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Representations, ILLNESS Experience and Coping Strategies of People Suffering from Epilepsy

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Abstract

Epilepsy is a chronic and common neurological condition worldwide. It generates psychological and social suffering in those who suffer from it. In order to objectify the effect of the representations and the experience of the disease on the coping strategies adopted by patients suffering from epilepsy, we conducted research with 46 patients aged 18 and over suffering from this condition.

Our data were collected using a questionnaire, Carver's Brief COPE scale (1997) and a semi-directive interview guide. The data was processed using the Sphinx Plus^2 program.

Our results show that most patients with epilepsy see the disease as being neurological (80.4%), curable (82.6%), and financially and/or socially burdensome (91.3%). Compared to the experience of the disease, the results show that patients suffering from epilepsy are frequently driven by fear (97.8%), shame (76.1%), a feeling of worthlessness (34.8%) and more adopt coping strategies centered on emotion (73.9%) and other strategies much more specific to the disease and the sociocultural context. Our results showed a significant effect of representations (at the .05 threshold) and illness experience (at the .01 threshold) on coping strategies (adaptation) adopted by patients with epilepsy.

This study therefore calls on health professionals to provide holistic care for patients suffering from epilepsy.

Keywords: Epilepsy; representations; experience; coping strategies

Introduction

Epilepsy is a chronic brain condition that affects 50 million people worldwide. It is characterized by recurrent seizures manifested by brief episodes of involuntary tremors affecting a part of the body (partial seizures) or the whole body (generalized seizures) (WHO, 2022).

The WHO recognizes epilepsy as a major public health problem. Nearly 80% of the 50 million people affected by epilepsy live in low and middle-income countries where the incidence is 2.8 times higher than that of high-income countries (Vergonjeanne, 2021).

In Europe, the prevalence of epilepsy is estimated in children and adolescents at 4.5-5.0‰; in adults aged 20 to 64 years at 6‰; and over 65 years at 7‰. The incidence of epilepsy is estimated in children and adolescents at 70 new cases per 100,000 per year; in adults aged 20 to 64 years at 30 per 100,000; and over 65 years old at 100 per 100,000 (HAS, 2022).

In sub-Saharan Africa, this disease is frequently encountered in the pediatric population. Although its exact prevalence is not known, there is reason to believe that it is not significantly different from that of the general population due to the early age of onset. It is generally considered more as a manifestation of mystical origin than as an illness relating to health (Kouassi et al., 2018).

Since ancient times, epilepsy has been, and remains today, a disconcerting disease due to the many prejudices surrounding it. In most African countries, although medical knowledge of epilepsy is progressing within populations, harmful sociocultural representations continue to worsen the prognosis of the disease as well as its experience and management (Pilard et al., 1992; Vergonjeanne, 2021). Togo is not immune to erroneous popular beliefs regarding epilepsy. The resulting attitudes and behaviors are sometimes more harmful to the person suffering from epilepsy than the disease itself (Apetse et al., 2010).

Sociocultural representations still constitute an obstacle to the effective management of epilepsy in Africa and in Togo in particular. Epilepsy is seen as a supernatural illness, a punishment, a curse and, as a result, engenders great fear and contagiousness. This explains the high number of people suffering from epilepsy burned or drowned. People suffering from epilepsy are is thus subject to deprivation of school education, work and marriage; they cannot be assisted even in danger of death (Apetse et al., 2010). Subjects living with this condition are singled out and this reinforces their social withdrawal.

Epilepsy, far from only affecting the body, also affects the minds of those who suffer from it (Caelius, 1950). The unpredictability and brutality of the onset of seizures are real sources of fear for people who suffer from epilepsy, especially of the tonic-clonic type. As Polard (2013) so eloquently mentioned it, they live in fear of crises, which generally occur without warning, thus causing humiliation and threatening serious injury. Sociocultural representations and harmful attitudes of society towards patients suffering from epilepsy lead to a feeling of rejection, devaluation, difficulties in socio-professional integration and difficulties in engaging in romantic relationships. The development of patients suffering from epilepsy therefore depends mainly on the frequency of seizures, the reactions and the support (moral and financial) of those around them.

The chronic nature of epilepsy added to sociocultural representations, reactions from those around them and psychological experience are the main stressful factors that push patients to react and cope with the illness by adopting adaptation or “coping” strategies. To cope with illness and seizures, many patients follow medical recommendations and pray a lot, since even with treatment, sometimes they have seizures. So patients devote themselves a lot to prayer in order to have complete healing (Unalan et al. 2015).

The present study was carried out with the aim of firstly describing the representations, the experience of the illness and the coping strategies of people suffering from epilepsy, and then to see if there is a link between these representations, this experience of the illness and the coping strategies adopted by them. We hypothesized the representations and experiences of the illness influence the choice and adoption of coping strategies in people suffering from epilepsy.

Materials and Methods

This study was carried out in the University Hospital Center of the Lomé Campus (Togo) and in the EYE AND BRAIN Medical-Surgical Clinic.

The CHU-Campus of Lomé is one of the two reference University Hospital Centers in Togo. It has several specialty services including the neurology department. It is in this last department that the study was carried out, with patients suffering from epilepsy receiving outpatient care. As for the Eye and Brain Medical-Surgical Clinic, it is a private health center which offers a whole variety of care, including neurological care.

Participants were patients aged 18 and over who had given their informed consent, and did not have major cognitive disabilities. Data were collected from 46 patients over the period of three months, using a questionnaire, the Brief COPE scale (Carver, 1997) and a semi-structured interview guide. This descriptive correlational study was part of a convergent mixed approach. The data were processed using Sphinx Plus^2 software. In processing the data we used two main analyses: descriptive statistics and analysis of variance. The analysis of variance allowed us to verify the existence of a relationship between the qualitative variables (representations of the illness and experience of the illness) and the quantitative variable which is the coping strategies.

Results

Sociodemographic data of the sample

The results of the sociodemographic data (Table 1) indicate that of the 46 patients, 47.8% are men and 52.2% are women. The distribution by age class shows us two strongly represented age classes. This concerns the age group [18-27] years with 37.06% of patients and the age group [38-47] years with 28.3%. We also found in the sample an average age of 36.80 years. Two levels of study are mainly represented: primary (30%) and middle school (26.1%). Furthermore, there is a high proportion of single patients (47.8%) followed by married ones (37.0%); and a predominance of patients with a student or student socio-professional status (21.7%). At the CHU-Campus, we met 16 patients, or a proportion of 34.8% of the sample; and at the “Eye and Brain” Medical-Surgical Clinic, 30 patients, or a proportion of 65.2% of the sample.

	Sample (N=46)	
Sex		
Male	22	47.8%
Female	24	52.2%
Age groups	*Average = 36.80; σ=14.20*	
[18 - 27]	17	37.06%
[28 - 37]	5	10.98%
[38 - 47]	13	28.3%
[48 - 57]	5	10.97%
58 years and over	6	13.03%
Level of study		
Illiterate	3	6.5%
Primary	14	30.4%
College	12	26.1%
High school	5	10.9%
University	12	26.1%

Marital status		
Bachelor	22	47.8%
Married	17	37.0%
Divorce	1	2.2%
Widower	6	13.0%
Care structure		
CHU-Campus	16	34.8%
Eye and Brain Clinic	30	65.2
Occupation		
Artisan	7	15.2%
Civil Servant/Employee	6	13.0%
Merchant / sales person	4	8.7%
Apprentice	5	10.9%
Pupil/Student	10	21.7%
Household	7	15.2%
Driver (Car/Motorcycle)	2	4.3%
Retired	1	2.2%
Unemployed	4	8.7%

Table 1: Sociodemographic data.

Representations of illness

In Table 2 we have the different representations of the disease in patients suffering from epilepsy. Among these representations, 87.0% of patients have an idea of identity about their condition. On the etiological level, 80.4% of patients perceive a natural origin of their disease. Unlike the latter, 19.6% attribute a mystical cause (spell) to their illness. Regarding the progressive perception of the disease, 82.6% perceive that their disease is curable and 17.4% of patients admit to a chronic evolution of their disease. Apart from these representations, we also noted a representation strongly present in patients suffering from epilepsy; it concerns the perception of illness as being both a social and/or financial burden. This latter representation is present in 91.3% of patients, i.e. a total of 42 patients.

Representations of illness	***Number (n)***	***Percentage (%)***
Common name of the disease (Adjigbo / Epilepsy / Neurological)	40	87.0
Spell-related illness	9	19.6
Neurological/natural disease	37	80.4
Curable disease	38	82.6
Chronic disease	8	17.4
Illness as a financial and social burden	42	91.3

Table 2: Distribution of patients according to representations of the disease.

This causal (enchantment) and progressive (curable) perception of the disease is reflected in these words from one of the patients:

> (...) in my opinion my illness is due to a spell, because following the crisis, I was taken to the hospital. After all the analyses, we found nothing, absolutely nothing, nothing at all. In my family no one else has this disease and since it is I who am the framework of my family and it is I who take care of the others, they (people around them, family and colleagues of work) are jealous of me, they envy me. A few months ago, I was at work when a person (a colleague) called me and said to me in my language, “The young man

> from Pya [an ethnic group from North Togo] there, you are wonderful"; She didn't do this to me but she knows the perpetrator. (...).
>
> (...) but I am confident that after my retirement, all this will end, they will no longer see me there as an obstacle to them. [Participant 22].

Experienced with illness

Experienced with illness	*Number (n)*	*Percentage (%)*
Feeling of fear (or sadness)	45	97.8
Feeling of shame	35	76.1
Feeling of rejection	13	28.3
Feeling of punishment	6	13.0
Feeling of worthlessness	16	34.8
Feeling of being limited in life	11	23.9

Table 3: Distribution of patients according to illness experience.

The results in Table 3 indicate that the experience of the illness of patients suffering from epilepsy is strongly characterized by a feeling of fear (and/or sadness) in almost all of the participants (45 patients or 97.8%).

Apart from this affect, we also noted the presence of other affects namely; the feeling of shame (76.1%); rejection (28.3%); punishment (13.0%); devaluation (34.8%); and finally that of being limited in life (23.9%).

For some patients, the fear of recurrence of seizures and their consequences limit their activities. This fear is sometimes combined with shame towards those around you. The following quote from a former seller at the market illustrates this well:

> Before at the market I sold shoes and I had a friend who sold necklaces next to my stall. One day at the market, in the middle of a sale, I had a fit. My friend told me that during the crisis I started to tear up my money that I had in my hand and upon seeing this, she took out part of the money in my hand during my seizures. Following the seizures, she gave me the rest and completed what I had torn. Faced with this situation, tell me, shouldn't I be ashamed? I was ashamed. (...), I can no longer sell because of my illness today, for fear of being picked up by a car if the crisis occurs or of knocking over my things during the crisis. [Participant 13].

Classic coping strategies developed

Coping strategies	*Problem-focused*	*Focused on emotion*	*Dysfunctional*
Low score	25 (54.3%)	12 (26.1%)	19 (41.3%)
High score	21 (45.7%)	34 (73.9%)	27 (58.7%)
Total	46 (100%)	46 (100%)	46 (100%)

Table 4: Distribution of patients according to coping strategies.

The results in Table 4 show us that 25 patients (54.3%) have a low score in terms of problem-focused coping strategies and 21 patients (45.7%) have a high score; 12 patients (26.1%) had a low score on emotion-focused coping strategies and 34 patients (73.9%) had a high score; 19 patients (41.3%) had a low score in dysfunctional coping strategies and 27 patients (58.7%) had a high score. These results imply that patients suffering from epilepsy preferentially and predominantly adopt emotion-focused coping strategies.

Other specific coping strategies noted

Coping Strategies	*Number (n)*	*Percentage (%)*
Use of medical treatment	46	100%
Religious coping	45	97.8%
Dietary and behavioral restrictions	45	97.8%
Use of traditional therapy	13	28.3%

Table 5: Other coping strategies noted.

Apart from the classic coping strategies that we evaluated using the coping scale (the Brief -COPE), we noted other coping strategies much more specific to people suffering from epilepsy in Togo. We have grouped them into four categories which are: the use of medical treatment (100%), dietary and behavioral restrictions (97.8%), the use of prayer (97.8%) and traditional therapy (26.1%). Regarding the use of treatment, all patients refer to treatment to control the occurrence of the seizures.

The next quote illustrate the coping or adaptation strategies centered on the use of medical treatment and traditional therapy:

> (...) apart from the treatment, I'm African, I know what I'm doing, but I can't tell you who I'm going to and what I'm doing. And I tell you that without that, their move would indeed succeed. Otherwise we are all Africans, we know each other and I know what I must do to protect myself. [Participant 22].

Coping strategies

Table 6 is a table of averages taking into account the modalities of the illness representations variable and the different categories of coping strategies.

	Coping Strategies		
Representations	*Problem-focused coping*	*Emotion-focused coping*	*Dysfunctional Coping*
Common name of the disease	40 (2.06)	40 (2.74)	40 (1.38)
Spell-related illness	9 (2.19)	9 (2.47)	9 (1.46)
Neurological/natural disease	37 (2.03)	37 (2.79)	37 (1.37)
Curable disease	38 (2.04)	38 (2.72)	38 (1.40)
Chronic disease	8 (2.15)	8 (2.78)	8 (1.33)
Illness as a financial and social burden	46 (2.06)	46 (2.73)	46 (1.39)
Total	46 (2.06)	46 (2.73)	46 (1.39)

Table 6: Relationship between illness representations and coping strategies.

In the last row of the table, these are the general averages obtained by the sample for each category of coping strategies. Comparing the means of the modalities of the variable "representations of illness" to those of the sample in each category of coping strategies allowed us to note a mean significantly different from that of the sample in the column of coping strategies focused on emotion. This is the average of the "illness as if linked to bewitchment" modality. This modality includes patients who perceive their "illness as linked to bewitchment". These last (09) patients obtained an average (2.47) which is significantly different (lower) from the sample average (2.73) at α=5% threshold. This reflects the fact that patients who perceive their "illness as linked to bewitchment" weakly adopt coping strategies focused on emotion.

Experience of the illness and coping strategies identified

	Coping strategies		
Experienced with illness	***Problem-focused coping***	***Emotion-focused coping***	***Dysfunctional Coping***
Feeling of fear (or sadness)	45 (2.06)	45 (2.74)	45 (1.39)
Feeling of shame	35 (2.04)	35 (2.78)	35 (1.39)
Feeling of rejection	13 (2.08)	13 (2.55)	13 (1.51)
Feeling of punishment	6 (2.08)	6 (2.55)	6 (1.36)
Feeling of worthlessness	16 (2.04)	16 (2.66)	16 (1.46)
Feeling of being limited in life	11 (2.11)	11 (2.67)	11 (1.39)
Total	46 (2.06)	46 (2.73)	46 (1.39)

Table 7: Relationship between illness experience and coping strategies.

In Table 7, table of means taking into account the modalities of the illness experience variable and the different categories of coping strategies, the comparison of the means of the modalities of the "illness experience" variable to those of the sample in each category of coping strategies revealed a mean significantly different from that of the sample in the column of dysfunctional coping strategies. This is the average of the "feeling of rejection" category. This modality includes patients who experience their illness through a "feeling of rejection". The latter (13 patients) obtained an average (1.51) which is significantly different and higher (at the threshold α=1%) than the sample average (1.39). We can estimate that patients who experience their illness through a "feeling of rejection" strongly adopt dysfunctional coping strategies.

Discussion

The present study highlighted different modalities of illness representations in people suffering from epilepsy. We noted 82.6% of patients who perceive a natural origin of their illness and 19.6% patients who attribute a mystical cause (bewitchment) to their illness. These proportions match those noted by Houeto (2005) and Akani et al. (2016) in their studies. The latter noted respectively in their study that 24.4% and 22.3% of people suffering from epilepsy attributed their illness to a witchcraft origin. This mystical perception of illness is explained by the fact that, in the Negro-African conception, illness is perceived as a misfortune which results from an aggression coming from outside (Sow, 1977). In their quest for meaning, Black Africans always find a cause which underlies the appearance of disorders of all kinds. Thus, illness in Black African thought is seen as the patient's rupture with the world on which he depends. It is not the object of chance, it is necessarily the work or the external action of an individual pursuing the ultimate goal of causing harm. The misfortune in the African conception comes from outside; and illness, being a misfortune, can only be considered as coming from outside. However, it is not a question of deciding by judging this thought because it has a meaning, which arises from the socio-cultural realities of these beings and their different lived existential experiences. This conception of illness gives it a meaning, thus allowing the individual to implement coping strategies to deal with (Leventhal et al., 1980). Indeed, in their quest for solutions, individuals will first try to make sense of their illness by developing personal cognitive representations about it. In the Common Sense theory of Illness, (Leventhal et al., 1980), this phase of developing representations is called the interpretation phase during which individuals develop their own representations.

Our assessment of the illness experience in patients with epilepsy revealed that virtually all patients experience a feeling of fear (and or sadness). Apart from this feeling of fear, we also noted other affects such as the feeling of shame, rejection, punishment, devaluation, and the feeling of being limited in life. These affects are in line with the theory of illness representations of Leventhal et al. (1980) which states that when an individual finds himself in an illness situation he reacts on an emotional level through a feeling of worry, sadness, fear, etc.

The occurrence of any condition, whether benign or not, naturally provokes not only biological but also psychological reactions (Bloch & Sivadon, 1973). We noted a high proportion (97.8%) of participants who experience the disease through a feeling of fear. This predominant anxiety was noted by Alvarez and al. (2004) and by Balogou et al. (2010) in their studies. Apart from the anxious experience of the illness, we have identified other affects which characterize the experience of the illness of people suffering from epilepsy such as the feeling of shame, rejection, punishment, devaluation and that of 'to be limited in life. This is consistent with the findings of other studies (Houeto, 2005; Bandstra et al., 2008; Laine et al., 2009, Diallo et al., 2015).

Indeed, when faced with a stressful situation such as illness, individuals adopt coping strategies. The nature of the latter varies depending on the possibility of controlling the stressful situation or not. Generally, in chronic illness, individuals preferentially adopt coping strategies focused on emotion. This adaptation seems more effective especially since it allows patients to more effectively reduce the anxiety induced by the illness (Lazarus & Folkman, 1984). This explains the fact that we noted among the participants in the present study a predominant adoption of coping strategies focused on emotion (73.9%). This result is also consistent with that of Hosseini et al. (2010); Unalan et al. (2015) and El Ghardallou et al. (2016); but diverges from that of Féki et al. (2019) who noted among elderly subjects with type 2 diabetes that the coping strategies most implemented were those focused on the problem (44%). This discrepancy can be explained by the fact that diabetes is certainly a chronic disease, but it is more controllable and less stigmatizing than epilepsy.

Wanting to highlight the nature of the link that exists between representations of the illness and their coping strategies on the one hand, and between their experience of the illness and their coping strategies on the other hand, we reached the results according to which there is a significant link between the representations of the illness and the coping strategies at the threshold .05, and between the experience of the illness and the coping strategies at threshold .01. With reference to the scientific literature, these significant links take on meaning through the Common Sense theoretical model of illness by Leventhal et al. (1980). They state that the cognitive representations of the illness and the emotional or psychological experience of the illness induce and influence the selection and adoption of adjustment or coping behaviors in patients, Furthermore, the link that we noted between the representations of the illness and the coping strategies of patients suffering from epilepsy is similar to that noted by Pierre (2001) and Houeto (2005) in their study on the one hand. On the other hand, the link that we noted between the experience of the illness and the coping strategies of patients suffering from epilepsy confirms the findings of the previous studies (Knibb et al., 2008; El Ghardallou et al. 2016; Féki et al. 2019; Lainé et al. 2022)).

Conclusion

The present study aimed to firstly describe the representations, the experience of the illness and the coping strategies of people suffering from epilepsy, and then to see if there is a link between these representations, the experience of the illness and the coping strategies. At the end of this study, we were able to identify a whole diversity of representations and affects linked to the experience of the illness, as well as a significant influence of representations and the experience of the illness on the coping strategies of patients suffering from epilepsy. To achieve these results we used different techniques which deserve to be discussed in order to prove their reliability. And given the limited number of participants in our study, the results cannot be generalized. However, we believe that this work has laid the foundations for a subject that deserves to be studied in much more depth. The results of this research challenge health professionals on holistic care of people suffering from epilepsy for a better quality of life for them.

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