social stigma and discrimination often cause more distress for PWE than the seizures [5]. Generally, efforts aimed at reducing the burden of epilepsy in developing countries are constrained by sociocultural factors that (a) sustain the undesirable attitudes about the cause and treatment of epilepsy and (b) underpin negative discriminatory and stigmatizing practices [35]. Negative beliefs that are usually associated with epilepsy have contributed to many people with the condition being shunned, stigmatized, and misjudged [12] in various spheres of life, such as education, employment, and marriage [5,13]. Stigma and discrimination, which may be either formal or informal, manifest or hidden, deliberate or inadvertent, contribute to the compromised employment position of PWE [36–

39]. Also, PWE may conceal their illness from their spouses before marriage because of fear of discrimination, as well as its consequences and influence on marriage negotiations [40,43].

Even though extant research studies conducted in other countries have reported on stigma and discrimination among PWE, in Ghana, there is a dearth of such studies. Thus, this study aimed to investigate experiences and perspectives of stigmatization and discrimination against PWE in Accra, Ghana. Specifically, the study sought to explore (a) views about epilepsy among PWE and key informants, (b) experiences and perspectives of PWE and key informants regarding stigmatization and discrimination, and (c) how PWE and key informants handled stigma and discrimination. This information is useful because people affected by epilepsy and their associates are likely to encounter various modes and levels of stigma, which could adversely affect their physical and mental health. While reasons for stigmatization may be different across communities and cultures, barriers such as stigma against PWE could prevent them from accessing and receiving the necessary assistance [32,45,46]. Also, evidence shows that inaccurate views and traditional beliefs could result in the denial of timely and appropriate treatment for PWE and their families [40], especially in countries (e.g., Ghana) where resources for treatment, rehabilitation, and research are deficient [41]. Moreover, since few qualitative studies in Ghana have focused on PWE, their caregivers and health professionals, this study contributes to filling this gap.

2. Material and methods

2.1. Study design

A qualitative research approach was employed for this study given that the design allowed the researchers to explore sensitive, subtle, and complicated issues, as well as understand the wider social contexts of study participants [45–47]. Thus, recognizing the sensitivity of the research topic, a qualitative research paradigm was considered suitable for this study. Besides, utilizing a qualitative research paradigm, the researchers were able to engage a small number of participants extensively to develop patterns and connections of meaning with the aim of gaining individual values rather than generalize findings [48,49]. The qualitative research methodology was appropriate for this study because it allowed the researchers to gain in-depth information about the phenomenon [50,51]. Thus, listening to participants' responses was essential to appreciating their experiences and views regarding epilepsy-related stigma and discrimination.

2.2. Participants and study area

The research sample included people who resided in the Greater Accra Region of Ghana and were 18 years and above. A total of 20 participants were selected, which comprised fourteen PWE (7 males and 7 females) and six key informants (two caregivers of PWE, two nurses from the epilepsy unit of a health facility in Accra, and two officials from BasicNeeds-Ghana). In a qualitative research, it is typical to study few individuals or cases, as phenomena only need to occur once to be part of the analytical map [52,53]. In addition, data saturation could happen within the first twelve interviews and subsequently; very little new phenomena may emerge [54]. People living with epilepsy were recruited because they were likely to have experiences of stigma and discrimination.

Furthermore, the key informants were included in the study because of their interaction with PWE in the course of discharging their respective duties. The PWE included in the study (a) had lived with the condition for at least one year, (b) received services from BasicNeeds-Ghana, and (c) could share their experiences with researchers. With regard to the key informants, they had worked with PWE for a minimum of one year. The study was conducted in Accra, the capital city of Ghana. The researchers contacted PWE with the assistance of BasicNeeds-Ghana, which is a registered nongovernmental organization that works with

PWE in selected communities. The organization identifies and renders services to PWE and caregivers in the areas of healthcare, financial assistance, and skills acquisition in various trades. The organization supports PWE to live and work in their communities and also works with polyclinics where PWE receive healthcare services.

2.3. Data collection and analysis procedures

The study was approved by the Faculty of Social Sciences Board of the University of Ghana. Before commencing the data collection, the directors at BasicNeeds-Ghana were contacted, and permission was obtained to visit the support group of PWE. Afterwards, the researchers were invited by the directors to visit the support group during their meetings in order to provide information about the research, interact, and build rapport with PWE and their caregivers. In addition, permission was sought from the medical superintendent of the health facility where the nurses were recruited for the study. Potential participants (PWE, caregivers, nurses, and officers from BasicNeeds-Ghana) who were willing to participate in the study at the time of the visits provided their contact details, and appointments were scheduled for in-depth interviews (IDIs) to be conducted at times and places convenient for potential participants.

Individual IDIs were conducted to collect data for the study. Open-ended questions were used to explore participants' experiences and views about stigma and discrimination. This offered them the opportunity to interact privately with the researchers and also to express themselves freely. Likewise, the open-ended questions allowed the researchers to (a) probe participants' responses for clarification and (b) deliberate on emerging issues extensively. The purpose of the study was explained to each participant before the data collection started, and they were individually informed of their right to withdraw their participation at any point during the study. Participation in the study was voluntary and potential participants were assured of confidentiality regarding information they provided. Both verbal and written informed consents were obtained from all participants. Participants completed a short demographic questionnaire prior to commencement of the interviews.

The interviews were conducted in English and Twi (the local dialect of the researcher and participants). The language used for each participant was based on his/her preference. This approach was appropriate because it limited the extent to which some linguistic nuances could be muffled [55]. The individual IDIs were audio-recorded with the approval/consent of participants, and notes were taken as well. A topic guide was developed by the researchers and used for the data collection. Each interview lasted between 45 and 60 min and were conducted at places that were convenient for participants. Questions asked included "What is epilepsy?"; "Have you ever felt you or your clients was/were treated unfairly because of the disease?"; "In what areas are PWE stigmatized and discriminated against?"; and "How do PWE manage stigma and discrimination?"

After the data collection, the audio recorder was replayed many times for the purpose of transcribing the data. The interviews conducted in Ghanaian languages were translated into English and some quotations were edited grammatically, but the researchers ensured that the content was preserved. The data were coded in order to mask the identities of participants and were stored in a secure location. The researchers independently extracted and coded broad themes from the transcribed data by taking into consideration statements of meaning that were present in the data. The sets of codes and themes developed were interpreted, discussed, and agreed upon by the researchers. Emergent themes and categories were used to address objectives of the study. The transcriptions were augmented by the field notes taken during IDIs.

3. Results

3.1. Demographic characteristics of participants

The ages of PWE ranged between 20 and 55 years (four: 20–30 years, five: 30–40 years, two: 41–50 years, and three: 51–55 years).

The age categories suggest that many of the PWE included in this study were youthful, and they provided information regarding their experiences about the disease. In terms of marital status, it was found that ten PWE were single, three divorcees, and one was widowed. Thirteen PWE were Christians, and one was a Muslim. In terms of educational background, all PWE had high school education or some level of it. However, many of them could not complete their various levels of education. This corroborates findings of extant studies, which reported that PWE were stigmatized and misjudged in key areas like education [5,13].

In addition, the findings indicated that seven PWE were self-employed, six were unemployed, and one was an employee. Those who were self-employed were engaged in petty trading and menial jobs. All PWE were experiencing generalized seizure type and had lived with the disease for 20 years and over. The age range of the key informants was between 30 and 60 years. The nurses and BasicNeeds-Ghana officers had been working with PWE for more than five years. The caregivers had been providing support for PWE since they were diagnosed with the condition — 20 years and over.

3.2. Views about epilepsy

The participants included in this study had different ideas about epilepsy. They viewed epilepsy as a spiritual, curable, and medical condition. For those who viewed the disease as a spiritual condition, they explained that many people were afflicted by the disease through the spiritual actions of family or community members. Besides, it was considered as a punishment for the atonement of sins. A participant who believed his family member struck him with the disease had this to say:

"Everyone tells me this is a spiritual sickness... my grandfather afflicted me with this shameful disease to stop me from becoming the great person in my family. My grandfather, a herbalist, requested that my parents brought me for a cure but they declined... he would have made my condition worse".

[(PWE 13)]

Another person with epilepsy who thought some community members afflicted him with the disease in order to prevent him from being prosperous in life noted:

"I think it is a spiritual disease that some people in this community have afflicted on me to prevent me from succeeding in life since they envy my family's good image. Do I look like somebody who has epilepsy? No, I do not... some people saw my bright future and decided to give me this disgraceful disease which has no cure".

[(PWE 3)]

Also, a caregiver was of the view that epilepsy was a spiritual disease because no cure has been found for it, in spite of the medications, asserted:

"I think it is a spiritual disease that is why as at now no medicine can cure it, despite consultations with traditional healers and spiritual churches at the early stages and now being put on medications by medical doctors. I am sure there is a spiritual force behind this disease and as such it is only God who can be of help".

[(Caregiver 1)]

With regard to atonement of sins, a participant explained:

"My situation is serious because I think I am being used to pay for certain sins my late father might have committed as a chief prior to his death. Also, I am paying for the sins of my grandmother who, my mother told me, refused to show appreciation to the gods when they gave her a child upon her request. I think the gods should have visited their anger on them and not me".

[(PWE 4)]

According to some participants, the disease could be cured and as a result, many PWE and their families consulted traditional and spiritual healers:

“My mother took me to a pastor who informed me of the person who afflicted me with this disease. He asked me to put coins on my bed, sleep on them and offer them as gifts to people, which I did. The seizures stopped, but I had a relapse few months after I had started learning a trade. I was sent to another pastor for prayers, but the seizures did not stop”.

[(PWE 12)]

A key informant who had concerns about PWE and their families using hospitals as the last resort, because of their belief in cure and healing from traditional and spiritual healers revealed:

“Before they come to the hospital, they would have consulted many traditional healers and prayer camps. They think it is not a medical condition, but a spiritual condition that needs spiritual healing. Such beliefs affect early diagnosis and treatment, which are crucial in the healthcare delivery process for PWE. There should be more education on epilepsy as a medical condition”.

[(Nurse 2)]

While some of the PWE viewed epilepsy as a spiritual illness, others described the disease as a medical condition. It was therefore emphasized that the most effective way to manage the disease was through consistent taking of antiepileptic drugs (AEDs). An official from BasicNeeds-Ghana explained: *“Epilepsy is a complex disease that is treated with hospital medications. It is caused by prolonged labor that cause head injuries and damage to the brain of a baby. It is also caused by convulsive fevers due to untreated malaria”.* Relatedly, a male person with epilepsy disclosed: *“Whether or not epilepsy is a spiritual illness, I don't want to go there. I don't believe in spirituality. When I visited the hospital, the doctor said it is caused by something in my brain and not witches or wizards”.* Moreover, a key informant who placed emphasis on influencing factors, echoed:

“Some predisposing factors contribute to epilepsy, such as improper handling of babies delicate heads during birth or just after delivery, especially by traditional birth attendants either during or right after delivery. The effect of this is brain injury with signs and symptoms that are shown through epileptic seizures. Tumors that grow in the brain can also cause seizures, as well as sudden withdrawal symptoms from alcohol intake and certain medications”.

[(Nurse 1)]

3.3. Anxious about infection, stigma, and discrimination

Although epilepsy is not a contagious disease, some participants thought that it was. In this regard, such people were concerned about being infected and therefore avoided contact with PWE. Remarking on the issue, a female person with epilepsy explained: *“Whenever I experience seizures, people do not assist me. They think it is an infectious disease so they do not want to come close to me for fear of being infected by my saliva. I am usually left alone”.* A male person with epilepsy also indicated: *“My sisters with whom we live together believe the disease is infectious so they do not associate with me. They do not take care of needs, including food and would not have anything to do with me in order to avoid infection”.* These beliefs limited the extent to which PWE received assistance when they experienced seizures. In addition, a caregiver noted:

“I have a shop and he usually accompany me when I go there for business. Anytime I am busy and I ask him to assist customers, they refuse to buy from him and insist that I sell to them. He is very friendly, but most often, people do not allow him to either touch or play with their children. People do not want him to come close to them... these are happening because people think epilepsy is contagious”.

[(Caregiver 1)]

Moreover, a key informant provided a description of how people avoided getting in contact with a PWE because of the condition. Such experiences could limit the extent to which PWE could interact with people:

“One of my patients was engaged in petty trading at a school. One day she had a seizure while selling to the students. Afterwards, the students refused to buy from her for fear of becoming infected. Even her family members who live with her refuse her cooking bowls and plates, as well as other items in the house. They believe in sharing items with her, they risk becoming infected with the disease”.

[(Nurse 2)]

3.4. Seizure-related stigma and discrimination

Many of the participants expressed concern about how some PWE were mocked and laughed at by community members because of their experiences of seizures at public places. A female person with epilepsy explained how she felt embarrassed after a seizure episode:

“Anytime I had a seizure outside my home, people came around to have a look at me and ridiculed me. None of them offered assistance until I became conscious... for me, this is stigma and discrimination”.

[(PWE 5)]

Similarly, another participant disclosed:

“Sometimes, I experience seizures outside home and people around tell me, after recovery, how dangerous it was. I feel ashamed and uncomfortable when I pass by the same route of the incident the following day. What makes the situation worse is that I hear people talk and point fingers at me in reference to the seizure incident. Some people refer to me as an insane person... even at church, people behave the same way toward me — they are all the same”.

[(PWE 4)]

Emphasizing how seizure-related stigma and discrimination forced PWE to lead secluded lives, an official from Basic-Needs Ghana asserted:

“Regarding the condition, PWE think they should not socialize with people due to fear of experiencing seizures in public, especially at public gatherings. This could lead to psychological issues... many of them have low self-esteem”.

Another participant explained how PWE experienced seizure-related stigma and discrimination at health facilities. Although health professionals were expected to be more accepting of PWE, some of them behaved otherwise:

“At times, when PWE are in a queue at the out-patient department for medical review, some of them experience seizures. When that happens, some of the nurses at the health facility do not assist them but would rather request ua to attend to the patient. They would not even provide first aid before we go in to help with the situation. This is a form of stigma and discrimination... they refer to PWE as ‘your people’ as if they are not patients of the health facility”.

[(Nurse 1)]

3.5. Unemployment, stigma, and discrimination

Finding and maintaining jobs were mentioned as crucial for PWE since they needed money to purchase their medications (when the hospitals run out of medications supplied by the government) and take care of their personal and family needs. However, both the PWE and key informants included in the study were concerned about society's perceptions about the condition, which adversely affected many PWE's chances of securing and maintaining jobs. One person with epilepsy revealed: *“I was working, but one day I experienced a seizure at work. It was*

not serious because I was able to continue with my work after the seizure, but I was sacked and I have become jobless since then". Adding his voice an official from BasicNeeds-Ghana noted: "Most often, PWE do not get jobs because of the system, as people are not educated on how to manage PWE they do not want to employ them." Sharing her experience, a female person with epilepsy asserted:

"While my educational background is good, finding a job is difficult; I have tried many times without success, employers do not employ me because of my disease. As I may experience seizures on the job, I disclose my condition to potential employers, but being truthful has affected me negatively. Employers think I would infect other employees with the disease. Besides, they believe I would not to perform up to expectation or that being an epileptic, I am incompetent".

[(PWE 11)]

For the few PWE who were able to secure jobs, they indicated that they concealed their health condition before they were employed, as one participant narrated:

"I did not disclose my health status before I got the job and I still have not. If I did, they would not have employed me. One day, I felt like I was about to experience a mild seizure. I quickly found a quiet place to lay down for some time. My supervisor inquired about what was wrong with me, but I did not give him details about my condition. He would have sacked me immediately if he had known my condition".

[(PWE 6)]

Some PWE concealed their condition in order to secure jobs were fired after their condition became known to their employers:

"I was working with an educational institution and I had seizure on the job. When I became conscious, my supervisor said I was epileptic. Although I told them I did not know about it, the authorities maintained otherwise and fired me. I did not disclose my condition initially for fear of failing to get the job. Before I was employed at the institution, I had moved from one place to another in search of job, but to no avail. Wherever I went, I was denied one because of the disease. Now, I am without a job".

[(PWE 14)]

3.6. Intimate interactions, stigma, and discrimination

Generally, people with stigmatized conditions, especially in Ghana may find it challenging to make and to keep intimate relations because of people's misconceptions and beliefs. People's beliefs about the disease being spiritual or contagious could serve as obstacles to finding suitable partners. A male person with epilepsy noted: "No lady would marry me with such a burden. I had a girl friend who did not know I had epilepsy. When she became aware, she ended the relationship. I don't think I would get married in the future." Likewise, one caregiver disclosed:

"Of course, on the issue of marriage and relationships, it is a great concern. Because of stigma, no man wants to marry a lady living with epilepsy; no matter how beautiful she is. Notwithstanding many assurances and explanations that PWE can live normal lives, they are usually perceived as sick people".

[(Caregiver 2)]

Furthermore, it was found that while some PWE were fortunate to be married, they were later divorced or became separated because of frequent seizures. A participant described her experience:

"The disease has become a padlock to my happiness and joy. If not, I would have been a married woman by now. I met an elder of a church, we dated and got married. We had a child, but when he became aware that I had the disease as a result of frequent seizures, he informed his mother who advised him to end the marriage and he did".

[(PWE 14)]

While some PWE had challenges with their marriage, a female person with epilepsy indicated that her husband of many years did not divorce her although he was aware of her health condition:

"We got married even though my partner knew that I was epileptic. I started having frequent seizures when I was pregnant with my second child. At a point my husband wanted to divorce me, but he was advised by his family members against his decision. He continued the marriage and we had four children before he passed on. After his death, I have decided not to get married again to avoid troubles from any man who might marry me and divorce me later upon realizing that I have epilepsy".

[(PWE 8)]

3.7. Managing epilepsy-related stigma and discrimination

Participants included in this study described different ways that PWE managed stigma and discrimination, and these were as follows: concealment, not responding to offensive comments made by people, involvement in religious activities, and joining a support group. A male person with epilepsy indicated that he concealed from people his disease in order to avoid losing friends and other close associates: "I don't disclose my condition to people, if they get to know, they will shun my company and not even buy from my mother's shop again — where I get money for my up-keep". Also, a female person with epilepsy revealed:

"Nobody is aware of my disease so people buy the items I sell. Some parents even ask me to help their children cross the road when they are going to and from school. If people knew about my illness, they will discontinue buying from me and parents would stop me from assisting their children".

[(PWE 2)]

Other people living with epilepsy managed stigma by rebuffing derogatory comments made by people about their health condition, as a caregiver revealed: "Many people in our communities do not have correct information about the disease, they make derogatory comments about PWE. Since it is difficult to change peoples' beliefs about PWE, it is best to avoid arguing with people". Another female person with epilepsy had this to say:

"I have decided not react to irritating comments about my disease from people in the community when I go about my daily activities. No matter what we do, they will gossip about PWE and call us names. The least I care about are these negative comments. It is better for me if I do not pay attention to what others say about me".

[(PWE 4)]

According to some PWE, they relied on faith and trust in God and also attended church to fellowship with people who they believed were less likely to stigmatize and discriminate against them even if they became aware of their health status, as a female person with epilepsy noted: "The almighty God is the creator of the universe and everything within it. He knows about my disease and my troubles. Even my family members are unwilling to accept and interact with me as they do with other family members". Another participant disclosed:

"The messages I hear from church help me to stay positive even if people say or behave negatively towards me because of my condition. It is God and His word that strengthen me in the face of the mistreatments that are meted out to me by others. I have faith and trust in God so I am less fearful. I feel happy when I meet brethren at church and we interact as one family".

[(PWE 2)]

Moreover, joining a support group helped some PWE to manage stigma and discrimination. Members of the support group shared knowledge and ideas about their condition, especially the challenges they encounter. A male person with epilepsy disclosed: *“The support group is very beneficial. During our meetings, the advice from colleagues gives me hope that all is not lost and that I am not alone... I am able to live with people who mistreat me”*. A key informant who confirmed the immense contributions of the group to members explained:

“They share experiences on best practices; especially in the case of caregivers as to how to give PWE medicine, particularly those who are totally dependent on caregivers. Some would even advise that the best medicine-taking compliance is to conceal it in their food. Also, when they meet, the PWE see themselves as not being alone, but have the support of others to help them cope with the situation”.

[(Official 2, BNG)]

4. Discussion

This study sought to explore perceptions and experiences of stigma and discrimination among PWE and key informants. The findings indicated that participants had diverse views about epilepsy. Notable among these was the belief that the disease is spiritual, and this has been reported in previous studies [12,30], which found that epilepsy was perceived as a sacred disease or a curse by evil spirits. Linked to this was the view that the disease was curable because some people hold the belief that gods and evil spirits could cure PWE if they are consulted. However, some people believe that epilepsy is not treatable because of traditional beliefs and practices [4]. Thus, the perception is that the disease cannot be treated, but possibly could be cured. Undeniably, certain outdated traditional beliefs, shame, as well as lack of appropriate information about epilepsy could influence how PWE are perceived and treated in the society.

Also, evidence showed that PWE were stigmatized and discriminated against through these stigma routes: enacted, anticipated, and internalized [20,21]. Some PWE experienced stigma because of the wrong perception that epilepsy was a contagious disease. It was found in other developing countries that epilepsy was perceived as a communicable disease, which is transmitted through bodily fluids like urine and saliva that are secreted during convulsion [12]. Based on these beliefs, PWE are often shunned and ill-treated, which could result in stigmatization and discrimination. Generally, PWE are mistreated by people who do not or have inaccurate information about epilepsy. Compared to other chronic medical conditions, the impact of epilepsy on the daily lives of PWE is enormous because epilepsy-related stigma normally creates a unique vulnerability [4].

Most often, PWE are stigmatized and discriminated against because of the unpredictability of seizures and social marginalization, which arise from negative attitudes toward them [31,32]. It is important to note that most often, stigma and discrimination cause more sorrow for PWE than the seizures [5]. Even though the social environment plays a crucial role in the lives of PWE [9], sadly, some of them reported of being deserted when they experienced seizures. This challenges the morals and values of the Ghanaian society that prides itself as caring, especially in times of sickness. In many African societies, including Ghana, many people depend on each other in times of need, which makes it arduous to be shunned because of illness. In such societies, a culture of belonging is upheld in view of the fact that individuals' identities are tied to their roles in families and communities [56,57].

While getting and retaining jobs, as well as intimate relationships, were essential for PWE, these were far from reality because many of them experienced stigma and discrimination, and this was confirmed by key informants. Generally, PWE are stigmatized and discriminated against in important areas of life like employment and marriage as a result of negative beliefs that accompany the disease [5,12,35]. Most often,

employment opportunities are limited for PWE because they are misjudged. Even for the few PWE who were employed in the past or who currently have jobs, their plight was no better. Those with jobs were fired when their health status became known, and those currently employed had to conceal their health status since they anticipated that they could be fired if they disclosed their condition. Employment-related stigma and discrimination may be felt hard in areas or times of high unemployment [36,37,39], as it is the case of Ghana, where unemployment rate is very high.

In terms of intimate relationships, the situation of PWE could be challenging because in the Ghanaian culture, traditional marriage is typically between two families, who usually conduct informal background checks on prospective couples, which could negatively affect the chances for PWE. In view of the fact that PWE were stigmatized and discriminated against in major areas of their lives on a daily basis, they handled the situation through different ways – concealment, ignoring offensive comments made by people, joining support groups, and involvement in religious activities. This is crucial because once people become aware of PWE's surviving strategies, they would appreciate the resilience and determination of PWE and possibly understand and have a positive attitude toward PWE.

It is important to emphasize that many PWE consent to the misconceptions and views people have about the disease, especially the belief that epilepsy is contagious, and therefore, PWE should not be touched or provided assistance during seizures. This could negatively impact on their self-esteem and may lead to severance from social life and self-isolation. [22,58]. Of major concern is the fact that many PWE are likely to internalize stigma or anticipate being stigmatized or are discriminated against and therefore keep their diagnosis a secret. This could contribute to many PWE to not seek or to access medical treatment very late in the course of the illness, which may result to health and psychological complications.

4.1. Limitations of the study

The findings of this study cannot be generalized because it was based on PWE and caregivers who resided in Accra and received services from BasicNeeds-Ghana. In addition, the study focused on key informants from two institutions. Nonetheless, the findings may be applied to similar situations [59,60]. Furthermore, the findings provide evidence regarding stigma and discrimination experiences and views as well as key informants. Moreover, future studies that consider PWE and key informants outside Accra would be useful.

5. Conclusions and implications

People living with epilepsy and key informants included in this study had different opinions about epilepsy. Thus, the disease was viewed as a spiritual, curable, and medical condition. Besides, the condition was considered to be contagious, which resulted in unfavorable attitudes, particularly stigmatization and discrimination toward PWE. This is mostly due to the lack of knowledge and traditional beliefs about the disease, which make it challenging for many people, including PWE to disregard the role of the supernatural in the cause and treatment of diseases like epilepsy in Ghana. Accordingly, the provision of public education about the causes and treatment of the disease is crucial since it would help many people to modify their beliefs about epilepsy and reduce the extent to which they stigmatize and discriminate against PWE.

In addition, the study provided evidence that PWE were stigmatized and discriminated against in employment and intimate relationships. It is important to emphasize that the experience of seizures was the main reason why PWE were stigmatized and discriminated against, and this could have negative effects on their daily activities. Many PWE would therefore be compelled to limit their interactions with people since they may be nervous about experiencing seizures. In order to reduce

the extent to which they were stigmatized and discriminated against, PWE employed these following strategies: concealment, ignoring offensive comments made by people, joining support groups, and involvement in religious activities. These approaches notwithstanding, it is imperative that PWE are provided the necessary assistance, particularly counseling that would help strengthen their self-worth and consequently enhance their psychosocial wellbeing. It is hoped that education and counseling would serve as pathways through which the constructed and upheld cultural practices and beliefs about epilepsy could be disputed.

Disclosure and conflict of interest

There is no conflict of interest.

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