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Chapter

Perspective Chapter: Practical Approaches to Enhance Successful Lives among People Living with Epilepsy

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Abstract

Epilepsy is a neglected noncommunicable condition in this era. Therefore, it is imperative that practical approaches to enhance the management of epilepsy for the success of people living with epilepsy (PLWE) be analyzed and described. The chapter will encompass the challenges faced by people living with epilepsy, their needs, the PLWE resilience and coping strategies, epileptic seizure first-aid management, and support for people living with epilepsy. The issues aforementioned can potentially shape the future of the people living with epilepsy if attended to effectively. It is high time that epilepsy and people living with epilepsy are given the attention they require to reduce the stigma attached, misconceptions, maltreatment, mismanagement, and negative cultural and religious beliefs, as this will encourage the people living with epilepsy to accept themselves and partake in the family, community, school, and societal engagements without any fear.

Keywords: management, people living with epilepsy, seizures, resilience, support

1. Introduction

Epilepsy is a condition characterized by experiences of unprovoked seizures caused by synchronous or excessive neural activity [1]. An enduring predisposition characterizes it to seizures and results in neurobiological, cognitive, psychological, and social consequences. People living with epilepsy (PLWE) experience altered sensations, behavior, and consciousness due to a discharge of nerve tissue on muscles. The misconceptions and ill understanding of epilepsy constitute the prevalence of epilepsy. The World Health Organization [2] shows that 70% of people living with epilepsy could live free of seizures due to effective scientific medication attained at a low cost. However, this is not so due to a lack of knowledge of the disorder. According to the World Health Organization [2], epilepsy does not get as much attention as it deserves from health practitioners and policymakers. There is a noticeable gap in

knowledge of epilepsy between African countries, European countries, Asian countries, and America. In the United Kingdom, a national survey collected shows very low stigma and knowledge satisfaction [3]. In Asia, although Karimi and Akbarian [4] show that PLWE have somewhat adequate knowledge about the disease, Thapa et al. [5] show inadequate knowledge in the general public. General awareness of the disease is not certain in Asia, especially because some believe sleep deprivation and certain drinks and foods trigger seizures [4].

In rural sub-Saharan African countries, there is a persistent prevalence of epileptic misconceptions [6], and this is supported by Kaddumukasa et al. [7] who reported among other things that epilepsy is considered a curse from God and is caused by witchcraft that PLWE are considered to be insane and should be isolated. A couple of studies done in African countries show how knowledgeable people in Africa are about epilepsy. Armah-Ansah et al. [8] state that although about 97.5% of people said to have heard about epilepsy, they still share negative attitudes toward it, resulting in isolation and stigma. In Ethiopia, 97% have never heard about epilepsy, 85.6% proved not knowledgeable about epilepsy, and 86.8% expressed a generally negative attitude toward epilepsy and PLWE [9]. These statistics are incomparable to the 5.9% who had never heard of epilepsy in Asia [5]. Kaddumukasa et al. [7] show that perceptions, stigma, and misconceptions about epilepsy are based on culture and wrong information taught. Besides an increased mortality rate, the ill information and knowledge on epilepsy bear fruit to several challenges experienced by PLWE, their families/caregivers, and those in close relationship with them.

In most cases, it is found that PLWE are excluded due to negative beliefs held by the general public. According to Kaddumukasa et al. [7], PLWE are excluded from community involvement. They are not allowed to play with other people as epilepsy is believed to be contagious, which adds to their isolation and segregation. This shows that PLWE, along with their families, are marginalized. In their study, Henok and Lamaro [9] show that 30% of their study's sample believe that PLWE should be isolated from society, and 40% said they are associated with PLWE and have their children isolated from any known person with epilepsy. As a means of precaution, their families put measures that isolate them. Along with forced social exclusion, PLWE isolates themselves because they feel ashamed and rejected.

A study revealed that people without the disease refuse to marry PLWE [7]. This results in a negative outlook on marriage from PLWE. How others view epilepsy and their attitude toward it causes great distress for PLWE. This results in interpersonal challenges, and they become impatient with other people expressing consistent general agitation [10]. Furthermore, the literature reveals that PLWE often experiences shame, which evokes guilt, grief, and anger [10–12]. Guilt often comes from the feelings of burdening others. For most, epilepsy leads to fear and anxiety [12].

In addition, PLWE generally experiences anxiety disorders and mood disorders. The weight of stigma, discrimination, and social limitation often leads to low self-esteem and depression, contributing to suicide. PLWE may not be able to perform day-to-day tasks, and they may also have physical injuries [13]. In addition, epilepsy can impact speech and add to language difficulties [14].

As a global crisis that affects over 50 million people and increasing due to new births, epilepsy implores intensive research, especially in low-middle-income countries. Countries in Africa show insufficient levels of knowledge mostly influenced by their traditional African culture and background compared to other countries, such as Europe and the United States of America, which do not share the same beliefs [15]. It is evident that the level of knowledge that one has on epilepsy ultimately influences

their ideas about epilepsy, which contributes to their attitudes and behavior toward epilepsy and PLWE. In most cases, these attitudes and behaviors result in negative impacts as they result from ignorance and prejudice.

PLWE generally experience a low quality of life and are burdened with the effects the disorder has on their lives and the lives of those close to them. The root of this is insufficient fallacious knowledge and understanding of epilepsy. Misconceptions about epilepsy, stigma, and ill social coping mechanisms of PLWE may be due to a lack of accurate knowledge about epilepsy. PLWE experience social exclusion, anxiety, guilt, and embarrassment because of epilepsy. The lack of education and precise knowledge on epilepsy prolongs such psychological and social distress. In addition to these, misconceptions hinder prompt diagnosis and appropriate treatment [16]. Misconceptions may be because community members are not open to talking about epilepsy. Epilepsy South Africa [17] shows that by the age of 20 years, 75% have already experienced their first seizure. This means that most people have their first seizure during their childhood. Murugupillai et al. [18] show that parents avoid talking about epilepsy with their children. This then promotes the misconceptions as they grow up believing in all that they come across in their life span.

Consequently, this is the start of stigma, and the spread of misconceptions about epilepsy as ideas about epilepsy are spontaneously made up upon experiencing the seizure or witnessing another young person having an epileptic seizure. Hence, this chapter aims to provide the challenges faced by PLWE, their needs, the immediate management of seizures, care, and support of PLWE to widen the understanding and provide practical approaches to promote a conducive environment for PLWE.

2. Challenges faced by PLWE

To improve the everyday living of PLWE and enhance their quality of life, it is important to ask the questions: “what is the impact of epilepsy?” and “How is it like PLWE?”. By answering these questions, we can begin to understand the challenges PLWE has and ultimately achieve the goal. This section will highlight the challenges experienced by PLWE, the physical, psychosocial, economic, and existential challenges.

2.1 Physical challenges

In the occurrences of seizures, more often than not, patients experience uncontrolled physical challenges, e.g. urinal excretion. Some patients sustain physical injuries in the least end; they are nonfatal; however, in the end, death may result. A study done evaluating injuries among PLWE found that 85.5% have sustained an injury during a seizure [19]. On the other hand, Bifftu et al. [20] reported 27.8% of physical injuries. Some of these injuries include as follows:

- Soft tissue injury [19, 21]
- Dental and tongue injury [19–22]
- Head and/or brain injury [19, 20, 22, 23]

- Burns [19–23]
- Fractures [20–24]
- Memory and concentration problems [25, 26]
- Treatment challenges in terms of experiencing a high number of adverse side effects [25–28]

Some physical challenges result from seizure aftermath and may only apply to PLWE who experience generalized or focal motor seizures. Regardless of the type of epilepsy, physical challenges (living with injuries and those that are a direct result of seizure occurrence) can negatively impact the quality of life. An epileptic experiencing mood and behavioral side effects are just as challenged as a person with a visible injury, e.g. a person with a burn or dental injury may encounter frequent stares that leave them feeling embarrassed. In essence, many physical challenges experienced are much connected with psychosocial challenges.

2.2 Psychosocial challenges

Generally, psychosocial challenges vary across ages [27–29]. PLWE are often stigmatized, prejudiced, and segregated because they are PLWE. PLWE are also often excluded from educational opportunities [30]. These challenges often result in comorbidities such as depressive disorders, anxiety disorders, and stress disorders. In addition to these issues, PLWE have suicidal thoughts, they fear being alone, fear being in social spaces, suffer continuous embarrassment, and lose relationships due to this disease, and this often leads to isolation [28–32]. In most cases, epilepsy's psychosocial consequences are not directly caused by the disorder; instead, they result from external factors such as behaviors and attitudes about epilepsy and PLWE.

2.3 Economic challenges

Epilepsy poses financial challenges for PLWE as well as their caregivers/families. The WHO [30] shows that “out-of-pocket costs” become burdensome. These costs are used to purchase treatment, travel to health care facilities, and pay for therapies. In some instances, young people drop out of school (and essentially become unemployed) due to the disease burden. In one study, experiences of epileptic seizures at a workplace resulted in resignation from their work [33]. Consequently, on a personal and household level, PLWE experience or contribute to a financial burden.

2.4 Treatment challenges

This challenge contributes to physical, lifestyle/social, and economic challenges. Patients on anti-epileptic drugs (AEDs) may experience tiredness, dizziness, headaches, memory loss, and issues with attention [25, 32]. Social side effects of treatment may include altering eating schedules and what they eat and monetary challenges because of treatment costs. In their findings, Fazekas et al. [34] report that epilepsy treatment side effects are often unbearable to PLWE. In addition to the hostile experience of treatment, about 7–20% of children and 30–40% of adults living with epilepsy are said to be drug-resistant [35]. In addition, convenience, drug side effects,

and unavailability of treatment result in the growing dependence on traditional treatment from traditional healers of epilepsy [36].

Treatment challenges are often experienced in low-middle-income countries where we find low-quality health facilities, access to health care services, short medicine supply, and cost of purchased medication. According to WHO [30], about three-quarters of PLWE may not receive proper medication, and there is a treatment gap within the low-middle-income countries. It is reported that less than 50% of PLWE have access to anti-epileptic medication.

Epilepsy is a disease that may be cured. However, in most instances, it can only be managed. In this regard, it is possible that PLWE may experience lifelong challenges if there is no intentional intervention to mitigate the effects of the factors deemed to be challenging and meet their needs.

3. Needs of PLWE

Reflecting on the previous section, the needs of PLWE are pivotal to increasing the quality of life, especially because their challenges influence areas where they need support. There is a need for easier access to care and treatment, especially in low-middle-income countries. What's more, PLWE needs financial support/access to more medication options, eliminating generalized diagnosis and prescription of medication.

WHO [30] suggests that to increase PLWE's quality of life, there needs to be a change in the legislature and an increase in the international standard of the law to be inclusive and considerate of PLWE. This may help protect PLWE in schools and workplaces and give them equal opportunities to attain a future and profession. PLWE who reside in underserved populations generally have low self-management because of a lack of education and equipment [37]. Musekwa et al. [12] and Yeni et al. [38] show that education (educating the public, PLWE, and caregivers about epilepsy) has become a need and a way to increase the quality of life and PLWE.

Fazekas et al. [34] reflect that the greater need is to relieve their psychosocial challenges, what's more, there is a need for therapy and social support for PLWE. Yeni et al. [38] add a close correlation between mental health and the quality of life for PLWE. Focusing on fulfilling this need will help in decreasing psychosis comorbidities, attaining positive mental health, strengthening coping mechanisms, and building resilience.

4. PLWE resilience and coping strategies

The ability to cope and function while living with epilepsy daily may be challenging. This section provides the strategies that can enhance and strengthen PLWE's resilience and coping with the condition.

4.1 Making connections

The importance of good relationships with close family members, friends, and others cannot be overemphasized [39–41]. This can be achieved by accepting help and support from those who care about PLWE and are willing to listen to them, strengthening resilience. Some people find that being active in civic groups, faith-based

organizations, or other local groups provides social support and can help reclaim hope [42–47]. As much as PLWE are making connections with the significant others, reciprocal attention must be provided from the significant others. It has been noted that assisting others in their time of need can also benefit the assister [48]. As a result, this puts PLWE in the position to help those in need, as it is likely to offer assistance in a crisis.

4.2 Looking beyond the crises

You cannot change the fact that highly stressful events happen, but you can change how you interpret and respond to these events. The psychosis of epilepsy can be overwhelming, and its neurobiological basis remains unclear [49]. The misconceptions, stigma, and myths attached to epilepsy arise due to a lack of understanding regarding epilepsy among populations. As a result, PLWE needs to look beyond the present to see how future circumstances may be better. In dealing with difficult situations, PLWE must be able to notice subtle ways in which they might feel a bit better.

4.3 Accept that change is a part of living

People with epilepsy often experience changes in their quality of life, such as reduced mobility and having difficulties learning, attending school, working, and interacting with others [50–52]. Most PLWE live a full, active life that includes school, friends, sports, and other relevant activities most people living without epilepsy engage in. The extent to which epilepsy interrupts a PLWE's life depends on the type of epilepsy, the effectiveness of treatment, and many other factors. To help PLWE become more independent, ensure they receive appropriate care and support throughout their transition in life. The vast majority of people with epilepsy can drive, go to college, get a job, get married, and raise a family [53–55]. Learning about epilepsy, your rights and responsibilities, and where to find support and resources will help you live a happy and fulfilling life [56]. As a result of epileptic adverse situations, some goals may no longer be achievable. However, PLWE can surpass this by accepting circumstances that cannot be changed to help them focus on changeable circumstances.

4.4 PLWE to take decisive action to achieve their goals

We all have goals in life, and PLWE are not excluded. Therefore, it is also essential for PLWE to develop realistic goals. These may be short- or long-term goals, but they provide a reason to carry on living and striving for a better tomorrow. PLWE should engage in regular activities no matter how small they may seem; small accomplishments will enable them to move forward toward their goals [46]. Focus on what you can accomplish today rather than on impossible tasks. Take action as much as possible when faced with adverse circumstances. It is better to take action than to avoid problems and stress by wishing that they would go away [46].

4.5 Look for opportunities for self-discovery and nurture a positive self-view

As a result of epilepsy, PLWE may learn something about themselves and find that they have grown somehow. Through the experience of the epileptic condition, epilepsy-related tragedies and hardship, most PLWE reported improved

relationships, a greater sense of strength even when feeling vulnerable, an enhanced sense of self-worth, and a more developed spirituality [57]. Resilience can be built by PLWE trusting their instincts and developing confidence in their ability to solve problems.

4.6 Take care of yourself by maintaining a hopeful outlook

People living with epilepsy should be attentive to their own needs and feelings. They should engage themselves in activities that they enjoy and find relaxing. Regular physical activities and exercises are highly recommended. Self-care helps PLWE keep their minds and bodies primed to deal with any situation requiring resilience. An optimistic outlook enables you to expect that good thing will happen in your life. Thus, PLWE needs to attempt to visualize what they want rather than worry about their fear. PLWE must identify ways that are likely to work well for them as part of their strategy for nurturing resilience.

5. Management of epileptic seizures first aid

This section intends to provide the first-aid quick guide for seizures, and the guide is particularly relevant for tonic–clonic seizures as the person fits, shakes, or jerks. Before the first aid, a brief description of the seizures is described. According Centers for Disease Control and Prevention seizures are classified into two groups [58], thus general and focal seizures.

Both absence and tonic–clonic seizures are generalized seizures that affect both sides of the brain. There can be rapid blinking or a few seconds of staring into space during absence seizures, which are sometimes called petit mal seizures. The effects of tonic–clonic seizures, also called grand mal seizures, can include crying out, losing consciousness, falling to the ground, having muscle jerks or spasms, and feeling fatigued afterward. As opposed to focal seizures, partial seizures occur only in one part of the brain. Depending on their complexity, they can be classified as simple focal, complex focal, or secondary generalized seizures. Simple focal seizures affect a small area of the brain and can cause twitching or unusual sensations. The other type of seizure is complex focal seizures, which can leave a person with epilepsy confused or bewildered. As a result, the person may be unable to react to queries or directions for a few minutes. Finally, a secondary generalized seizures originates in one section of the brain but extend to both sides. In other words, the individual has a focused seizure initially, followed by a generalized seizure [59].

Although seizures can be terrifying to witness, they are not always a medical emergency. Habitually, once the seizure stops, the person recovers, and their breathing goes back to normal. Now it is important to know what to do in case of a seizure, and the following guide [59] provides a step-by-step directive of how to attend to the person:

- Try to stay calm.
- Look around—is the person in a dangerous place? If not, do not move them. Move objects around the person like furniture, away from them.
- Note the time the seizure starts.

- Cushion their head with something soft if they have collapsed to the ground.
- Look for medical jewelry or an ID card for information about what to do.
- Do not hold them down.
- Do not put anything in their mouth.
- Try to stop other people crowding around.
- After the seizure has stopped, gently put them into the recovery position and check that their breathing is returning to normal. Gently check their mouth to see that nothing is blocking their airways, such as food or false teeth. If their breathing sounds difficult after the seizure has stopped, call for an ambulance.
- Try to minimize any embarrassment. If they have wet themselves, deal with this as privately as possible.
- Stay with the person until the seizure ends and they are fully awake. After it ends, help the person sit in a safe place. Once they are alert and able to communicate, tell them what happened in straightforward terms. They may need gentle reassurance.
- Do not give them anything to eat or drink until they are fully recovered.
- When to call for medical assistance

Usually, when a person has an epileptic seizure, there is no need to call an ambulance. However, always call for emergency assistance in case any of the following apply:

- you know it is the person's first seizure;
 - they have injured themselves badly;
 - they have trouble breathing after the seizure has stopped;
 - one seizure immediately follows another with no recovery in between;
 - the seizure lasts 2 minutes longer than is usual for them; or
 - you do not know how long their seizures last.
- Suppose you need to call the emergency services on an Android or iPhone device. In that case, there are ways to send your GPS location to the emergency services simultaneously automatically.

Some people recover quickly from a tonic-clonic seizure, but they will often be exhausted, want to sleep, and may not feel back to normal for several hours or days [60].

6. Supporting people living with epilepsy

Caring for people living with epilepsy can involve several skills, including technical tasks such as dealing with medical equipment, emotional support, being able to adapt if needs change, or working with health care professionals involved in the person's health or care. These roles may be in addition to other demands in terms of parents or caregivers such as their family, other relationships, work, home, financial constraints, social life, their own health, and hopes and wishes. Parents or caregivers may cope well with multitasking, or they may find it difficult to cope as some areas of their lives are being neglected. As a teacher in a school setting, it may be hard to merely focus on PLWE while having a class with multiple learners with different care needs that also seek their attention, let alone their teaching role. However, according to the Epilepsy Society (UK) [61], it is essential that parents, caregivers, and teachers who are caring for someone with epilepsy, the following are the aspects or activities they should do to support PLWE:

- keeping them safe during and after a seizure,
- calling for medical help, or giving first aid or emergency medication,
- staying with them or seeing them home safely after a seizure,
- noting any pattern or trigger to their seizures, which may help if they do not recall their seizures,
- helping them with their routine of taking anti-epileptic drugs (AEDs),
- going with them to appointments, helping to take notes, or providing descriptions of seizures to the person with epilepsy and their health care providers,
- acting as a representative or advocate for the person, with their health care providers involved in their care
- joining in with leisure activities that might pose a safety risk if they were to have a seizure, such as swimming, etc.
- providing transport if necessary
- helping them to adapt their home or lifestyle to provide a safe living environment.

The activities aforementioned are critical to the care of someone with epilepsy and may present a lot of responsibility to the parent, caregiver, or teacher. It should also be noted that these activities are very vital and valuable to PLWE. Apart from attending to the presented activities, it should be noted that co-morbid exist as well. Thus, PLWE may also have other conditions that require extra care needs. Given the need for social welfare's support for PLWE, sometimes this becomes a turmoil as seizures may be infrequent or unwitnessed by others. Thus, other people may not see the need for care; hence, some social services do not always distinguish epilepsy as a condition with particular care needs.

Caring and supporting PLWE carries physical attention and psychological and emotional attention needs. Thus, living with epilepsy can have a psychological impact which may also affect parents, caregivers, or teachers as their caregivers. This could include stress, depression, or mood changes. In addition, as epilepsy is an individual condition, it can change over time [61]. The amount of care that is needed may increase or decrease. The situation of the parent, caregiver, or teacher could change. They may become physically unable or have now focused on their own health needs as well as the need to regain their independence. It may also be that those providing care are even caring for more than one person, increasing the caregiver's strain. This is some of the baggage that comes with caring for people living with epilepsy, and there is a need to find ways to cope and maintain the caring role. In contrast, some people may expect that the caregiver can continue to manage regardless of their own needs or strains just because they always have done before.

7. Conclusions

The chapter provided the challenges faced by PLWE as well as their needs. We further provided approaches to promote resilience and coping among the PLWE, the immediate management of seizures, and care and support of PLWE. The issues aforementioned can potentially shape the future of the PLWE if attended effectively. It is high time that epilepsy and PLWE are given the attention they require to reduce the stigma attached, misconceptions, maltreatment, mismanagement, and negative cultural and religious beliefs, as this will encourage the PLWE to accept themselves and partake in the family, community, school, and societal engagements without any fear.

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Conflict of interest

The authors declare no conflict of interest.

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