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Multiple impacts of epilepsy and contributing factors: findings from an ethnographic study in Vietnam

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Abstract

We investigated issues related to treatment, impact of epilepsy, attitudes toward epilepsy and disclosure in Vietnam by using in depth interviews with people with epilepsy (PWE) and their family members. We found that although participants prefer Western treatment methods more than traditional ones, they experience problems in accessing different kinds of anti-epileptic drugs (AEDs) and higher-level treatment facilities and with respect to treatment expenses. The impact of epilepsy can be observed in a wide range of daily living activities which include working, education, marriage prospects and family formation. Although both families and society at large do not hold negative attitudes toward epilepsy, most PWE reported a sense of burden to others. Both PWE and family members generally prefer disclosing epilepsy rather than concealing it from others. Our findings strongly suggest a need for different types of AEDs, and supporting information for PWE, family members and general public about epilepsy.

Keywords

Epilepsy; Treatment; Psychosocial; Stigma; Disclosure; Impact; Attitude; Vietnam; Global Campaign against Epilepsy; Qualitative Research; Traditional Medicine

1. Introduction

Epilepsy is the most common serious neurological disorder, affecting 50 million people worldwide; fourth-fifths of whom live in developing countries [1].Incident studies of epilepsy show higher rates (median, 68.7/100.000) - thought to be attributable to parasitic and infectious diseases and peri-natal trauma [2,3]- in developing countries than in developed countries (median 43.4/100.000) [4].

Conflicts of interest statement: We have no competing interest.

Not only is the incidence rate of epilepsy higher in the developing world, but the consequence of the `treatment gap' (the numbers of individuals going untreated) – reported as high as 90% [5]- has led to profound social consequences for sufferers in developing countries, greatly adding to the burden of the condition [2]. Factors which contribute to this huge gap in treatment include, lack of prioritization, lack of well-structured health care systems, and a limited and often erratic supply of anti-epileptic medications (AEDs) [2]. In addition cultural beliefs and attitudes about the source and treatment of epilepsy, for example attribution of its cause to evil spirits, may influence individuals in developing countries to seek help from traditional healers or local religious figures rather than from Western medicine [6,7]. It follows therefore, that epilepsy is not simply a clinical condition, but also one whose cultural meanings can impact markedly on its social course [8].

As well as the physical impact of seizures, epilepsy also impacts on the psychosocial functioning of those affected by the condition [9]. The degree of this impact is dependant upon a number of contributing factors, which include, the severity of the condition, and the effectiveness of clinical management, the burden of the symptoms; the meanings individuals themselves, significant others and wider society attach to the condition, the restrictions imposed by the condition, the affected person's innate coping abilities, and, the level of practical and emotional support available to them. The combination of all these factors contributes the patient's perception of and adjustment to the illness [10]. In addition, epilepsy is often accompanied by both `felt' and `enacted' stigma [11], which can have long term effects on the lives of those affected.

According to Goffman's [12] definition of stigma, epilepsy is a discreditable condition whereby the stigma attached to it is not immediately apparent or known; this situation makes it problematic for persons with epilepsy to decide how much information to reveal about their condition to others. Many people with epilepsy opt not to disclose their illness, thereby passing as `normal` [13]. The culturally specific nature and extent of epilepsy stigma is highlighted by a number of authors [14,15,16]. Baker et al. [14] proposed a number of possible hypotheses to explain cultural differences in the experience of felt stigma, including country-specific socio-cultural biases against epilepsy, health care systems organization, educational differences, and the existence or not of equal-opportunity provisions. Addressing both the clinical and social realities of epilepsy has been the central tenet of the Global Campaign against Epilepsy (GCAE) partnership. Through the establishment of `Demonstration' projects in various developing world countries, a number of strategies have been introduced to bring epilepsy `out of the shadows' [17]. These strategies include the identification of people with epilepsy and the provision of appropriate treatment, the reduction of social and physical burden, the education of health care professionals, and supporting prevention and dispelling of stigma. The present authors and colleagues, conducted in collaboration with the GCAE, large ethnographic studies in China and Vietnam to explore the stigma and social impact of epilepsy in these two developing world countries [18]. Our findings enhance understanding of the reasons behind previously reported negative attitudes towards epilepsy within these two cultural contexts, and as such provide insight for the required direction of future intervention studies. Within this article we report only on our findings from Vietnam; data from China are the subject of a separate, previously published paper [19].

2. Study context, method and sample

The prevalence rate of epilepsy in Vietnam is reported variously in studies as between 4.4–14 per 1000 of the population [20,21]. Treatment for epilepsy is provided through the National Mental Health Program; a vertical structure comprising four tiers of health care service at national, provincial, district and commune levels. Psychiatrists have the main responsibility for epilepsy care although AEDs are mainly distributed from Commune Health Centers on a weekly or monthly basis. Phenobarbital is the most commonly used AED in Vietnam [22]. Although other AEDs are available in big cities like Hanoi, their supply is often irregular and limited. Vitamin B and antihistamines are used extensively alongside Phenobarbital. As epilepsy is classified as a “social disease” within the vertical program, the provision of medical care and AEDs is free of charge. However, as a consequence of cut-backs in provincial health care budgets, not every patient with epilepsy is provided with free medication; consequently many patients are forced to purchase their drugs from half-private hospital pharmacies or private independent pharmacies [23].

Earlier quantitative studies conducted in Vietnam indicate low levels of understanding about causes and treatment of epilepsy, and prevailing negative attitudes [24,25]. To appreciate more fully the contextually driven meaning of such responses, the present investigation employs an ethnographic approach to facilitate the exploration of local ontologies of epilepsy, lay beliefs and experiences of people with epilepsy and their family members in treatment of epilepsy, impact of epilepsy, attitudes toward epilepsy and attitudes toward disclosure of epilepsy. For a detailed description of the research methods employed see Jacoby et al. [18].

The Vietnamese research sites for this study were Hanoi in North Vietnam and Cantho in South Vietnam. Hanoi is the capital of the Socialist Republic of Vietnam. One of the biggest cities, with the highest development index, Hanoi boasts a strong healthcare network, with several large hospitals. Participants in Hanoi were recruited from two districts; Dong Da - a highly urbanized district, and the rural district of Soc Son. In Southwest Vietnam participants were recruited from two areas of urbanized Cantho; the predominantly urban area of Ninh Kieu and the largely rural area Binh Thuy.

Our current analysis draws on data extracted from individual in-depth interviews, from a sub-set of the target population. This sub-set of study participants (see Table 1) includes 12 people with epilepsy and 11 family members from Hanoi and 21 people with epilepsy and 15 family members from Cantho regions of Vietnam. Age of informants ranged from 14 years to 82 years, with no significant differences observed between participants from South and North Vietnam.[1] The interviews, conducted in informant's homes in the Vietnamese language, where undertaken by local research teams, led by one of the authors (DVT). All encounters were tape-recorded, with participants' permission, transcribed verbatim and translated into English by DVT, then cross-checked with AJ and DS for clarity of translation and meaning of any culturally specific terms. All checked and cleaned data were stored as password protected Word files.

Ethical permission to conduct the study was obtained from Hanoi School of Public Health Institutional Review Board.

3. Results

We analyzed the views of Vietnamese people with epilepsy and their family members in terms of multiple impacts of epilepsy with factors that contribute to them. The framework of the present investigation is based around issues in relation to access to treatment, different types of treatment applicable to epilepsy in Vietnam and attitudes towards applying them, impact of epilepsy for both a person with epilepsy and for the family, attitudes towards epilepsy and stigma and attitudes towards disclosing epilepsy to others. We also examine how respondents' demographic characteristics influence attitudes and actions.

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[1] Differences were non-significant for age [$t(56) = -0.45$, $p > 0.10$] and gender [$X^2(1, N = 59) = 0.82$, $p > 0.10$].

3.1. Treatment

3.1.1. General Health Seeking Behavior—

The majority of participants from both North and South Vietnam stated that after the occurrence of seizures, treatment was sought from a hospital, infirmary or communal health station. Very few reported attendance at traditional healers as a first option for health seeking and those who did subsequently sought out care from the hospitals or communal health stations, once they realized traditional methods were ineffective in controlling seizures:

> "I wanted my granddaughter to be examined in health station but her father let her treated by traditional medicines. For a long time she took them, but her condition did not relieve. Then we took her to see a doctor"` [FAMS43][2].

All but two of the participants with epilepsy were currently receiving treatment for their seizures. The duration of treatment ranged between one and several years though a few participants were unsure about the length of the treatment period. Participants commonly reported accessing a number of doctors and hospitals as well as utilizing both Western and traditional treatment methods; spending a great deal of time and money in their search for appropriate treatment.

Participants commonly acknowledged trying every method they knew as a potentially effective method of treatment:

> "I applied every remedy that was told me effective, include hedgehog's stomach" [FAMN34].

Other cited treatment practices included the use of spiritual methods, Chinese and Vietnamese remedies and other Western drugs and responses indicate that several participants were still searching for a more effective way of treatment.

3.1.2. Experiences regarding treatment and the healthcare system—

Although electroencephalogram (EEG) is one of the commonest tests used to aid diagnosis of epilepsy [26] only a very small number of participants reported having had one, the majority of whom lived in North Vietnam. One participant from South Vietnam reported being asked to have an EEG, but because of the financial cost involved was unable to undergo the investigation. Other infrequently reported tests undergone by people with epilepsy were blood tests and some unspecified head, brain and bone morrow tests. None of the people with epilepsy reported having had Cranial computed Tomography (CT), or Magnetic Resonance Imaging (MRI).

Very few participants with epilepsy reported being treated at a hospital. Almost all received their drugs, generally Vitamin B1 and Phenobarbital (known locally as Gardenan), from commune health centers or district health stations for free on a weekly or monthly basis. A number of participants bought their medicines from a drug seller or pharmacy; including two participants reporting they imported Western AEDs from France.

Just over half of the participants, including people with epilepsy and their family members stated that treatment with Western medicines was effective and seizures were reduced in the affected person after the commencement of such treatment. However, some individuals reported that although they/their relative with epilepsy took the medication regularly, there was no improvement in their condition; and one person with epilepsy considered his condition to have worsened after starting treatment. A number of individuals reported buying additional AEDs, either because they believed the current dose was not enough or that by increasing the

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[2] In this and subsequent quotations, informant type is denoted by the codes in the parentheses; PWE, person with epilepsy; FAM, family member; N, North Vietnam; S, South Vietnam.

dose their recovery would be quicker. In addition some participants reported buying or using other types of medicine, either traditional or Western, in an attempt to protect against the side effects of the AEDs they were taking or as a means to maximize their effects:

> "Sometimes I have to buy more drugs when I had a serious seizure because I think may be seizures are caused by inadequate dose of the drugs" [PWES23].

Expressed concerns in relation to medication taking centred around either the potential for or the experience of drug side-effects, the clinical effectiveness of drugs, and the cost and accessibility of drugs. Some participants had concerns about the potential toxic or poisonous effects of Western medicines specifically:

> "Patients just want the adequate amount of medicines because medicines are poisonous so who wants to have more" [FAMN08].

Alleged AED side-effects were reported by around one fifth of the participants, including memory problems, weakened heart, teeth and liver, tiredness, feeling depressed, constipation, skin problems, weight gain and ulcerated mouth:

> "I had to return him many times to the hospital to change the meds because they caused side effects like pimples on the face and his eyes almost closed" [FAMN34].

A few participants who had experienced side-effects quit the drugs without consulting their doctors; others had continued taking them, but expressed the desire to quit the drugs or change to another.

Related to the cost of medicines, participants only recently accepted into the Government epilepsy program and those still not included in it reported finding it hard to afford medicines and that doing so caused financial difficulties in the family. This meant they sometimes went without treatment. With regard to the issue of accessibility of care, the majority of people with epilepsy and family members reported that they/their affected relative received medicines without any problems or difficulties. Nonetheless, there were a few who said they experienced problems in getting their medicines at the scheduled time and sometimes had to wait to receive them or needed to buy medicines from a pharmacy because of the limited stocks available in local health centers or hospitals:

> "One time when I went to the communal health station to get my son's medicines, the staff did not give me the medicines and they told me come 2–3 days later and they asked me to go somewhere else" [FAMS37].

Also, access to treatment, especially to higher health care units and different kinds of AEDs was reported to be problematic by a number of participants:

> "I asked neurologist from district level to come and examine the patient, but no one came. And I experienced the same situation for medicines also. It is difficult to get additional tablets - there are only vitamin B1 and B6 tablets but nothing special about restorative meds" [FAMN08].

No direct reference was made to use of local or traditional treatments by around half of our participants; and a few stated specifically that they have never made use of such methods. Among those that admitted to doing so, traditional remedies used for the treatment of epilepsy included eating the gall bladders, stomachs or other parts of animals, or drinking special powders such as powders made from human bones. Some participants reported the use of `unspecified' Chinese and Vietnamese applications. Praying as a means of treatment was reported only rarely. The most commonly cited effective traditional intervention to stop seizures when they occurred was giving the patient lemon or citronella juice. Applying massage to the legs and arms of the patients or coin rubbing, glass cupping or applying acupuncture to soften rigid muscles after a seizure were also cited as traditional treatment approaches. The majority view, however, was that traditional or local methods were less effective than Western ones, as one mother from South Vietnam explains:

> "My daughter had acupuncture for 2 months before getting better and has also taken traditional medicines. I took a quack to home to do acupuncture on my daughter. I also asked a grave digger for human bone, which I ground into a powder for my daughter to take with water which was suggested as a folk remedy for epilepsy, but was unsuccessful" [FAMS33].

With regard to our participants' experiences of health care workers, these appeared to be more often negative than positive. The most common complaint made by both people with epilepsy and their family members was not receiving sufficient information about either epilepsy or its treatment from their doctors:

> "Doctors did not provide information about condition - just prescribed medicines, but sometimes didn't even do that" [PWEN05].

Healthcare workers were also reported as not always being helpful and not always being polite. In contrast, some participants stated that healthcare workers were doing their job in a friendly manner and were enthusiastic and helpful, providing useful information, especially about safety issues and prognosis. Almost equal number of participants expressed the view that healthcare workers were doing what they should be within the limitations of their role, namely, dispensing medicines or conducting health checks, and providing a diagnosis.

3.2. Perceived Impacts of Epilepsy

3.2.1 Impact for psychological well-being and physical health for PWE—

Especially in South Vietnam, most people with epilepsy and family members said they did not feel different from others, and that epilepsy did not affect their lives or present any extra difficulties for them. A smaller number of people with epilepsy, however, saw themselves as different, not normal, because of their condition. Additionally, some reported negative feelings toward having epilepsy: these included feeling ashamed of it, feeling suicidal, feeling inferior to others, feeling self-pitying, feeling a burden to others, and finding epilepsy a hard condition to cope with:

> "I am not really sure of the significance of epilepsy but because I have been infected with epilepsy I have to bear it" [PWES01].

Although not a common theme, a few respondents with epilepsy thought that having epilepsy would affect their future badly and that as a consequence, they just lived for the present and did not think about the future.

> "I can only live for today and unsure about tomorrow - feel very sad" [PWEN07].

Most participants with epilepsy reported a sense of being a burden to others, particularly financially and psychologically to their families.

> "I am a burden to my family because they have to take care of me and they worry about me" [PWEN04].

The psychological impacts (feeling sad, miserable, frightened) of epilepsy were highlighted by many participants. One person with epilepsy reported suicidal ideas and another reported an actual attempt at suicide. Character changes, such as being angry, stubborn, hot tempered, aggressive toward others or having drinking problems following the diagnosis of epilepsy were reported frequently by family members:

> "Child's character has changed. He is very irrational and hot tempered at times, often hitting out at us and then apologizing" [FAMS35].

Memory problems, learning difficulties and cognitive impairment were reported frequently, especially in relation to patients who were still in education:

> "My daughter passed all her exams but her memory is not as good - when she answers the phone she cannot remember any thing about the conversation" [FAMN39].

Another common theme was that around concerns and fears about sudden death in epilepsy or being at risk during a seizure. Linked to such fears, many people with epilepsy and family members, especially in South Vietnam, believed people with epilepsy should stay away from lakes, rivers or ponds to avoid the risk of drowning during a seizure. Some participants recounted anecdotes about serious accidents which happened to other people with epilepsy whom they had known or heard about; most of these accidents, most often involving drowning, had ended in death:

> "I have heard about another boy in the village with epilepsy who had a seizure by the river, fell in and drowned" [FAMN38].

In reality, despite the frequency with which such fears were held, few participants reported any personal experiences of seizure-related injury. In contrast, most participants with epilepsy complained about feeling weak, unhealthy, tired and looking pale, some of these symptoms participants felt may be related directly to their epilepsy while other symptoms may be as a consequence of anti-epileptic drug side effects. Other physical complaints which were commonly attributed to epilepsy included headaches, feeling hot inside, being thin, experiencing a racing heart, difficulty in sleeping, delay in menstruation, facial acne and arrested development. Some participants also complained about post-ictal effects such as headaches, tiredness, exhaustion, and weakness for a couple of days after the seizure.

3.2.2. Impact for working, social life, daily living activities and education—Several participants listed jobs which are forbidden to people with epilepsy or should not be done by people with epilepsy, including physically heavy work, work at high altitudes or in water, work involving driving or climbing. Participants who were able to work generally stated that they did not encounter serious problems due to epilepsy during working hours; on the other hand very few participants worked without experiencing difficulties such as impaired attendance due to seizure occurrence and an inability to do certain types of work for fear of triggering a seizure.

While a number of people with epilepsy currently in employment commented on the supportive attitudes of their employers, others stated that, despite their willingness to work, no one would hire them and they had been refused employment many times because of their condition. Unfortunately, respondents who were not in employment, had taken early retirement or quit their jobs due to epilepsy were more numerous than those who were able to work and in employment. Some participants unable to work in paid employment were, nonetheless, able to work in and around the home, for example doing gardening or taking care of children. Very few of those out of employment wanted or expected to be able to work again.

> "My parents restrict me from going into the kitchen or going outside to play. I am not allowed to go near water or to go fishing" [PWES02].

With regard to daily living activities, people with epilepsy not uncommonly commented that they just stayed at home, being unable to do anything without the help or supervision of others. Participants who had responsibilities for care of others - children or other family members, or domestic animals such as cows – sometimes had problems fulfilling these roles due to seizures:

> "I am afraid of holding my own children in my arms in case I have a seizure and let my child fall many times when I was holding" [PWEN01].

Other daily living activities that they could not do or were not allowed to do including washing clothes, cooking, having a bath, play outside, go near to rivers or lakes, and playing sport. People with epilepsy also complained about being unable to go out or travel alone. In addition to facing official driving restrictions, some were not allowed by their families to do so, due to their families' concerns about their safety:

> "I can go to work everyday. If I feel tired then I will take a couple of days off from work and return when I feel better" [PWES01].

With regard to education, almost half of the participants with epilepsy reported dropping out of school once they started having seizures. The reasons cited for this were learning and memory problems and concerns for their safety:

> "I do not let my child to attend at school because she can fall down suddenly" [FAMS35].

Common complaints stated by people with epilepsy who were still in education included cognitive impairments, memory and learning difficulties and not being as academically able as unaffected classmates following the onset of epilepsy. A number of participants considered epilepsy had affected their/the affected person's educational progression negatively:

> "People with epilepsy have no future and can not go to school" [FAMN34].

Perceived impacts on social life included the possible negative effects in terms of finding a girl/boy friend or marriage partner. Some participants saw this issue as related to the possibility of epilepsy being inheritable, as one person with epilepsy from North Vietnam explains:

> "I saw a TV program about epilepsy which said that a girl could not get married because she may genetically transmit epilepsy" [PWEN11].

Among the few participants with epilepsy who were married, two, both men, reported they had been abandoned by their wives because of their seizures. Several participants believed that epilepsy would impact negatively the issue of family formation: some reported having had children without any problems, but others said they had no children, or did not dare have any more, out of fear that epilepsy would affect the offspring in some way.

3.2.3 Perceived differences in impact by gender and socio economic-status—

The majority of participants expressed the opinion that epilepsy is worse for women than men, mainly because women are physically weaker and it can be much more difficult for a woman with epilepsy to marry or give birth to a healthy baby since epilepsy was commonly seen as inherited from a mother, rather than from a father. Only two married people with epilepsy disagreed with the view that epilepsy affects marriage prospects. Epilepsy was also seen as presenting more difficulties for a woman because women were viewed as more timid than men and so less able to go out and make friends easily:

> "Epilepsy is more difficult for girls since if my child were a girl instead of a boy it would be a bit difficult for me to take care of when she had a bath or went to toilet. Also epilepsy can be more difficult for women in terms of getting married, go to school or finding a job" [FAMN34].

Those participants who supported the idea that epilepsy is more difficult for men explained this by the need for men to earn money for the family:

> "Epilepsy is more difficult for men because men are the workforce of the family. If a man does not work, it would be a burden. But a woman could get something to eat in anyway" [FAMN35].

However, some participants did not consider there were important differences in terms of gender, the impact being more dependant on the severity of the epilepsy.

In terms of economic status, almost all participants agreed that epilepsy is worse for poorer people since it is more difficult for the poor to receive treatment and medicines:

> “The disease (epilepsy) is horrible if you don't have money. If you are rich it can be treated” [FAMS31].

3.2.4. Impact for others—

The greatest impact of epilepsy for family members appeared to be on psychological health. They reported feeling scared and hopeless about future, angry, sorry, and fearful of their affected family member experiencing sudden death or injury due to having a seizure. In addition, family member participants also stated concerns and worries about the current health status of their family member with epilepsy:

> “I constantly worry for my daughter's welfare, especially on roads or if she fell and banged her head unsure what medicines to get to cure condition. Always has a feeling that she will die suddenly” [FAMS31].

Family members also expressed concerns about the burden of caring: that they had to take care of the person with epilepsy constantly, were facing difficulties due to the family member with epilepsy, or shouldered all the responsibilities for the management of treatment of the person with epilepsy:

> “Family has suffered a lot of hardship looking after my daughter who has had condition from birth and is now 41 years old. My daughter requires total care - toileting, meal preparation etc. She is totally dependant on other adults” [FAMN08].

There was also a significant financial burden to carers, either because the family member with epilepsy was unable to work, and other family members had to work to compensate for this situation; or because carers themselves were forced into early retirement or to quit employment in order to look after the person with epilepsy. Meeting the costs of health care and drug treatment expenses was another source of financial stress. When asked whether epilepsy impacted negatively on society as a whole, most participants considered this not to be the case.

3.3. Attitudes and actions

3.3.1. Attitudes and actions of family members—

Generally family members were seen as holding very positive attitudes towards epilepsy and were commonly reported as assisting in the healthcare of their affected family member and the daily management of their condition, and as offering support, help and encouragement and showing sympathy and compassion:

> “He is our child regardless of whether we are rich or poor we have to help him to treat the disease. Nothing is difficult I have to try my best to help him” [FAMN33].

Family members were reported as keen to receive information about epilepsy; and as trying to earn enough to pay for the treatment of the person with epilepsy.

In keeping with the literature on familial attitudes to people with epilepsy, some families were seen as having overprotective attitudes toward their family member with epilepsy. These were manifested as not allowing people with epilepsy to do anything at home or in the community, not allowing the person with epilepsy to attend school, and encouraging people with epilepsy to quit employment after the commencement of seizures:

> “Generally we don't let our son do too much and he doesn't have to think about too much – we like to keep him close so that if he 'falls down' we can be there to hold him” [FAMN41].

Unsurprisingly, despite their willingness to help and support a family member with epilepsy, family members, especially in North Vietnam, themselves commonly endorsed more widely held beliefs about the lack of employability and marriageability of those with epilepsy:

> "She may have problems in the future with marriage and having children" [FAMN39].

3.3.2. Perception and attitudes of others—In order to explore the extent to which the daily life impacts reported by people with epilepsy and family members were related to the attitudes of others, we asked both groups what they considered to be the attitudes and responses to epilepsy of other family members, friends, near-neighbors, teachers and society more widely.

As reported by people with epilepsy themselves and family members of people with epilepsy, near neighbors' and wider community members' attitudes and actions toward people with epilepsy were more often positive or neutral than negative. Most people with epilepsy and family members regarded their neighbors and community members as not treating them differently from others, not being afraid of seizures, showing kindness, support, sympathy, affection, compassion and care towards the person with epilepsy and other family members alike:

> "People in my community treat me as same as others and when I have a seizure they come to help and after the seizure ends they talk with me as if nothing happened" [PWES14].

> "Neighbors treat child in a friendly manner and talk to her. They just feel sorry for her…they can't help anything" [FAMS31].

Feeling sorrow or pity, curiosity about epilepsy and its treatment, or thinking of epilepsy as a form of misfortune was also reported. In contrast, a few participants had experienced very negative attitudes and actions from friends, neighbors and community members including discrimination, teasing, abandonment, rejection and avoidance, harassment, and negative labeling for example, being called mentally disordered or mad:

> "Friends used to visit me but once they found out about my epilepsy they stopped coming, some friends even stopped talking with me. Also, some of my work colleagues did help me but others picked me out for hostile criticism to prevent me from teaching [PWEN05].

In terms of the attitudes of the teachers, although few respondents mentioned the subject, the general view was that teachers generally held either positive or neutral attitudes toward their students with epilepsy, rather than negative ones. This included sending the student home or contacting the parents after a seizure, being helpful and supportive and not showing any discriminatory behavior. Teachers were also positively recognized for the role they played in giving advice and information about the student's current condition to the family. Only one person with epilepsy reported being advised by a teacher to drop out the school:

> "He learnt almost nothing because he was having many fits. He repeated grade 1 many times and in grade 2, teacher advised him to stay at home" [FAMN34].

3.4. The question of disclosure

Most participants with epilepsy and family members stated that they freely disclosed the condition to others. However, some participants preferred selective disclosure, only disclosing to relatives and/or close friends, or under certain circumstances for example, when someone asked directly, or when they heard a conversation about a possible remedy. Few participants had disclosed the epilepsy to classmates and teachers. Disclosure of epilepsy to a prospective marriage partner or girl/boy friend appeared more common than keeping it secret from them. Only very few participants reported that they strictly concealed epilepsy from others, including relatives and friends, though in one case a parent had concealed the condition even from the patient, her daughter:

> "My mother hide my medical report so I have only just found out that I have epilepsy - when I asked about my condition to my mother she told me it was normal and nothing serious" [PWEN11].

The most common motivation for disclosure was the possibility of getting help such as seizure intervention, guidance and advice about treatment or any kind of psychological support from others or just protecting the person with epilepsy from any kind of psychological or physical strain. Other justifications for disclosure were related to the visibility of the seizures and acceptance of the non-transmittable nature of epilepsy to others:

> "I would always speak out to get assistance from relatives and others. In this way they would be able to encourage me and I would feel better. I would not keep quite because without the assistance of others I would find the disease difficult to cope with on my own and worry" [PWEN09].

The most important motivating factor for non-disclosure or selective disclosure was the view that telling others was pointless, since there was nothing that they could do to help. Further, if seizures always occurred at home or at night only, it was not considered necessary to tell others. A more serious reason for non-disclosure was the fear of discrimination by others:

> "Although my classmates saw I loose consciousness I have not told them that I have epilepsy because I fear they may discriminate against me" [PWEN11].

4. Discussion

The present paper is aimed at understanding the real life experiences of PWE and their family members in Vietnam in terms of treatment in, impact of and attitudes toward epilepsy by using " the local words" [27] of the participants. In terms of treatment, our analysis indicates that one of the most problematic conditions that PWE have to face with in Vietnam is the limited options with regard to availability of different kinds of AEDs. In the national anti-epilepsy program, the only choice of free treatment is limited to Phenobarbital due to its relatively affordable financial cost relative to other AEDs [22]. Consequently, it is argued that not the diagnosis of epilepsy but the non-availability of AEDs is both a cause of the treatment gap in developing countries and probably the most important obstacle in reducing this gap [5].

The second most often stated difficulty related with treatment is the cost of AEDs. This is a general problem across Southeast Asia, since the cost of Phenobarbital is 2.7 times higher in Southeast Asia than it is in Europe [3] and 2–6 times higher than in Sub-Saharan Africa [21]. Third, beliefs and common practices about taking western drugs, such as the belief that Asian people have a very different physiological constitution than whites and thus western medicines are too heavy for Asian bodies [23], also creates a negative outcome for treatment and experienced real side effects of the drugs also contribute to this situation.

Additionally, while in general our informants' reports lend support to the Vietnamese Government's provision of free western medical treatment for people with epilepsy, informant responses also highlight areas of this provision which they believed had failed them. This perceived failure, underpinned by individuals' `situated experience', appears to be shaped by a number of factors including: the structural mechanisms for recruitment and access of people with epilepsy to this program of care; limited access to physical facilities such as EEG and MRI; lack of epilepsy surgery centers, and limited knowledge of and satisfaction from health professionals in their provision of appropriate care and support. If the challenge to provide quality care in the treatment and management of epilepsy is to be met and in order for these issues to be solved progressively, greater multidisciplinary links between co-ordinators of care, pharmaceutical companies, health professionals and educators must be integral to the Government's support program..

In terms of health seeking, the typical first response to seizures is seeking treatment at hospitals. Most participants had turned to a health facility soon after onset of the disease. For relieving seizures Western medicines obtained through the formal referral system are preferred. Both formal and informal traditional medicines are generally considered as a second choice after western medicines. Thus, only very few participants prefer to seek western health care only after traditional methods fails. This finding is also consistent with previous findings ([e.g. 24,28,29]) such that although people believed that epilepsy should be treated with traditional medicine, when an actual health problem occurs people prefer taking western medicine, finding western-trained physicians better at diagnosing illnesses [29]. Even in Western societies it is not unusual to apply - especially among ethnic minority groups - alternative-traditional treatment methods as well as orthodox medicines [28,30–34].Therefore, it is surprising to observe the rare application of traditional treatment methods in a country like Vietnam, which has a rooted traditional treatment practice.

In terms of impacts and limitations caused by epilepsy, participants experienced them across a wide range of different life domains. Most of the restrictions and limitations are based on a lay theory that seizures often follow overworking or nervous tension. Participants stated that over work and tension does not *cause* epilepsy, but since PWE already have “weak nerves” these factors can exaggerate the weakness, which in turn leads to a seizure. Therefore, PWE often kept away from tension and overwork in order to prevent a seizure and PWE are “treated more gently”. As a result, PWE cannot do two important tasks for Vietnam: working in the rice field and doing household chores [22]. However, there is no consensus in the narratives to explain the reason behind the “weak nerve” belief. Some people explained the “weakness” as hereditary. All these beliefs about “weak nerve” and inheritance might be a risk for overprotection and prejudice which creates disability and discrimination, especially with regard to the marriage prospects of women with epilepsy, even if the seizures themselves are not severe enough to affect a person's ability to lead a normal life. Too much emphasis on risks and limitations attached to the disease might strengthen the stigma related with epilepsy and dependence to others [23]. This “weak nerve” belief also leads to avoidance of all kinds of physical and mental strain including working, farming and education. When we investigated the condition in relation to education, we saw that in order not to create mental and physical tension in the child with epilepsy, parents lowered their expectations and the child studied as much as s/he could and dropped out whenever s/he wanted. Concerns related to the safety of the child during and on the way to the school also contributed to school drop outs. Memory impairment and difficulties in learning related with seizures and/or AEDs are the other reasons stated by our participants for school drop out. Therefore, the majority of our participants ended their education at elementary level and just one participant graduated from high school. This result is also in concordance with results from western societies which reported lower level of education among PWE [35].

Another limitation reported by our respondents is dependence in mobility. PWE cannot have driving license in Vietnam, like in some western societies [36–38], therefore public transportation is the only available means of transportation for PWE, and not affordable for many participants. Thus, they can travel only on feet or by bicycle. For long distance travel, they have to rely on others. As a result of all these limitations stated above, most of our participants do not work, do not have any occupation and spend all their time within their homes by basically doing nothing. When financial difficulties caused directly or indirectly by epilepsy were added to this situation, most of our participants with epilepsy reported a sense of burden to others, social withdrawal and reduced expectations for the future. This finding corroborates the findings from Western societies which also reported low level of employment among PWE

[37,39–43].These feelings also contribute to their sense of stigma and negatively affect their psychological well being and adjustment to epilepsy. Similarly, family members expressed carer burden and financial difficulties caused by epilepsy.

To understand the attitudes toward epilepsy in Vietnam we looked how epilepsy is seen and treated in Vietnamese culture. Within traditional medicine, epilepsy is officially regarded as a psychiatric disease and all people with epilepsy are considered to have a psychiatric illness or to be intellectually impaired. The terminology relating to epilepsy also tells us a lot about how epilepsy was explained and perceived in Vietnamese culture. Đông kinh (unstable nerve) is the most common term used for epilepsy. Both western and traditional practitioners use this term in diagnosis and naming the illness. Almost all of the other terms to describe epilepsy and a seizure are the combination of kinh (nerve) and phong (wind). The word for epilepsy used by the traditional doctors is “Kinh Gian” and it can be translated as “kinh” meaning convulsion and “gian” meaning mad [22].

Contrary to the above statement that epilepsy is accepted as a mental illness in Vietnamese culture, most of our participants with epilepsy and family members do not seek to hide epilepsy from others. They reveal epilepsy in a way that we would call “pragmatic disclosure”; they disclose epilepsy when they need advice or guidance for a new remedy or when they think the person could be helpful during a likely seizure. Only very few of our participants strictly conceal epilepsy from others and few of them do this from the fear of enacted stigma. This result is also interesting, since previous findings [44–46] from Western societies reported more non-disclosure of epilepsy than we observed in Vietnam.

In terms of the attitudes and actions of neighbors and wider society, most informants stated that they or their family member with epilepsy do not experience any stigma or discrimination because of epilepsy. However, we observe differences between North and South Vietnam in terms of actions, perceptions and attitudes toward epilepsy and people with epilepsy, such that participants from South Vietnam are more likely to report that they do not feel different due to epilepsy. Also, protective and supportive attitudes and actions, such as concern about the safety of, or compassion toward a person with epilepsy or willingness to help a person with epilepsy during a seizure, were reported more commonly by South Vietnamese participants. On the other hand, North Vietnamese families reported more negative attitudes toward their children with epilepsy such as expressing negative expectations about working and marriage prospects of their child with epilepsy or believing epilepsy is a kind of bad luck and showing negative actions. But, of course this finding should be taken into account with a certain degree of precaution since we have limited numbers of participants, especially from North Vietnam.

This paper is a part of an extensive research project called CREST (Collaborative Research on Epilepsy Stigma Project) and limitations of the study are discussed in detail in Jacoby et al. [18]. But, we believe we need to say a few words about the limitations here. The most important of these is the limited number of study sites. In Vietnam, our studies focused on samples drawn from one northern (Hanoi) and one southern (Cantho) province only. We therefore acknowledge that our findings may not reflect the views of people in Vietnam as a whole and can not necessarily be generalized to other settings or contexts beyond those sampled.

As a conclusion, to reduce the impact of epilepsy, limitations and stigma related with epilepsy in Vietnam, community based free rehabilitation programs which are accessible to all PWE, access to different kind of AEDs and high level treatment and diagnostic test facilities are needed. Also, supporting information for PWE, family members and general public about epilepsy, treatment and psychosocial effects of epilepsy is necessary.

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Table 1

Vietnam Informant type and Demographics

	North Vietnam (Hanoi) N=23		**South Vietnam (Cantho) N=36**	
Informant Type	**Gender**	**Age (Mean/Median/Range)**	**Gender**	**Age (Mean/Median/Range)**
People with epilepsy	4 Males 7 Females	37.82/38.00/ 15–77	10 Males 11 Females	39.57/37.00/ 14–82
Family members	5 Males 7 Females	47.17/42.00/ 15–74	3 Males 12 Females	53.14/56.50/ 32–74

Table 2

Summary of key findings

Treatment issues	Perceived impacts	Attitudes/Actions	Disclosure issues
• Majority in both S/N Vietnam initially sought Western medications • Access to diagnostic facilities limited and costly • Post-diagnosis, search for appropriate treatments continued • Western and traditional medicines commonly utilized • Western AEDs seen as more effective, but concerns also expressed • Generally negative perceptions of HCWs	• Particularly in S Vietnam, PWE seen as no different • Many PWE felt were burden to others • Multiple restrictions on daily living identified • Epilepsy seen as worse for women	• Family members generally held positive attitudes • Family members keen to receive information • Family members actively sought support for PWE	• Disclosure by both PWE and family members common • Disclosure often pragmatic

Key messages: Limited AED options; high drug costs; lay beliefs create potential for major life limitations; disclosure common; stigma more marked in north than south.

Key implications for epilepsy care: improved links between care providers, pharmaceutical companies, health professionals and educators integral to Government support programmes.