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# The stigma of people with epilepsy is demonstrated at the internalized, interpersonal and institutional level in a specific socio-cultural context: findings from an ethnographic study in rural China

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## Abstract

Epilepsy is a common chronic neurological disease. One of its characteristics is that it can bring severe stigma for patients. At the same time as controlling the epileptic seizures, taking appropriate measures to reduce the stigma of epilepsy is an important aspect of any comprehensive intervention strategy. We examined the views of 106 participants of different target groups, including patients with epilepsy (PWE), their family members, neighbors, teachers, employers, community administrators, doctors and nurses, using one to one in-depth interviews and group discussions. The discussions covered the following aspects related to epilepsy: the participants' understanding of epilepsy, the patients' own perception of epilepsy, the attitudes of surrounding people, the social and cultural environment, the social support available to them, and government regulations and policies. We found that the stigma of epilepsy is a very negative self-feeling from the patients' perspective. Many complex and diverse factors determine its formation and severity. The stigma of epilepsy, in a particular social and cultural context, can be demonstrated in the internalized, interpersonal and institutional levels. Hence, we suggest that effective measures to alleviate stigma should be based on ways of eliminating factors which cause institutional stigma. Additionally, depending on the specific circumstances of PWE, a personalized approach to eliminate factors which cause internalized and interpersonal stigma needs to be adopted. Only by addressing impacting factors at each of these three levels, can the stigma of PWE in China be alleviated or even eliminated.

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## Conflict of interest statement

We have no competing interests.

## 1. Introduction

Epilepsy is a brain disorder characterized by an enduring predisposition to generate epileptic seizures and by the neurobiological, cognitive, psychological, and social consequences of this condition. The definition of epilepsy requires the occurrence of at least one epileptic seizure. [1]. There are about 9 million people with epilepsy in China, around 6 million of who experience continuing seizures every year. There are estimated to be 400,000.00 new cases every year [2], of which about 60 % – 70% are in rural areas. The education level of the rural Chinese population is generally low and they lack appropriate knowledge about epilepsy. The symptoms of seizure onset such as a sudden fall, the convulsion of limbs, foaming at the mouth and so on, can easily lead to misunderstanding and fear of surrounding people. This makes patients in rural areas more likely to become the subjects of prejudice, discrimination and alienation. Individuals with the condition are often left out by others in social activities and will experience a loss of social identity or even be cut off from normal social life. This will cause a sense of stigma [3–6].

European surveys indicate that more than 50% of PWE feel stigma [3]. Due to the larger cultural difference across Asian countries, the range of reported stigma is between 9% to 89% [4–5]. Studies in China report stigma to be felt by 71% in urban areas and by 89% [6] in rural areas. Several other studies concerning quality of life indicate that the score for the quality of life of a PWE is lower than that of normal control subjects. One of the reasons is that they possess a higher degree of stigma [7–9].

The stigma of PWE can be seen as a negative self-evaluation, accompanied by a negative emotional experience stimulated by the responses of others. Sufferers often try to conceal or deny their condition. Many studies show that the degree of stigma is influenced by age, sex, age of onset, course of the disease, seizure frequency, seizure type, understanding of epilepsy, knowledge and the attitudes of people around, the treatment process and side effects of drug and many other factors [10–11]. The mechanisms, through which these factors cause stigma, and the weight and interaction of these factors, depend upon the social and cultural context of specific groups or For example, in developed countries and among people with a higher education level and a better health care system, the stigma of PWE is significantly different from that in developing countries in both the content and extent. For example, whereas 15% of interviewees in Australia are against the marriage of their children to PWE [12], this proportion is as high as 62.2% in South Korea [13] and even higher in China at 87% [14].

In 1996, the International League Against Epilepsy (ILAE), International Bureau for Epilepsy (IBE) and World Health Organization (WHO) jointly launched the Global Campaign Against Epilepsy (GCAE), the aim of which is to reduce the treatment gap and bring PWE “out of the shadows”, and so prevent and eliminate the stigma.

The analysis presented here is drawn from a subset of data we obtained from a large-scale ethnographic study (CREST) conducted in China and Vietnam in collaboration with the GCAE. The study aimed to explore epilepsy-related stigma and related socio-cultural factors. We focused on analysis of data from PWE and their family members in Shunyi District, a rural area in Beijing, China. The data included the epilepsy-related knowledge and beliefs of PWE and their family members, the meaning of epilepsy held by people around them including teachers, employers, doctors, nurses, social administrators, neighbors, and their attitudes towards PWE. Also included in this analysis is the impact of the social medical insurance system and government policies and regulations on PWE. We have explored various factors and mechanisms linked to stigma of epilepsy in this specific social-cultural context. Base upon this analysis, we highlight the need to draw up effective

measures to prevent and reduce stigma of PWE, improve their quality of life and bring them 'out of the shadows'.

## 2. Method

Our study is a part of CREST project that explored the views of rural Han Chinese people about epilepsy and the causes of stigma associated with this disorder. The study group consisted of 106 participants from rural Shunyi District of Beijing. We carried out one to one in-depth interviews with 24 PWE, 24 family members (FM) of PWE, 18 doctors (DR), 6 village doctors (VD), 6 town clinic physicians (TCP), 6 traditional medicine practitioners (TMP) and 4 employers (EMP). We also conducted focus group discussions for nurses, primary school teachers, junior high school teachers, community leaders and neighbors with six participants in each group (Table 1). The 24 patients, of whom 13 were male and 11 were female, were assigned into four age groups: 14–19 years old ( $N = 5$ ), 20–35 years old ( $N = 7$ ), 36–59 years old ( $N=10$ ), and 60 years old ( $N = 2$ ). All patients signed the informed consent. 15 patients were married and the remaining nine were unmarried. Apart from one patient had never attended school, the number of patients had the education level of primary school, secondary school, high school, and college, are 4, 15, 4 and 1 respectively. Of 21 adult patients, only 8 were employed, mostly in low-paying jobs, such as bricklaying and decoration; 4 were farmers; 3 were unemployed; and the 6 female patients engaged in domestic labor. The number of patients in each of the following annual household income ranges is: <1000 Yuan RMB, 1; 1000–5000 Yuan RMB, 6; 5000–10000 Yuan RMB 10; and 10000 Yuan RMB, 6. All the patients had been correctly diagnosed by qualified hospitals. They understood the questions for the interview and were capable of expressing themselves accurately. The data collection was undertaken by a team from Beijing Neurosurgical Institute who received formal training in qualitative research methods prior to the commencement of fieldwork. The training also included conducting rapid appraisals of the condition of a PWE before the interview [15].

Table 2 shows the demographic information of the 24 medical workers in this study population, including their education background

All the interviews were recorded (with the permission of the participants), transcribed and subsequently translated into English. The translation was reviewed and cross-checked by the project leaders with special attention paid to the specific meanings of any cultural terminology. The interview data were collated by theme codes and supported by the results of qualitative data analysis. Three experts summarized the interview transcripts and compiled an initial set of codes for major themes and sub-themes. To ensure the quality and consistency of the coding process, every fifth transcript was double coded, and any discrepancies were discussed and resolved by the coding team. Coded data were tabulated by using Excel to facilitate transfer between group members. The detailed method is described in a previous publication [16].

## 3. Results

Our analysis shows that all the patients with epilepsy in this study felt stigma, the severity of which varied dramatically due to different factors between cases that caused the formation, enhancement or weakening of the stigma. Acting upon different individuals with epilepsy, the same factor may elicit a similar or significantly different reaction. These factors cause two kinds of relatively independent reactions for PWE: the psychological response experienced by PWE themselves that they may therefore be able to control and manipulate; and the interpersonal responses they encounter in their dealings with others, which are

largely beyond their control. These two kinds of reaction can be demonstrated as aligning to Mulhauers's analysis [17] of internalized, interpersonal and institute stigma.

### **3.1 Factors relative to internalized stigma: PWE's knowledge, beliefs and perception of epilepsy, and the impact on their daily life**

Most of the patients we interviewed in this study had a low level of education and were unable to access good health care. They often obtained inappropriate knowledge about epilepsy from irregular channels. Their knowledge about epilepsy included both Western medicine and Chinese traditional medicine, but also included views of superstitious nature.

Most of the PWE participants recognized epilepsy as a neurological disorder. The cited causes of their condition included head injury, perinatal trauma, encephalitis or meningitis, hypertension, stroke, malnutrition, febrile convulsion and so on. A number of patients said they did not know the causes. Patients who knew the causes had less fear, a more positive attitude and higher confidence in the cure or control of their condition than those who did not know the causes.

The interviewees decided whether epilepsy is hereditary or not according to what they heard and observed, but they were not confident in their judgments (see Box 1). The patients who believed epilepsy is hereditary usually felt a higher degree of stigma. They felt inferior to the people around them, such as friends, neighbors, or workmates; and often had a skeptical attitude to their own ability for learning or working. They were more cautious about dating and marriage, and often tried hard to conceal their condition. They were likely to lower their criteria for choosing their partners. In contrast, those who believed that epilepsy is not hereditary condition felt less stigmatized and generally had none of the above problems.

Most of the interviewees were confident that epilepsy is not contagious based on their own life experience and that of the people around them, and accordingly some of them had no reservations in contacting other people in social activities. However, some patients, even though they believed that epilepsy is not contagious, were still self-conscious in their social life and kept their distance from others, indicating that they felt fear and suffered from low self-esteem because of their condition (Box 1).

The sudden onset, without warning, of epileptic seizures forces PWE to pay particular attention to the triggers for their seizures (see Box 1). A number of emotional traits were frequently cited as triggers for onset. These included stress, anger, fear, excitement, grief, and depression. Other cited triggers included fatigue, cold, drinking, narrow mindedness, bathing and washing clothes in cold water, and even the wading through fields of cold water. Interviewees showed polarized attitudes towards triggers. Some tried hard to avoid triggers in their daily life in order to reduce the occurrence of seizures. Others showed an indifferent attitude to triggers because they believed that seizures might still attack without any warning even though they tried hard to avoid those triggers; and they observed that triggers did not always lead to seizures.

### **3.2 Factors relative to interpersonal stigma: clinical manifestations, clinical course and treatment of epilepsy**

The manifestations of seizures described by the interviewees varied. Most of them experienced generalized tonic-clonic seizures with loss of consciousness. Other symptoms included convulsion, dizziness, brief lose consciousness and so on. Generally, the severity of stigma felt by the patients positively correlated with the frequency and severity of seizures (see Box 2). However, under the same conditions, the difference between individuals was very evident.

A small number of highly educated interviewees with better knowledge and understanding of epilepsy prepared themselves for the possibility of seizures not only psychologically but also with counter-measures. Thus, they had less fear of seizures. Most of interviewees expressed fears about the unpredictable and variable nature of seizure occurrence. At the same time, our interviewees also mentioned that persons with epilepsy hardly show any difference from other healthy people during the seizure-free time.

Most PWE lose consciousness during a seizure. A small number of people with partial seizures remain conscious. After the seizures, most of them just feel a little tired but without any physical pain (if the seizure attacks have not caused any body injuries). Therefore, the stigma brought by the seizure is often a psychological reaction. The various manifestations of seizures may cause fear and anxiety in the surrounding people, including family members and friends. Their descriptions of seizure symptoms, often influenced by the traditional and pejorative beliefs about epilepsy that are still prevalent in rural areas (for example, seizures are called “Yang jiao feng” in the rural term, meaning, “looks like a mad sheep”) enhance the negative self-feelings of PWE. In short, the stigma which could be called interpersonal stigma felt by PWE is an inner reaction of the patients caused by their response to the attitudes of surrounding people and those traditional and pejorative beliefs about this condition (Box 2).

All patients we interviewed acknowledged that epilepsy is a chronic disease and requires long-term treatment. They noted that epilepsy was difficult to cure, but that proper treatment could bring the seizures under control. They had three main kinds of treatment to choose from: Western medicine (Western AEDS), Chinese traditional medicine and folk remedies (see Box 2). Due to the limited knowledge about epilepsy, traditional beliefs and financial hardship, they often failed to get the appropriate treatment. Instead, most of them would first try the cheapest folk remedies, for example, burying catgut (catgut laid under the skin surface by means of a small incision). When this kind of treatment did not work, some turned to traditional Chinese medicine, which in many cases, was not effective and very expensive.

Nearly all the patients acknowledged that Western drugs played a significant role in control of their seizures. However, the cost was a big financial burden to some patients. Many patients had the problem of non-compliance, which compromised treatment effectiveness. Some people simply denied or even went to extra lengths to hide their condition. Some were too scared to see the doctor and to fill the prescription in person. They tended to forget or stop taking medicine as soon as their condition had improved slightly. Some patients believed that seizures would not have any effect on their daily lives when they were not active, so they only accepted treatment immediately after the seizure attack, but did not adhere to the long-term regimens. Such non-compliance often resulted in the failure to control their recurrent seizures, and subsequently impaired their confidence in treatment.

### **3.3 Other factors relative to interpersonal stigma: attitudes and practices of the family**

The epilepsy patients we interviewed often emphasized that the attitudes and responses of their immediate family and the other relatives towards their condition had a great effect on the stigma they perceived. They also conceded that they could not do anything but passively accept those attitudes and responses no matter how bad or negative they were.

Close family members (parents, children and spouses) were the main source of support and care for the patients we interviewed. The first seizures caused panic and confusion in family members, who did not know how to deal with the condition and thought their loved ones were going to die.

The views of the family members changed gradually as they learnt more about epilepsy. Most of them realized that epilepsy could be controlled though it was difficult to cure. They learnt from their experience of living that epilepsy was not contagious, but they were not sure whether it was inheritable or not (see Box 3).

All of our interviewees were from rural areas and their living or working environments were complicated with many hazards. Seizures often caused accidents and injuries, for examples, falling into water, scalding and fractures. This imposed extra stress upon the patients with epilepsy and their family who were struggling to cope with both mental and financial burdens of this illness.

The PWEs were self-conscious about the burden their family had to bear because of their illness. This had a big impact on the patients' social life. In order to avoid having a seizure in public, which they thought would embarrass their family, or having a seizure in a deserted place, which was more likely to cause accidents, they consciously reduced their social activities and isolated themselves from the outside world.

Patients from poor families were cost-conscious in choosing their treatment. In a bid to reduce the financial burden, they tended to go for the cheap regimens of uncertain efficacy, or were reluctant to stick to the long-term medication, which was one of reasons underlining the non-compliance in epilepsy treatment.

PWEs living in extended families, which are common in rural China, were often given the cold shoulder or even discriminated by some distant family members, who were also reluctant to provide any financial support

### 3.4 Factors relating to institutional stigma: attitudes of society

There was a lack of information on epilepsy in the rural schools. When the students or members of staff first witnessed seizures, they just panicked and failed to provide any appropriate first aid to the patients (see Box 4). There was no overt discrimination against our patients in school when others became more aware of their condition. Still, the patients had fewer friends than their peers partially because they did not take part in the school activities as often as others did for the fear of seizures.

Of all the employers we interviewed, only one knowingly employed a person with epilepsy who was also a relative of his. These employers had a very limited knowledge about epilepsy, mostly based in hearsay. They believed that epilepsy is not contagious, but is hereditary. The employers did not want to employ PWE mainly for two reasons (Box 4). Firstly, they were concerned about the possibility that people with this condition might cause accidents and the consequent loss to the business if they had a seizure during work hours. Secondly, they believed that a PWE would be regarded by other employees as a cause for concern and hence would have a negative impact on their productivity. In short, from the employers' point of view the liability of hiring people with epilepsy was simply too big, and there was a lack of incentive for them to do so.

With regard to healthcare, the patients with epilepsy in this study could choose from the three-tiered health facilities (village clinics, local town health centres, and the Shunyi District Hospital) for treatment. Due to convenience and cost most of them went to the village clinics or town health centres. The doctors we interviewed, especially those working with the village clinics and town health centres had not received systematic training on epilepsy as they had on other chronic diseases, such as hypertension, coronary heart disease and stroke. Instead, they acquired their knowledge on epilepsy through self-study and communication with colleagues. They cited that brain disease or brain trauma was the cause



of epilepsy, and anger, stress and fatigue were the triggers. They had a limited choice of Western medicines for the treatment. They generally had low confidence in the cure of epilepsy and the control of seizures. They also thought that seizures could cause severe damage to the patients (see Box 4).

Doctors from the village clinics and town health centres expressed their concern about the PWEs who tried to hide their condition. They did not think there was severe public discrimination against epileptic patients. Those doctors complained that their patients did not comply with treatment, either stopping taking the medicines or making their own decision to increase the doses when the effect of the medicines did not show clear effect at the early stage of treatment. Only in very rare cases the patients had their condition checked regularly. They were treated by different doctors, and were not been followed up over the time.

### 3.5 Other factors relative to institutional stigma: laws, government regulations and policies

Most interviewees in this study acknowledged that there was no clear legal restriction on the employment of individuals with epilepsy in terms of job categories and activities. However, if the employers found out that the job applicants or employees had this condition, they would turn them down or dismiss them with other excuses. Therefore, the persons with epilepsy had no choice but to take low-paid jobs such as farming, or even had no job at all.

During seizure-free periods, PWEs are indistinguishable from normal people, and hence they are not classified as disabled, and not eligible to benefit from the preferential policies in employment available to other disabled people, including working in the welfare enterprises specially set up for disabled people. There is also a lack of any social support and care system for people with epilepsy.

Students with this disorder usually received special treatment supposed to help them in school; for example, they were not given the permission to participate in certain sport activities, productive internship or some community labour with potential dangers. However, such arrangements also had the effect of making them feel isolated from their peers and even ashamed.

The patients and doctors we interviewed did not report any problems for patients in participating in the Rural Cooperative Medical Scheme, but they received very limited benefit from it. This insurance scheme only covered 5–10% of the patients' medical expense, and the patients had to pay the rest from their own pockets. This was a big financial burden for those low-income families. There was no special registration and follow-up for epileptic patients in this medical insurance scheme. Patients often abandoned treatment mainly due to the fact that they had financial difficulty, had lost confidence in the treatment, or were concerned by the side effects. This non-compliance with treatment resulted in frequent seizures. There was a lack of systematic training or education on epilepsy for the patients and those around them, including their doctors and family members.

Interviewees from all categories supported the idea of creating an organisation to provide care and support to PWE. As for the funding, they proposed that the government should provide most of it, with the rest coming from corporate donations and individual members. The members should include the patients, their family members, medical professionals and volunteers. They all believed that such an organisation would be of great help to those individuals suffering from epilepsy.

## 4. Discussion

Our study indicates that stigma of epilepsy is a complex interaction of negative inner feelings of people with the condition and their external situation. Its components and severity are influenced by many factors. In a particular socio-cultural context, these factors cause stigma in individuals with epilepsy which can be defined at three levels, internalized stigma which is mainly influenced by factors such as knowledge and beliefs about this disorder, its aetiology, triggers, heredity and contagiousness; interpersonal stigma which caused by factors related to the attitudes of people surrounding PWE, include family members, colleagues, teachers and doctors. Factors related to the attitude of society, the medical care system, and government policies contribute to institutional stigma. Internalized stigma varies significantly according to the traits of the affected individual, such as education level, personality and ability to handle difficult situations. Institutional stigma, on the other hand, is relatively consistent among different individuals.

The stigma of epilepsy exists in all cultures and societies in the world, even though it variously presents in terms of both modality and content [18]. A study carried out by Lim and Chan et al in Asia shows cultural and psychological factors have a significantly higher impact than physical factors on the quality of life of people with epilepsy [19]. In Africa, some people believe that epilepsy is a punishment for those who break the social taboos or rules. It is also associated with spiritual possession [20]. In developed countries, stigma of epilepsy is often defined as the shame of being undesirably different to others and the fear of encountering discrimination in social interaction [21]. In traditional Chinese culture, epilepsy is regarded as lunacy [22]. PWE feel stigmatized mainly because of their physiological defect, reduced social status or value, and failure to fulfill the mutual-beneficial principles operating in their society.

Scrambler categorizes stigma into ‘felt’ stigma and enacted stigma [23]. A survey conducted by Baker et al in European countries reveals that over 50% of PWE still feel stigmatized even though great advances have been made in the treatment of their condition [3].

In this study, we have found that patients’ internalized stigma arising from their knowledge and beliefs about epilepsy, their attitudes and their ability to deal with seizures constitutes an important part of the stigma felt by them. For example, patients who believe that epilepsy is caused by other brain conditions such as trauma and encephalitis feel less stigmatized than those who believe that it is hereditary. For many people living in rural China, it is a deep-rooted value and obligation to continue their family bloodline. A person with epilepsy will therefore bring shame to the whole family. Those individuals with epilepsy who do not know the pathogenesis of their diseases or think heredity is the cause of their condition feel extremely ashamed and inferior to others especially with regard to marriage and having children. They often adopt negative strategies to deal with this situation, such as concealing the truth about their condition, or giving up chances for social activities. Only a small number of young and well-educated patients in this study had appropriate knowledge about epilepsy, and hence were less concerned about the issue of heredity. In general, sufficient and appropriate knowledge about epilepsy can help sufferers to reduce the sense of stigma. [24]. However, some people with epilepsy do not want to know too much information on their condition, worrying that such information may affect their confidence in treatment [22, 25]. As for the triggers of seizures, some patients have no concerns at all, while others are extremely careful to avoid them due to the fear of seizures. Unsurprisingly, the latter group of patients feels more stigmas. This demonstrates that an individual’s ability to deal with difficult situations can influence the severity of stigma he or she perceives [26–28]



Link believes that PWE feel de-valued and discriminated by the prevalence of old beliefs and theory systems about this disorder, so that they try to conceal their condition or withdraw from social activities. Such negative coping strategies consequently bring negative impact on their quality of life and strengthen the stigma [29]. Regardless of their clinical manifestation, some people with epilepsy concede that stigma associated with them is life-long, while others do not feel stigmatized [30]. From the interviews with community administrators, we found that the rural communities in this study had made progress in promoting appropriate attitudes toward and correct knowledge about epilepsy, and were making some suitable jobs available for persons with this condition living in their communities. However, previous experiences of discrimination were preventing some individuals from taking the opportunity to reestablish themselves in the society.

In contrast to the individualized nature of internalized stigma, the reactions of PWE to the interpersonal stigma or the institutional stigma seems relatively consistent. To avoid losing face due to seizures in front of others, family members of the person suffering from epilepsy may become over protective, and deny him or her social opportunities. Subsequently this practice will impair the individual's hopes and ability of living an independent life and deepen the stigma [6]. Recently, a large-scale study involving an intervention program for over two years to promote knowledge on epilepsy and its medication in patients and their family members confirmed that stigma perceived by the epileptic patients can be significantly reduced once their family members are convinced that people with this condition can live a normal life as others [31]. In this study, we found that the patients who receive support and care from their family feel less stigmatized than those who do not. Although the friends or colleagues of PWE understand that this condition is not contagious and harmful to others, most of them believe that it is hereditary and not curable. Hence, they still keep a distance to those affected, and especially oppose their own children going out with them. In rural China, people with epilepsy have a relatively small and fixed social circle compared to those in urban areas, therefore the attitudes of others have a much greater impact. Furthermore, they do not have any proactive and effective strategies to deal with those negative attitudes; instead, they passively bear the burden. We can consider that attitudes of others contribute to the main component of the interpersonal stigma in PWE.

PWE and their family have to bear the huge financial burden of long-term treatment. To make the situation worse their employment opportunities are limited due to their condition. Discrimination and wrong perceptions from the public are still evident. The employers we interviewed in this study admitted that they do not want to employ persons with epilepsy because of concerns that they may cause accidents and upset other employees. They argue that persons with this condition will increase their business costs due to higher medical insurance premiums and loss of working hours etc. and that there is a lack incentive and support from the government. In some countries, PWE can work in "day care" centers, and employers enjoyed certain preferential policies for hiring those people. With no doubt, a stable income will help the individual suffering from epilepsy to overcome the associated stigma.

Research on multi-national life quality status of PWE in Europe indicates that differences of availability and accessibility of social provisions and health care are the reason for varying stigma levels of PWE in different countries [32]. In China, organizations dedicated to provide support to people suffering from epilepsy only exist in a very few big cities. We found in this study that the PWE receive little but sporadic help from the community. There is a huge gap in both education and income between PWE living in urban and rural areas in China. It is urgent to provide care and support to rural patients through charity organizations, community volunteers or other suitable channels. There is also a huge treatment gap in rural areas of China [2], where patients desperately need an effective

treatment to bring their condition under control. On one hand, they cannot afford to seek treatment in a big city; on the other hand, their local doctors lack of proper training on this disease. In addition, the Rural Cooperation Medical Scheme does not help enough to reduce their financial burden. Due to the lack of effective treatment their condition deteriorates, and inevitably feel more institutional stigma.

Research by Baker et al revealed that the most consistent predictor of stigma is seizure frequency; people with high seizure frequency are more likely to report higher levels of stigma than those with low seizure frequency [33]. A survey by Wang et al showed that at the top of the patients' worry list is "when the next seizure is" with a score of 80%, which is far higher than 42% for the second on the list, which is the worry about discrimination [31]. In 2002, Jacoby reported that among patients in seizure remission, only 14% of them feel stigma, while this percentage is up to 51% in self-help groups [30]. Consistent with above findings our analysis indicates that the fear of next seizure is the biggest psychological burden for the patients and their family and is the most important component of the stigma, except a small number of patients with mild and less frequent seizures. The cause of this fear is twofold. One is the experience of a recent seizure, and the other is the worry and helplessness about injuries their next seizure may cause. Therefore, we should tackle the fear of the next seizure on two fronts. We should first reduce seizure frequency with effective treatment, and meanwhile, educate the public how to help a person having a seizure. In other words, we have to deal with not only the factors causing internalized or interpersonal stigma, but also those causing institutional stigma in patients. We argue that eliminating the factors relative to institutional stigma in patients is fundamentally important in the campaign to disperse stigma of epilepsy. Without that, any effort to erase their internalized stigma will be less effective.

## 5. Conclusion

As highlighted by previous studies, to reduce stigma of epilepsy it is important to promote appropriate knowledge and views about this disorder among the sufferers, family members and public, and to make effective treatment available. The factors related to epilepsy stigma are complex. We have identified that those factors link to three levels of the stigma in PWE, internalized, interpersonal and institutional stigma. We hence propose that to achieve the goal of dispersing stigma of epilepsy we should first eliminate those factors relating to institutional stigma by supporting relevant communities in medical care, education and employment; and then take a personalized intervention approach to erase interpersonal and internalized stigma.

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**Box1: Comments about internalized stigma of epilepsy**

*It might be hereditary. Maybe my kids would have problem in finding a boyfriend or girlfriend when they grow up. My disease may cause concern of others and I am worried that my kids will develop the same disease later on. Therefore, I keep it as a secret.* (PWE9)

*I never eat at others' house. I do not even if they ask me to stay. I am afraid I may pass it to others.* (PWE15)

I remembered that one day I was very angry after a quarrel with my sister. I got ill at night. Since then, each seizure was triggered by anger. There were two seizures after induced abortion. The main cause is anger. (PWE5)

The second seizure happened at the noon of a summer day in 2004. After drinking beer, I had a nap. ....The seizures happened twice when I was working with friends. They were drinking alcohol but I did not. I just smelled it. I had seizures later in the night. (PWE15)

**Box 2: Comments about interpersonal stigma of epilepsy**

*I had not had seizures for a year, apart from small ones. It happened once in one or 2 months, but this week it happens every day when I am falling asleep; ...-Some people stay away from me or laugh at me. There are a few people look down on my mother and me, they do not say it out aloud but we can find out because of their tone and expression. (PWE7)*

*The disease frequently attacked before the Spring Festival. They look down on me, including my uncle and poppa. They always ask me 'can you go to work?' I can see what they mean from their implication. Anyway, they treat me differently. (PWE8)*

*Our family was all nice to her, but she looked down upon herself because of the disease, she made her head lower when she walked. People around told each other she jerked and called her "neuropathy, madwoman". (FM3)*

*I went to "Shanxi" to see a doctor when I had grown up. I received the treatment of "burying catgut", and ever took Dilantin and Valproate. I cannot afford to see a doctor as often as I need because my family is poor. I would go to see a doctor and buy some medicine when my family has the money. When the money has run out, I would simply have no medicine to take. I have never received a long-term treatment. I take medicine irregularly. (PWE3)*

*I had treatments at his place for 3 years. I took his Chinese medicine but it did not work. (PWE14)*



**Box 3: Comments about interpersonal stigma of epilepsy**

*Other people said it can be inherited, but no one on her father's side or on my side ever has this disease. However, her father got meningitis in his childhood. ....I feel that my daughter's disease has something to do with this. It is hereditary. However, her elder brother does not have this disease. I think this disease is not contagious because all the persons in close contact with her are OK. Those who had a dinner party in the house of a person with epilepsy in our village are also OK. (FM14)*

*This disease is not contagious. It is not an infectious disease. She was not born with this disease. She got it later on. So maybe she did not inherit the disease from somebody else. However, I do not know whether somebody else will inherit it from her. I do not want to guess. (FM1)*

*We used to labor hard to making a living. I only let him do some light jobs, such as setting up the fishing net in the river. Well, one day he had a seizure and fell into the river. Since then I have never let him do anything. (Fm18)*

*Others, even his uncle, look down on us because we are very poor. We are even poorer because we have spent over 20 thousand Yuan on our child's treatment. His uncle, who is very rich shows us more contempt and refuses to lend us money because he worries that we will not be able to pay it back. (FM11)*

**Box 4: Comments about institutional stigma of epilepsy**

*They said he was making muffled sounds, and his hands were twitching. His schoolmates were all scared because they did not know what was happening to him. He bit his tongue, and bloody foam came out of his mouth. He was also grinding his teeth but not drooling. His schoolmates thought there was something wrong with his internal organs and rushed him to the Shunyi district hospital. (FM1)*

*I am concerned that they will cause accidents if they have a seizure during work, and the responsibility is far too big for me. Therefore, I do not want to hire those people. (EMP1)*

*We do not employ people with this condition in principle. We are a private business. It is too risky to use them. (EMP4)*

*It is important to control the seizure of epilepsy, for which the external factors are the key. Recurrent seizure attack is likely to cause syndromes of the nerve system, to damage neural cells, to affect patients' intelligence, and to disturb the balance of internal organs. (VD6)*

*It is not easy to prevent and treat seizures. This disease is very stubborn and difficult to cure completely..... More worryingly, (seizures) often cause accidents. Severe seizures have a big impact on the central nerve system. Some patients lost consciousness, and even wetted or soiled themselves in the street. ....Some patients had not been cured until their deaths, and most of them died at a young age. Their seizures became more severe after each attack. (VD1)*

*He only came to see me when he had a seizure, and had stopped taking the medicines as soon as he felt a bit better. He thinks that he is cured. But, I don't think so even he is currently not showing any symptom and able to carry on his life as usual. (VD3)*

*The patients were sent to our clinic when they were in a seizure. We were asked to stop their seizure. It is very rare for them to see us proactively. (VD4)*

### Highlights

Dear Editors/Reviewers,

Our manuscript entitled “The stigma of people with epilepsy is demonstrated at the internalized, interpersonal and institutional level in a specific socio-cultural context: findings from an ethnographic study in rural China” was based on the data as part of the CREST (Col-laborative Research in Epilepsy Stigma) Project.

We have conducted analysis of our data with specific focus on the stigma of patient of epilepsy in rural China. We examined the views of 106 participants of different target groups, and found that the stigma of epilepsy is a very negative self-feeling from the patients’ perspective.

The stigma of epilepsy, in a particular social and cultural context, can be demonstrated in the internalized, interpersonal and institutional levels. We have identified that those factors link to three levels of the stigma in PWE. We suggest that we should first eliminate those factors relating to institutional stigma by supporting relevant communities in medical care, education and employment; and then take a personalized intervention approach to erase interpersonal and internalized stigma.

Only by addressing impacting factors at each of these three levels, can the stigma of PWE in China be alleviated or even eliminated.

Guo, wencui

**Table 1**

The number of in-depth interviews and focus groups conducted on the study population from rural Shunyi District of Beijing

<b>Interview</b>	<b>Number</b>	<b>Focus group</b>	<b>Number</b>
People with epilepsy	24	Nurse	6
Family members	24	Community leader	6
Employers	4	Teachers of primary	6
Village doctors	6	Teachers of junior high school	6
Town clinic physicians	6	Neighbor 1	6
Traditional medicine practitioners	6	Neighbor 2	6
Total=	70	Total=	36

**Table 2**

Demographic data of medical workers

	No	M/F	Age	Education College/HTS	Met PWE Before, Yes/No
Village doctors	6	5/1	46–51	0/6	5/1
Traditional medicine practitioners	6	2/4	25–37	6/0	0/6
Town clinic physicians	6	1/5	23–49	5/1	4/2
Nurses(FGD)	6	0/6	23–42	5/1	2/4