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Literature Review

Living with Neurological Disorders of Ataxia and Epilepsy in Ghana: Patients' Adaptations

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Abstract

Background and Objectives

The need exists for researchers to study the backgrounds of neurological disorders patients and how they cope with their symptoms. Patients often go unnoticed in present-day technological Ghana because of wrong knowledge and attributions. There exists a lack of knowledge, so people wrongly interpret their activities as the workings of some spiritual powers. The study's objective is to investigate the neurological disorders of Ataxia and Epilepsy in Ghana and to focus on the hereditary transmission of the diseases rather than spiritual causes.

Method

The study employed the convenient sampling technique and the snowball method to gather the sample. In this case, we did not use the probability sampling methods in this significant research to muster the sample. The study used the clinical interview method, open-ended and structured interviews, naturalistic observation, and biographical data to accomplish its aims. These interviews took place in the hospital environments, home settings, and public/street settings of various patients.

Results

Patients are aware of people's attributions of these disorders to spiritual beings. There are spirits, witches, alcoholic behaviors, wizards, distant relatives, and other relationships that cause these disorders. Some of these patients agree with the genetic-biological and physical-injuries hypotheses of origin. But, they do concur that this would not change their perception and handling of their disorders.

Conclusion

Appropriate knowledge concerning the sources of their disorders would pave way for meaningful handling and treatment of the disorders. Was this supported in our study? On the part of the patients, we did not see any available data supporting these assertions. Patients want their disorders to be carefully treated and given important focus. They care less about the causes of their disorders whether they are genetics, injuries, or the spiritual causes they mostly alluded to in the investigations. The results of this research are more beneficial to caregivers and practitioners than patients, the latter who suffer stigmatization and lack of self-esteem, and a host of other psychological problems. These prevent them from enjoying healthy and normal lives and, coupled with humiliation, disturb their self-esteem and human dignity.

Introduction

There are many neurological disorder patients in Ghana, but patients do not always consult biomedical practitioners in modern hospitals because of wrong diagnoses, which they receive from uninformed traditional practitioners, pastors, and priests. The country lacks modern doctors/practitioners with the requisite education and specialization to handle and treat these disorders. This is all the more reason why patients flock to the religious centers, where they often attribute their causes to the powers of witchcraft and evil spirits who attack them.

In Ghana, the need exists for researchers to study the backgrounds of these patients with neurological disorders to find out how they cope with their illnesses' symptoms. They often go unnoticed in present-day technological Ghana because of wrong knowledge and attributions of their causes. Researchers follow the history of individuals who have suffered these illnesses. It appears there is a lack of knowledge, so they wrongly interpret their activities as the workings of some spiritual powers who are harming patients. They hardly touch and discuss hereditary spread and injuries. There are shreds of evidence to show that some patients who had their disorders earlier have transmitted these disorders to their offspring. Instead of approaching competent practitioners for treatments, some practitioners in worship centers manipulated these individuals where patients' fragile conditions caused them to suffer while they made money from them. These centers of worship are in West Africa, especially Nigeria and Ghana. These centers harbor many of these uninformed adherents who are sick themselves. In their sick roles, they still pretend to have been cured by these practitioners. Other patients whose conditions require proper treatment die because of these malpractices.

Mental health and neurological disorders as a whole pose major problems in Ghanaian society. They have been described in words by scholars as having generated socio-political consequences, adding that it is inundated with financial, operational, and logical challenges, including lack of essential medication, inadequate infrastructure, and low numbers of professionals.

The Objective of the Study

The study's objective is to investigate the neurological disorders of Ataxia and Epilepsy in Ghana and to focus on the hereditary transmission of the disease rather than spiritual causes. Some patients and caregivers lack this knowledge concerning how these illnesses come through hereditary means. Some people simply repudiate these notions. The study shall find out how patients, as well as caregivers, understand these concepts, and whether the gaining of knowledge of hereditary causes could influence how to deal with these illnesses in the communities differently. If the awareness can be shifted from spirits to injuries and genetic/hereditary, a better knowledge of the disorders would be gained and this could influence the use of financial resources. We will interview patients who live with these disorders to find out how they are dealing with their stigmatization in society. This investigation will consider the conversations with close relatives or caretakers about the social situations of neurological disorder patients.

Research Questions and Prediction

Our focus is on injuries and the genetic origination of these disorders. The comprehension of these disorders will pave the way for meaningful management and treatment of the diseases in Ghana. From the perspectives of caregivers and relatives, how do injuries play a role in the causes of ataxia and epilepsy? Could the handlings and treatments become less challenging in society when appropriate knowledge is acquired and disseminated? How will this knowledge awareness contribute to the adaptations of these patients in the communities to which they belong? Would the implementation of these programs reduce the stigma which is confronted by patients in society? The working hypothesis is that when caregivers and relatives of neurological patients with ataxia and epilepsy get essential knowledge concerning their genesis, as injuries and hereditary, it will teach them meaningful handling and treatment of these disorders in society.

Significance of the Study

Epilepsy and ataxia (movement disorder) are common neurological disorders in Ghana. Unfortunately, uninformed individuals and some lay counselors attribute the causes to spiritual agents and the patients' evil behaviors. This impedes meaningful management, handling, and treatments given by caregivers and patients' relatives. When adequate competent knowledge concerning its origination is obtained and disseminated, it will make uninformed people pay serious attention to its controls, handling, and treatments of these patients in society.

Literature Review

Ataxia is a neurological disorder that causes a patient to have low muscle power or coordination of voluntary movements, such as walking or picking up objects. The disorder makes a patient possess underlying

symptoms which can affect various body movements and generate complications with speech, eye movement, and swallowing [1].

Ataxia disorder is caused by damage to the brain that steers muscle coordination, in this case, the cerebellum. Apart from this damage to the neuron, alcohol misuse, certain medications, stroke, tumor, cerebral palsy, brain degeneration, and multiple sclerosis can all cause a patient to have this neurological disorder. Inherited defective genes from parents can also generate this painful condition [2,3].

While treatment is possible, there is no hard and fast rule that treatment can successfully eliminate the disorder. Practitioners speak of the treatment for ataxia as dependent on the source of the disorder. The cause determines what practitioners can do to alleviate or lessen the burden of this disorder. A patient can maintain independence through adaptive devices, such as walkers or canes. Other well-known therapies such as physical therapy, occupational therapy, speech therapy, and regular aerobic exercise can also contribute to the success of these multi-treatments of the disorder [4].

As a central nervous disorder, epilepsy results when the brain activity functions abnormally, generating seizures and bizarre behavior, sensations, and sometimes loss of awareness. Epilepsy can disturb both sexes of all patients, irrespective of educational backgrounds and ages. The abnormal activity in the brain results in seizures which affect the process the brain coordinates. The seizure causes symptoms that include temporary confusion, a staring spell, stiff muscles, uncontrollable jerking movements of the arms and legs, and loss of consciousness or awareness, together with psychological symptoms such as fear and anxiety [5].

Symptoms of epilepsy alter depending on the type of seizure the patient exhibits. An individual with epilepsy will tend to have the same type of seizure each time, so the symptoms are alike from episode to episode. Researchers classify seizures as either focal or generalized ones based on how and where the abnormal brain activity commences [6,7].

Focal seizure has two categories: focal seizures without loss of consciousness and focal seizures with impaired awareness. Generalized seizures have six different categories: absence seizures, tonic seizures, atonic seizures, clonic seizures, myoclonic seizures, and tonic-clonic seizures [8].

Notable Features

As a neurological disorder, Ataxia disorder can progress over time or could advance abruptly. Poor coordination emerges, unsteady walking, a tendency to stumble, having difficulty with motor tasks, such as eating, writing, or buttoning a shirt. There is a change in speech, and involuntary back-and-forth eye movements, which is nystagmus. Patients experience difficulty in swallowing. Because there is damage, degeneration, or loss of nerve cells in the part of the brain that powers muscle coordination called the cerebellum. The cerebellum contains two sections of crumpled tissue placed at the bottom of the brain near the brainstem. The cerebellum aids the brain with balance, the movement of the eyes, swallowing, and speech [9].

Apart from these causes, certain diseases that injure the spinal cord and peripheral nerve structures that connect the cerebellum to the muscles can also generate ataxia disorder. These diseases consist of the following: head trauma, stroke, cerebral palsy, Autoimmune diseases such as multiple sclerosis, sarcoidosis, celiac disease, and other autoimmune conditions that can cause ataxia, infections, paraneoplastic syndromes, abnormalities in the brain, toxic reactions Such as alcohol and drug intoxication, Vitamin E, vitamin B-12 or thiamine deficiency, thyroid problems, and COVID-19 infection.

Moreover, no specific causes can be attributed to some adults who develop sporadic ataxia. Sporadic ataxia takes several forms, including multiple system atrophy, a progressive, degenerative disorder [10].

Similarly, epilepsy has many causes which are: genetic influence, head trauma, brain abnormalities, infections, prenatal injury, and developmental disorders with several risk factors. The developmental factors are age, family history, head injuries, stroke and other vascular diseases, dementia, brain infections, and seizures in childhood. Seizures lead to certain complications such as falling, drowning, car accidents, pregnancies complications, emotional issues, status epilepticus, and sudden unexpected death in epilepsy (SUDEP) [11].

Genetic Factors

There is extensive data concerning some types of ataxia and some rare conditions which could originate from hereditary ataxia. When a patient has any of these conditions, the likelihood that he will possess a defect in a certain gene that makes abnormal proteins is very high. The abnormal proteins impede the function of nerve cells, primarily in the cerebellum and spinal cord, and these will trigger them to degenerate. Once the disease advances, coordination becomes a problem [12,13].

The genetic effects can similarly cause some categories of epilepsy, which are that the affected brains could run through these patients' families. Researchers associate some types of epilepsy with specific genes, but for most people, genes are only part of the cause of the epilepsy problem. Some genes make a person more sensitive to environmental conditions that trigger seizures [8].

Empirical Studies of Treatment Outcomes of the Disorders

In a WHO study of the "Fight against epilepsy" initiative in Ghana," [14] (which took place between 2012-2016,) Ghana, a population of 27 million, about 270000 live with epilepsy. However, only 15% of these people had received treatment and care, resulting in an epilepsy treatment gap of 85%. In this study, epilepsy is the most prevalent neuropsychiatric disorder seen in rural hospitals and clinics and among the top five medical conditions in the country. The national health experts acknowledged it as a high priority in the country in the year 2011 [14]. This investigation compelled the Ministry of Health Authorities and WHO to commence a formidable fight against epilepsy in 2012. The results of the five-year project improved the recognition and management of individuals who had the convulsive form of epilepsy within the existing primary health care system. Later, they built a model of epilepsy care at the community level that extended to the whole parts of Ghana. They carried the project across five territories that consisted of 10 districts that possessed 55 hospitals and clinics. This is how they organized it: Firstly, they built a strategy for delivering

epilepsy care; secondly, they trained health care workers and volunteers; thirdly, raised awareness and educated the communities; fourthly, engaged traditional and faith healers; and fifthly, strengthened the monitoring and evaluation of the epilepsy disorder [14].

In Kumasi in the Ashanti Region, another study that commenced in 2011 was to outline the incidence of neurological disorders and demographic data in an adult neurology outpatient service. The study setting was the Okomfo Anokye Teaching Hospital in Kumasi. In this established hospital, for three year period, a neurologist reviewed all medical records of patients admitted to the outpatient neurology clinic and classified neurological diagnoses according to ICD-10. Between 2011-2013, among the 882 males and 930 females he investigated, the primary neurological disorders he found were strokes, epilepsy and seizures, and movement disorders (ataxia) at occurrences of 57.1%, 19.8%, and 8.2% respectively. The study revealed that cerebrovascular diseases, epilepsy, and movement disorders were prevalent as they contribute to neurologic morbidity among Ghanaians in an urban neurology clinic [14].

In a study in Kintampo in the middle belt of Ghana by Auurebobi *et al*. (2015), they were most interested in looking for the factors associated with epilepsy and its onset. They used a questionnaire and determined their demographics and potential risk factors. The researchers found out that 5000 individuals reported having seizures during their lifetime. The average onset of epilepsy was eight years (IQR: 2.8-15 years). The seizure median duration was 10.2 years (IQR: 4.7-16.1 years). For children below 18, the risk factors were genetically related, a family history of seizures, complications during birth, issues after birth, challenges with feeding, crying, or breathing after birth, and exposure to tropical diseases onchocerca volvulus [15].

Deegbe *et al*. (2019) also investigated the beliefs of those who live with epilepsy in the Accra metropolis. The researchers used a descriptive exploratory qualitative design to gather their data. They sampled their study group from the capital city of Ghana, thinking of gaining the most accurate perceptions of the most enlightened in Ghanaian society. The themes from their study were the signs or symptoms, causes of the diseases, and how they could be controlled or cured. Epilepsy was a disgraceful illness that caused spiritual beings to attack humans even though many had had injuries before it resulted in the disease.

The disease affects their education, employment, and the relationship between these sufferers. Research results show that false beliefs about their origin are the underlying causes. But progress has not been made concerning awareness and treatment of this neurological disorder in Ghana by professionals.

Health professionals must intensify their campaign to demystify the illness to enable the government to promote knowledge and acceptance [16]. The work of Sarfo *et al*. (2016) gives us the profile of neurological disorders in an adult neurology clinic in Kumasi [17]. It shows how prevalent Epilepsy and Ataxia disorders are in the communities of Kumasi and its surrounding urban areas.

Summary of Review

The review furnishes us that epilepsy and ataxia are common neurological disorders in Ghana. The government and the NGOs are doing their utmost best to educate the people about the causes and handlings of these diseases in society. Individuals and some lay counselors are not giving the right kind of information that

help the management of these diseases in society. They continue to attribute the causes of the illnesses to spiritual agents and the patients' evil behaviors. These theoretical and empirical works found on the subjects are informative. We assert that these impede meaningful management, handling, and treatments given by most caregivers and patients' relatives as well. Therefore, the treatment outcomes of these disorders do not settle the right picture of the meaningful treatment success of these disorders. These studies intend to look for adequate and competent knowledge concerning its origination from patients and caregivers themselves. The dissemination will make many uninformed people pay serious attention to the controls, handling, and treatments of these numerous patients in Ghanaian society.

This is one of the reasons why patients who live with these disorders find it hard to adapt to the stigmatization in society. The current study will take the conversations with close relatives and caretakers of patients seriously about the social situations in general of neurological disorder patients. We believe if they are furnished with essential knowledge concerning the genesis of the illnesses to be a result of injuries or hereditary, it will lead the way for meaningful handling and treatment of these disorders in society.

Methodological Considerations

The study employed the convenient sampling technique and the snowball method to gather the sample. In this case, we did not apply the probability sampling methods in this significant research to muster the sample. The research used a clinical interview method buttressed with open-ended and structured interviews, naturalistic observation, and some biographical data to accomplish its aims. The patient interviews took place in the hospital, home, and public/street settings. In other words, we decided to combine patients in these different settings to make the investigation utilize diverse places and backgrounds where the patients of these illnesses reside. In Ghana, not all patients have access to hospital treatments. While the lucky patients with good financial access could get the hospitals to help them treat and manage their illnesses, other families whose patients look fragile prefer to keep their affected patients at home. Those detected in the public places or streets of the cities have migrated from the neighboring countries or the Sahel regions where wars occur frequently.

Data collection took place within six months to one year. The Covid-19 global pandemic seriously affected the collection periods. On the whole, 21 patients became involved in this clinical research. We enlisted professional help from the hospital's workers, such as nurses and mental care workers, where we found it difficult to obtain permission by ourselves. Apart from these, research students who had received adequate research training methods and qualified research works complemented the additional data gathering. We feel compelled to mention a few hurdles we encountered in mustering these research materials. Firstly, we encountered problems securing permission from the hospitals in Ghana. But later it was surmounted through an official permission to do so. It is tedious to go through this lengthy process to acquire permission. But once given the permission, we did our utmost best to see that all methods were performed in accordance with the relevant guidelines and regulations stipulated in the rules. Secondly, it was a bit difficult to get the right and competent persons from the patients' homes to do the clinical interview. Thirdly, those we interviewed in the public areas and the streets of the cities were the poor and needy people who requested compensation for their used time. They may not have given credible information even though we found them more willing and happier to do so.

However, the positive side of the research reduces the burdensome nature of the work of the clinical interview and the naturalistic observation. One observes the greater need of patients in the developing nations and the scarce resources they utilize to cater to the numerous patients who need healthcare in Ghana. It informs one of the imminent issues about healthcare in Urban Ghana and its surrounding regions. The government's intention to build one hospital each (dubbed "Agenda 111") in every constituency in Ghana is a bold step to deal with the needs of needy patients such as Ataxia, Epilepsy, and other well-known neurological patients in Ghana. They continue to have less attention.

Background statistical data reveal 10 females (48%) and 11 (52%) males who participated in the study. The different age groups consist of 3 patients between (14%) 11-18 years old; 8 patients between (38%) 18-35 years old; 5 patients between (24%) 35-55 years old; 5 patients between (24%) 55-75 years old and 0 (0%) between 75-95 years old. Husbands, wives, parents, friends, sisters and brothers, concubines, and church members were the helpers in the home environment and assisted as caregivers. Among those we interviewed, parents are the highest. Regular visitations by specialists or practitioners included medical doctors, psychiatrists, social workers from the social welfare department, nurses, herbalists, and NGO practitioners. Some patients expressed that they had never received help from any of the mentioned practitioners.

Ethical Consideration

The researchers executed the ethical procedures practiced by researchers in conducting research, which is approved by Regent University College of Science and Technology Ethical Research Committee, amongst them are the following:

Informed Consent: With respect to the principle of informed consent, introductory letters were sent out to the authorities to seek permission before conducting the research. The topic, and purpose were clearly outlined in these letters to the authorities as well as the participants. A copy of the structured interview was also shown to the authorities.

Assured Confidentiality: The researchers assured the participants that their responses would not be disclosed to any third party and indeed it was not disclosed to any third party.

Anonymity: The participants of the study were assured that their identities would be concealed as there is no way to trace back responses to them. To achieve this there was no option for any form of identification by name or number on the structured interview and participants were advice not to put down any. Later, alphabetical letters were used to help distinguish between the individual participants.

Avoiding Plagiarism: To avoid the issue of plagiarism in this study, all research works, and articles used in this study for reference or other reasons were acknowledged in reference.

Avoiding Coercion: In administering the tool for data collection, all participants were informed that they were participating in the research at their own volition and could opt out at any point in time. The participants were made to understand that they were not obliged to participate in anyway. This Ethical research committee also agrees with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Availability of Data and Materials

The data that support the findings of this study are available from Uppsala University Research Data Repository, but restrictions apply to the availability of these data, which were used under license for the current study, and so are not publicly available. Data are however available from the corresponding author, upon reasonable request and with permission of Uppsala University Research Data Repository.

https://mp.uu.se/en/web/info/forska/forskningsdata

We now move on to deal with the empirical data of the research, which is mainly qualitative. The research purpose allowed us to employ these soft materials to answer the patient's and caretakers' answers, which are the focus of the current research about Ataxia and Epilepsy patients.

Results

Patients and Care-givers Perspectives

Epidemiological Matters

What has caused these disorders to come forth? There are many views: BP thinks that she is a river child.

She cannot become a woman. That means she should have been born a man instead of a woman. DN talks of spirits, witches, and demons. EM reasons physical injuries as the cause. He had ataxia disorder and concluded that a motor accident caused it. FL says someone from the extended family caused his epilepsy. GK believes her mother who was a witch had caused his disorder. II says a demon caused his epilepsy condition. JH has a divergent view as partly a spirit caused the illness and partly, a developmental problem caused one. KG thinks it is a curse or punishment that a past family member employed on him. LF has the notion of genetics: "mother is the cause of the illness as she is the birth giver." ME believes the cause is from both parents. ND, a male epileptic, thinks his alcoholic behavior caused his epileptic condition. Finally, OC female-epileptic says that "we are witches and wizards" ourselves. Here, we must be explicit in arguing that many of our patients believe that evil spirits, problems in the mother's womb, and demons are the causes of these two disorders we investigated.

Physical Injuries and Biological Factors

If injuries and genetic transmissions were to be the causes, could these affect how you perceive yourself?

FL male-epileptic informs us about doctors' information concerning genetic transmission while his Reverend says that the family members have brought this disorder upon him. But, "My parents agree with the Reverend more than the diagnosis made by the doctor." But these have not been his concern. "I try to live with it." "I have read about this illness, and that knowledge I have now encouraged me to live and cope." GK male-ataxia says: "I don't know whether it is an injury or genetic." "I was born like this, which means I had it from childhood." "They say my mother was a witch that caused this to happen to me."

"Knowledge that it is an injury or genetic will not help me. I still have pains all over my body. But I can walk with the support of this stick I am holding." HJ male-epileptic says: "it is hard to comprehend whether it originated in my mother's womb or an injury caused it. I do not believe it is genetic or had anything to do with my wrong behavior. People talk a lot, and I know whatever the situation is, they will still talk about it."

II female-epileptic believes that the illness is the genes transmitted to her. "I believe I have gotten mine from a distant relative great grandmother." "Knowing that it is genetic, I have to cope with it. If it had not been genetic, I would be able to do something about it." JH female-epileptic is aware that some family members had it earlier. They still do not understand, but it is genetically transmitted. She is more confident in living with it and adapting to the illness because she is not the only person in the family who has it. KG male-epileptic does not believe in the genetic transmission of the disorder. "Because my parents had not suffered." The knowledge that both parents had the illnesses before would make me "discouraged because it makes me feel my whole family live in a curse."

Stigmatizations, Coping Strategies, and Self-Acceptance

How do you deal with stigmatizations in your community? What are the coping strategies apart from doctors' treatments? OC female-epileptic says that people stare and point at me all the time, which makes life unbearable for me. She sees herself as a likable person who helps people when in need. What gives her hope in coping is that her husband and two children support her. Her children will suffer most if she gives up. PB female-epileptic says that stigmatization is disheartening. She gets assistance and encouragement from doctors and pastors. Help from hospitals in the form of medication and therapies can assist her in life. OA female-epileptic intimates that people make me feel I am "a child of a shrine/god." I get sympathy from others, while other people are afraid of me. Thus they are not too comfortable being together with me. My relatives and church members help me to cope with life. AQ male-epileptic says that he surrounds himself with many people who some beliefs in God, "so that makes a difference. They do not discriminate against me." They have education, so they comprehend the cause and nature of the illness. "I do not experience any serious stigma. I feel welcome to participate in the church service and be among a group of students. I have friends who are mostly college students. Some have wives who invite me to their houses during weekends when we are not at school." Female-ataxia BP does not have social relationships at all since her caregiver mentioned, "she feels very discouraged and has difficulty with coping because she is alone most of the time." EM male-ataxia attends mosque frequently and moves around in a wheelchair. It is better in Ghana than Niger where he hails from. "I can beg for money, drinks, and food in the streets." His association with other Muslim brotherhoods helps him to receive alms. They have empathy for him concerning his illness. "I am like a normal person, and this makes me forget that I am suffering from a disorder." GK female-ataxia cannot go out by herself. She got pregnant with a man. Later, the man ran away and left her and her five-year-old girl alone without any support. That made her sad.

HJ male-epileptic says these: "I am not able to walk well. I have a stroke while my right hand cannot properly move. I also secret saliva always from my mouth when I talk to children, so they go after me and shout as if I am a madman. But I am not mad." He adds: "I can think well and follow normal conversations with everybody. I have no one to wash my clothes, so they are dirty." II female-epileptic thinks that people

believe her illness is contagious but it is not. This is the reason why people avoid having a relationship with us because they are afraid they could catch the same disorder.

Neuropathic and Chronic Pains

Neuropathic pains have to do with pains in the neurons and their environments. Chronic pains cause consistent suffering of pains all over the body, which includes the bones as well as the muscles. These permanent conditions exist side by side with the human organism's experiences with the disorders of ataxia and epilepsy. They make them have to deal with pains throughout their lives. The patients we interviewed made it salient concerning the help they receive. They consist of herbs by traditional herbalists; drugs by biomedical specialists doctors; extra physiotherapists' help; and naprapathy. These professionals prescribe medicine to deal with their excruciating pains. While these treatments occur to some, unfortunately, a sizable number of patients have no way they can deal with and handle their chronic pains in the body. Some patients resort to drugs prescribed by quarks, and these behaviors can present additional dangers to these patients. Those in the hospital settings have appropriate drugs to treat their pains, while those in the home and street settings have no proper sanctioned drugs to utilize. Neuropathic and chronic pains are the main problems with patients suffering from disorders of ataxia and epilepsy.

Group Support

How does the African communal mindset help to contribute to management? Patients receive group support through traditional treatment avenues. Doctors, pastors, herbalists, and faith healers usually champion these support systems. They also get support through funds donated by NGOs. Because they have no adequate help from the biomedical centers, they fall into the company of these important caregivers who work closer to them. Some patients experience disappointments concerning the treatments they hardly receive from hospitals and go far as to pinpoint the faith and hope they have in the traditional care systems. "A little hope is all I have left," indicates KG male-epileptic patient as he expresses the current support and treatment he receives from caregivers. These patients, however, receive group support: LF, ME, ND, OC, PB, QA, and many others. The group support encourages patients to move on in life despite their illness troubles and predicaments. It helps some serious ones to embark on educating themselves to make them professionally oriented individuals in their various communities.

Governments and NGOs on Caregiving

What are the messages given in connection with caregiving by Governments and NGOs? Patients have some needs and pieces of advice from the authorities we have mentioned above. The disorders are not contagious, so people should have mercy and sympathy for those who suffer from epilepsy and ataxia.

They need to receive sympathetic care to understand the complicated situations between them and the public. In Ghana, for example, people see epilepsy as a disease that has come to the patient through punishment. Or a witch from a family member has brought it to the doer and a sufferer. Government must encourage awareness about this disease in society. "We take some prescription drugs to treat it, and so we have the awareness that they should treat us patients with respect and dignity." Patients admit that they do not

regularly consult doctors in the hospitals, yet they need empathy and support. They also mentioned that they do not work as other healthy people in society do and, therefore, they need some support of items that should be able to help maintain a healthy livelihood. They insisted they need to receive regular contact with government agencies and NGOs to continue to treat and serve them. They usually need clothes, groceries, and free medications to help them to survive.

Psycho-biographical Material of Three Patients.

The Case of Epileptic Patient JAA

She was around two years when her mother presented her as a gift to a Volta Region Traditional Medicine practitioner. Her mother had met and slept with a stranger who visited their hometown. Because her mother was not properly married to the man, she did not see why she should keep her child. Right from this tender age, the traditional practitioner beat her severely with a rod, which made her develop chronic pain which affected her spinal cord and her brain. The marks of the beating remained until her death. She then grew up to experience brain and spinal cord injuries that troubled her in her youth and older ages.

Her brain attacks received attribution to spirit possession due to her constant attachment to spiritual churches. But before her death, she was most of the time attached to a charismatic leader and his spiritual Church called Feden International. During church service, the band music would intensify; this heightened atmosphere would cause her to be possessed, and the usual interpretation was her household witches wanted to kill her. JAA later managed to travel to America and got pastoral education which enabled her to become a reverend minister of the Church. She later founded her church organization and attached it to the Full Gospel Church International in Ghana. Her brain and spinal cord injuries made her develop neuropathic pain and tension headaches which did not get any treatment before her death. She always associated her neurological disorder with evil powers. The leader used sex to calm most of the women who had problems with neuron disorders. This will occur after they have fallen, pretending to be spirit possessed.

The Case of Epileptic Patient YAA

YAA inherited the gene from her mother. He died at the age of 61. He suffered from brain attacks constantly but did manage to complete secondary school. Later in life, he had high blood pressure (BP) and a stroke. Stroke events became rampant, and he did not survive the COVID-19 epidemic.

The Case Ataxia Patient SAA

SAA inherited the epileptic disorder from the accident his mother had. He died at the age of 21. He suffered from Ataxia when he was in an international school. During the time he entered secondary school, unfortunately, the epileptic disorder had reached a stage that he could not control. Constant attachment to spiritual churches caused the sickness to become worsen, and he passed away later.

Comments

The biographical data also enlightens us on the same problems facing these patients, among other things: low productivity in life, depression, anxiety, and loneliness. While others see limited ability to be living to adapt, some go further to see themselves as cursed or wizards.

Discussion

The work sought to find how epilepsy and ataxia disorder patients deal with their illness situations in Ghana. We were more interested in the study and comprehension of patients' understanding of genetic and injuries' origination of their disorders and how they are also adapting to these complicated disorders.

The methods of the investigations were clinical interviews buttressed with structured and open-ended interviews. We also employed naturalistic observations of the hospital settings, public/street settings, and home settings of the various patients studied. We were particularly concerned with the meanings these patients give to their experiences as they look for answers and appropriate interpretations.

Importantly, we found out from epidemiological points of view what these patients and their caregivers understood to be the genesis of their disorders. We were there to find out if, in the context of handling and treatments, they comprehend the genetics and injuries in the origination of these disorders that will allow them to accept themselves, cope and live with their neurotic disorders.

Patients are aware of people's attributions they make concerning their disorders. Among other things, spirits, witches, alcoholic behaviors, wizards, distant relatives, and relationship problems cause these disorders. Though some agree with the genetic-biological and physical-injuries hypotheses of origin, they concur that would not change their perception and handling of these disorders. While some concur that might help them to think that they are not alone, they do not see this as contributing to any coping strategy/ source they will have in their lives. These people suffer from their illnesses, and they need a way to survive and continue to exist.

One of the cardinal predictions was that when patients get the right knowledge concerning the sources of their disorders, it will teach them meaningful handling and treatment of the disorders. How has the data supported this? On behalf of the patients, we did not see any available data supporting this assertion.

Patients want their illnesses to be treated and given important focus, and they care less about the causes of their disorders, whether genetic, injuries or the spiritual origins they mostly alluded to in their interviews. Probably, the results of this research are more beneficial to caregivers and practitioners than patients, the latter who suffers stigmatization and lack of self-esteem, and a host of other problems.

Stigmatization is also a problem, not only for these patients we interviewed but also for the workers in the hospital settings in Ghana that work with mental patients. Recently, Buertey has come with the diverse problems facing psychiatric nurses in Ghana. According to Buertey, community psychiatric nurses experience various effects of stigma, such as low productivity, depression, and anger. Participants recounted

how stigmatization had affected their work, both in the hospital setting and in their various communities [18].

Neuropathic and chronic pains are prevalent among these patients we investigated in the hospitals, streets/public, and home settings. The patients get all forms of treatments that help them adapt and cope with these disorders.

Governments and NGOs should intensify their efforts and generously allow them to receive more assistance, such as clothes, food items, groceries, treatments, and support, which consists of medications and diverse therapeutic approaches.

Concluding Remarks and Implications

Patients recognize the difficulties that are present in the genesis of their illnesses. Making attributions to spiritual beings and wrongdoings of patients' behavior are uncommon. Yet their concentrations on them are not their priorities. They want to get over their illnesses and become well so that they can function normally in their work environments, which exist with stigmatizations and abhorrence behavior toward them. These things prevent them from enjoying healthy and normal lives. Coupled with humiliation, their conditions take away their self-esteem and human dignity. Satisfactory treatments should be mingled with proper education to caregivers and patients on the sources of these disorders to help them possess adequate well-being and self-esteem. This will give them equilibrium minds and help them settle down without fearing stigmatization. These patients need group and family support and acceptance in the different communities. Church members and their reference systems should work to lead to the propagation of good news on this matter. This will consequently bring about meaningful transformation as they receive healthy and competent treatments from specialist practitioners, both biomedical and lay workers in the medical and traditional care fields.

Limitations of the Study

The results of this study, despite its vivid description of patients' experiences with their disorders, cannot be generalized. The qualitative method allowed us to comprehend the meanings these patients give to their experiences and how these help them to structure their worldview to enable them to cope with life.

However, our study contributes to patients' adaptation to their environments with diseases that continue to baffle medical scientists and traditional practitioners concerning their treatments and management.

This work will add to research data and literature concerning the development and handling of ataxia and epilepsy disorders in developing countries where there has not been significant progress in these disorders' treatments.

Declarations

Ethics Declarations

Ethics approval and consent to participate. Regent University Ethics Committee on Research permitted us.

We, therefore, acquired the right permission. Furthermore, we tried to hide the identities of the individuals involved in the research. Informed Consent and Anonymity complied.

Consent for Publication: Not applicable

Competing Interests

The authors declare no competing interests.

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Bibliography

1. Subramony, S. H., Fratkin, J. D., Manyam, B. V. & Currier, R. D. (1996). Dominantly inherited cerebella-olivary atrophy is not due to a mutation at the spinocerebellar ataxia-l, Machado-Joseph disease, or Dentato-Rubro-Pallido-Luysian Atrophy locus. *Movement Disorders, 11*(2), 174-180.

2. Terwindt, G. M., *et al.* (1998). Migraine, ataxia, and epilepsy: a challenging spectrum of genetically determined calcium channelopathies. *European Journal of Human Genetics, 6,* 297-307.

3. Geschwind, D. H., Perlman, S., Figueroa, K. P., *et al.* (1997). Spinocerebellar ataxia type 6. Frequency of the mutation and genotype-phenotype correlations. *Neurology, 49*(5), 1247-1251.

4. Sidhartha, C., *et al*. (2021). Seizure after recovery from COVID-19. *Journal of Family Medicine and Primary Care, 10*(7), 2713-2715.

5. Pennacchio, L. A., *et al*. (1998). Progressive ataxia, myoclonic epilepsy, and cerebellar apoptosis in cystatin B-deficient mice. *Nature Genetics, 20*(3), 251-258.

6. Marcian, V., *et al*. (2016). Cerebellar Dysfunction and Ataxia in Patients with Epilepsy: Coincidence, Consequence, or Cause? *Tremor Other Hyperkinet Mov (N Y)., 6,* 376.

7. Jen, J., Kim, G. W. & Baloh, R. W. (2004). Clinical spectrum of episodic ataxia type 2. *Neurology, 62*(1), 17-22.

8. Rajakulendran, S., Graves, T. D., Labrum, R. W., *et al*. (2010). Genetic and functional characterization of the P/Q calcium channel in episodic ataxia with epilepsy. *J Physiol., 588*(Pt 11), 1905-1913.

9. Baloh, R. W., Yue, Q., Furman, J. M., *et al*. (1997). Familial episodic ataxia: clinical heterogeneity in four families linked to chromosome 19p. *Ann Neurol., 41*(1), 8-16.

10. Matsumoto, M., *et al*. (1996). Ataxia and epileptic seizures in mice lacking type 1 inositol 1,4,5-trisphosphate receptor. *Nature, 379,* 168-171.

11. Levite, M. (2002). Autoimmune epilepsy. *Nature Immunology, 3,* 500.

12. Zhuchenko, O., *et al*. (1997). Autosomal dominant cerebellar ataxia (SCA6) associated with small polyglutamine expansions in the α1A-voltage-dependent calcium channel. *Nature Genetics., 15*(1), 62-69.

13. Trottier, Y., *et al*. (1995). Polyglutamine expansion is a pathological epitope in Huntington's disease and four dominant cerebellar ataxias. *Nature, 378*(6555), 403-406.

14. WHO (2018). "Fight against epilepsy" initiative in Ghana. WHO program on reducing the epilepsy treatment gap 2012-2016 World Health Organization. (Pp. 1-57).

15. Ayuurebobi, K., *et al*. (2015). Prevalence and risk factors for active convulsive epilepsy in Kintampo, Ghana. *Pan African Medical Journal., 21*(29).

16. Deegbe, D. A., *et al*. (2019). Beliefs of People Living with Epilepsy in Accra Metropolis, Ghana. *Seizure: European Journal of Epilepsy, 73,* 21-25.

17. Sarfo, F. S., *et al*. (2016). Profile of neurological disorders in an adult neurology clinic in Kumasi, Ghana. *eNuerological Sci., Elsevier B. V., 3,* 69-74.

18. Buertey, A. A. (2022). The professed effect of stigma on community psychiatric nurses in the Greater Accra region of Ghana. *BMC Psychiatry., 22*(1), 456.