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Stigma of People with Epilepsy in China: Views of health professionals, teachers, employers and community leaders

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Abstract

To identify the possible sources of stigma of epilepsy in key informant groups, “mini-ethnographic” studies were conducted in rural and urban locations in China. Data from 45 semi-structured interviews and 8 focus group discussions (6 persons each) were analysed to investigate the world experienced by people with epilepsy. Underpinned by a social constructionist approach to data analysis, emerging themes were identified with the use of computer-assisted data analysis (NVivo 8). A hierarchical model was then constructed, to include: Practical Level issues: attitudes to risk, attitudes towards costs of epilepsy; and Cultural Level issues: the contrast between rurality and tradition and urbanization and modernity in the Chinese context. The analysis enriches current research on factors and sources of stigma of epilepsy and highlights issues for future practice.

Keywords

Epilepsy; Stigma; China; Ethnography; Social Constructionism

1. Introduction

Behind migraine and stroke, epilepsy is the third commonest neurological disease in China [1]. Yet in 2002, the treatment gap (the percentage of patients in a defined population on any one day, with active epilepsy, not receiving anticonvulsant medication of epilepsy [2]), was 63% [1]. In China, only public servants with epilepsy, neither non-government employees

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Conflict of interest statement

No competing interests.

[3] nor the unemployed, are financially covered by the Government for the health costs of treatment of epilepsy; although from 2000, the government has provided about 30,000 rural people with convulsive epilepsy with free treatment with Phenobarbital [1]. For most people with epilepsy, worry about seizures, discrimination, and medical costs are the principal factors in the psychological burden of their condition [4].

In agreement with findings from a large European survey of 15 countries [5], data from a recent multicenter survey conducted in mainland China supports the view that the primary goals of epilepsy management need to be to ensure people with epilepsy remain as free from seizures as possible and that treatment side effects are minimized [6]. However, when considering the quality of life of people with epilepsy in non-Chinese populations, it has been found that stigma accounted for twice the amount of variance in quality-of-life scores as did clinical variables such as seizure frequency and antiepileptic drug side effects [7]. Further, feelings of stigma reported by patients are known to be associated with non-compliance with antiepileptic drug regimes [8] and increased levels of reporting of anti-epileptic drug side effects [9]. Stigma, both felt and enacted, has been shown to be both a cause of and contributor to ill health [10]. Studies in China since the 1980s have estimated that stigma is felt by as many as 90% of people with epilepsy and 75% of their family members [11], supporting that reducing stigma is a key public health concern. In a recent survey conducted as part of the Global Campaign Against Epilepsy initiative [12], more than a third of respondents considered they were treated differently by others because of their condition and around a half opted to keep their condition secret from others.

Previous research shows that attitudes and knowledge gaps have the potential to evoke discriminatory behavior [13]. Sometimes it leads low social, cultural, economic, and/or political power groups to attempt a process of 'reverse' stigmatization - for example, clinicians may be labeled as 'pill pushers', a cold, paternalistic, and arrogant "them" to be despised and avoided [14]. Stigma and discrimination have been shown to be experienced in both the private and public domains, accounting for interpersonal difficulties within families which include a member with epilepsy [4, 15], or being implicated in the lower educational and employment achievements of people with epilepsy [7], for example. It has been proposed that stigma operates at three different levels: internalized (within the person with epilepsy); interpersonal (within the affected person's immediate and extended family systems); and institutional (an indirect, impersonal, expressions of stigma) [16]. These three proposed levels at which stigma is operationalised are echoed in subsequent theoretical propositions about the nature of stigma as direct, insidious or structural in base [14]. Evidence suggests that tackling the problem of stigma effectively requires that each of the three levels is systematically addressed [17–18]. However, little is known about how to effectively change negative attitudes, both within the stigmatized person (the 'target' of stigma [19]) and of significant others (the 'perpetrators' of stigma [19]); and investigating how stigma operates at the institutional level has rarely been the focus of research [18]. Therefore, understanding of the causes and sources of stigma at the internalized, interpersonal and institutional levels remains limited.

We sought to explore attitudes and beliefs about epilepsy in both the targets of stigma and the perpetrators of stigma in urban and rural China, to identify possible foci for future stigma reduction campaigns [20–21]. Attitudes and beliefs about epilepsy in people with epilepsy and their family members in urban and rural China have been reported previously [22]. In this study, we sought to explore the attitudes and beliefs of non-family 'others' who, by virtue of operating in public position and the institutional sphere, represent potentially key perpetrator groups.

2. Methods

We utilized an ethnographic research approach to qualitatively explore data about sources of stigma for people with epilepsy in China as part of the CREST (Collaborative Research in Epilepsy Stigma) Project[10]. Health professionals and teachers, among others, are thought to constitute key groups in the issue of stigma – potentially acting as ‘stigma coaches’[17]. They are either the distributors of resources (healthcare, education) to people, or exploiters of resources (human resources) in China. We anticipated therefore, that data collected with purposive sampling from health professionals, school teachers, community leaders and employers about knowledge, attitudes and beliefs about epilepsy would have the potential to reflect the world in which people with epilepsy in China experienced their condition. Details of the sample groups from which our data are drawn, together with the data collection methods employed, are outlined in Table 1. Data were collected from May to November 2005 and an in-depth explanation of study methods has previously been reported [20]. Ethical permission to conduct this work was obtained from the Institutional Review Board at the Beijing Neurosurgical Institute, China.

With the assistance of qualitative data analysis software (NVivo 8) [23], data were subjected to a process of thematic coding and mapping. Two of the Chinese authors (RRY, GC) inductively coded the original Chinese language transcripts. In the first stage of the analysis, randomly selected transcripts from each of the informant groups were reviewed to identify an initial set of codes, representing major and minor (sub-) themes. Coding and subsequent theme development was reconciled with other members of the research team, using English translations of the transcripts for comparison and discussion. The revised initial code set was applied to the remaining transcripts for every informant group, and additional codes were identified as appropriate. Data codes were then mapped electronically, in order to streamline the themes and to map their relationships. Specifically, coded comments were extracted by theme, using ‘tree nodes’ in NVivo, to provide an overview across the whole sample. This overview explained “why our informants thought what”.

To analyse the patterns, if any, of the informants’ comments, we re-analysed the information by informants’ social-demographic characteristics. This second analysis focused on “who thought what”, using matrix coding in NVivo. Cases were classified by gender (male/female), age (under 35 years, 35–45 years; and 45 years and over), living situation (rural/urban), and profession (school teacher, health professional, community leader, and employer). Social constructionism was deemed an appropriate epistemological position from which to approach the analyses reported here, since it maintains that the reality a person perceives is the product of specific social, historical, and individual contexts [24]. Informed by a constructionist perspective, an explanatory theory was abstracted and tested against the original transcripts.

In a whole, This article seeks to explore and understand the reasons behind the negative attitudes towards epilepsy among significant professional groups who may act as the ‘perpetrators’[19] of epilepsy stigma in China. Our analysis focuses particularly on informants’ comments on the nature of epilepsy compared to other common chronic conditions of ill-health, its treatability and curability. The conversational prompts for the discussion are shown in Table 2.

The electronic process of data management facilitated transferability of files among research team members, regardless of geographical location. Researcher and data triangulation throughout the analytic process, including the generation and mapping of codes and themes and data abstraction and verification, enhanced validity of the analysis.

3. Findings

Informants' beliefs on causes, treatment, and prognosis of epilepsy were briefly documented. Most believed that epilepsy was either congenital or induced by some kind of stimulation or psychological pressure which, as some informants believed, was the product of 'recessive heredity'. It could be treated, but it would be induced 'once there was a kind of stimulation' it was 'hard to be radically cured'. While most informants accepted that epilepsy was not contagious, one commented that 'epilepsy can be transmitted via saliva foaming during the seizure.'

3.1. Attitudes towards epilepsy and people with epilepsy

About half of the informants perceived epilepsy as a 'terrible' condition, with very few considering people with epilepsy as being the same as those without. Epilepsy was viewed as terrible because it was considered to be a fluid and unpredictable condition in terms of seizure occurrence; and because the affected person being seen as 'out of control' during the course of a seizure. Seizures were recognised as having the potential to cause fatal impacts to the body and the brain of the patient. As a result, "it [*epilepsy*] brings a great deal of pressure to him [*patient*]. The family worries a lot too, and cannot leave him alone." Additionally, the patient with epilepsy has to take medicine for prolonged periods or even life-long; and epilepsy "is a misery for the whole family, not knowing how long it will take to cure it, that there may even be no hope, just spending money on medicine continuously". A community leader (male, aged 37 years, living in an urban area), commented,

"No psycho disease can be radically cured. [the patient] has to take medicine for the long-term. It impacts on daily life seriously, increasing the burden for the family. They can maintain things well if they persist with taking medicine, but cannot be radically cured and will have seizures easily when being anxious, angry and tired. It is therefore a heavy economic burden and a psychological pressure to the patient and the family."

Furthermore, it was noted that the disease was not curable and may be hereditary. Complications were seen as common and people with epilepsy as more likely to experience social rejection including obstacles to attending school, getting married and being employed. These factors were recognised as reducing the quality of life of the family as well as the patient. Another informant commented:

"Horrible, [the person with epilepsy] needs to take medicine regularly, which seriously impacts on his quality of life. For example, it would be impossible to marry or have children, for some patients. Moreover, the unpredictability of seizure occurrence causes unforeseen accidents always. I worry very much about him, a person with epilepsy in my factory, I never let him have any heavy work, or work alone." (male, employer, aged 47 years, living in an urban area)

Additionally, respondents commented that it is "horrible to see a person having a seizure" and people around about may be frightened by it. An informant commented:

"Personally, I am not scared by his [patient's] horrible appearance during a seizure, but I think it is really troublesome, reducing the quality of life, even putting life in danger, not to mention the cost for medicine daily, and jobs not guaranteed." (female, aged 36 years, physician from a rural township hospital)

Informants who did not consider epilepsy 'horrible' were mainly from a medical background. Although they also acknowledged that epilepsy was horrible "to look at", and represented a "heavy disease burden" to the patient, the family and society at large, they also noted that epilepsy "has a low incidence rate among the population", and since it is not an

infectious or contagious disease “does no harm to other people and society”. With regard to the disease per se, they noted that it can often be controlled by medicine, and the patient “usually would not lose their life through having seizures”.

We explored differences in views about epilepsy by gender, age, living situation and professional group. Male informants were far more likely than female informants in our sample to believe epilepsy to be a ‘horrible’ disease. Male informants mainly justified this view by focusing on disease burden and the risks involved when coming into contact with people with epilepsy. For example, a male employer from a rural area commented:

“All his [PWE] colleagues keep their distance from him, try1 to have less contact, and to avoid any conflict with him. Mainly they are afraid of stimulating his seizures; so that they do not have to bear liability for his seizures.” (male, 44 years, rural area employer)

Female informants expressed much greater concern about the impact of the unpredictability of seizures for people with epilepsy themselves. As a 46-year-old female village doctor commented, “Very horrible... the seizure always comes, no matter when and where. Very troublesome. Very dangerous, too.”

Both males and females who did not consider epilepsy as a frightening condition appeared to view it in a more positive light, often referring to the potential curability of epilepsy in non-serious cases.

The youngest informants were most likely to consider epilepsy frightening, while the eldest were least likely to do so. However, reasons for holding this belief were similar across the different age groups: epilepsy was seen as “horrible to look at”, unpredictable or representing a heavy disease burden.

Informants from rural areas were far more likely to consider epilepsy a frightening disease than those in urban areas; but again the reasons for holding this view did not differ.

As referred to previously, informants who did not consider epilepsy a frightening disease were mainly from a medical background; there were no differences in expressed views among the other professional groups.

3.2. Health status comparisons for people with epilepsy compared to others

Among informants who offered views about the likely health status of a person with epilepsy, many believed having epilepsy would increase a persons’ susceptibility to other health problems. Justifications for this belief included concerns about the need for long-term treatment of epilepsy and the associated risk of side-effects from anti-epileptic drug regimes. As one informant reflected,

“It is quite easy to become worse, generally due to trauma, as well as the side effects of medications. I diagnosed a patient who was hospitalized due to a badly damaged liver from the side-effects of anti-epileptic drugs. Some children have even died because of lack of oxygen during prolonged seizures.” (female, 39, urban paediatrician)

Informants also frequently cited the risk of physical injury during seizures:

“Very often, they break their legs or sustain a head injury, or fracture, resulting in a worse physical condition and neuro-functional deficit.” (male, 51, urban TCM Doctor)

Of particular note, a number of both neurologists and TCM practitioners pointed out that people with epilepsy were likely to have an epileptic ‘character’, with negative changes to their personality and behavior. They and their family members were also believed to suffer great psychological stress because of the disease per se and arising from the worry of being subject to stigmatization.

“What impresses me most is that people with epilepsy tend to have mental sickness and problems, namely an epileptic character.” (male, 29, urban, neurologist)

“Definitely worse health status than the normal population. People with epilepsy change their character and behavior. Especially people with mentally kinetic epilepsy, who may kill somebody or commit a vicious crime.” (male, 37, rural TCM Doctor)

Conversely, informants who thought having epilepsy did not necessarily predispose to an increased risk of having other health problems explained that there was no necessary link:

“Not always, no causation... If the person has other health problems, I think it may have no association with his epilepsy. But it may be associated with his living standard, medical condition, life style, surroundings, and so on.” (female, 50, urban, Middle School Teacher)

In addition, the majority of those informants who commented on the health status of people with epilepsy also considered having epilepsy to be worse than having other types of serious diseases such as, for example tuberculosis, hypertension or diabetes. Epilepsy was seen as being “troublesome”, either because of its unpredictable treatment duration or because of the burden of the condition for others engaged in caring and coping with people with epilepsy. Many were of the view that other serious diseases could be controlled better.

Those informants who believed having epilepsy was better than having other serious diseases commented that while epilepsy could reduce a person’s quality of life, other serious diseases had comparatively higher mortality rates, greater risk of complications and represented a heavier societal disease burden because of the threat from contagion.

Seeing through the informants’ social-demographic characteristics, some interesting patterns of the informants’ comments emerged. Male informants were more likely to describe the heightened vulnerability of people with epilepsy to other health problems from a physical perspective such as, for example, the potentially fatal impact of seizures; whereas female informants more often focused on social-psychological factors including “psychological abnormality” and being “afraid of being looking down upon”. While females seemed to strongly support that having epilepsy was worse than having the other exemplar health conditions, males were far more likely to argue that having epilepsy was better. Female informants frequently mentioned that seizures could occur “anywhere, anytime”; they also more often observed that the social positioning of people with epilepsy was different to the social positioning of people with other serious diseases:

“People think differently about it [epilepsy]. It is not like hypertension ... Everybody knows about hypertension. Not only the patients with hypertension but also normal people talk about hypertension freely and widely. But people regard epilepsy as something peculiar.” (female, 34, rural, Nurse)

Overall, younger informants were more likely to focus on the physical effects of epilepsy per se, while the older informants were more likely to focus on social factors. Younger informants were also more likely to mention the psychological harm arising out of the uncertainty associated with having seizures; while older informants mentioned the risks of antiepileptic drug side effects and of stigma and patients’ responses to it. Likewise, older

informants were more likely to cite as the reason why having epilepsy was worse than having other serious diseases, factors related to stigmatization arising from misconceptions about epilepsy.

Urban informants were far more likely than rural informants to think that it was likely that people with epilepsy would have other health problems compared to the general population. In fact, urban informants generally strongly agreed with the statement; while rural informants tended to disagree. Urban informants were also more likely to discuss the potential medical complications associated with having epilepsy and its relatively poorer prognosis:

“Comparatively, I think epilepsy is worse than Tuberculosis. There is no medicine fully contributing to the curability of epilepsy. And people know more about tuberculosis or hypertension. Television programs describe it in many ways, for example. And (TB) can be cured fully following a period of treatment. However people are poorly informed of epilepsy, and there is some unknown pathogenesis, and little hope of being cured fully.” (female, 50, Middle School Teacher, living in an urban area)

Rural informants appeared more likely to think about the social psychological consequences for people with epilepsy; and thought the disease burden of epilepsy was less, compared with treatment costs for other serious diseases:

“Epilepsy is simpler, it can be controlled by medicine or surgery in a short time. The other listed diseases need medicating lifelong. Even Tuberculosis needs a half-year of treatment at least.” (female, 45, Community leader in rural)

Among the health professionals, about two-thirds thought that people with epilepsy were more likely than the general population to have other health problems, and that having epilepsy was worse than having other serious diseases. No other clear differences by professional group were manifested.

3.3. Attitudes to the concealment of epilepsy

Most informants considered concealment of epilepsy understandable. Beliefs about why people with epilepsy might wish to conceal their condition included the need to secure schooling, employment and equal marriage rights, as well as to reduce disparity in social life. Failure to be accepted in the labour and marriage markets was perceived as a major driver for concealing epilepsy:

“Some children, especially young people, would like to cover it up, for some worries, scruples, you know. If the employer knows [one applicant has epilepsy], the vacancy will definitely be given to the other applicant without a history of having epilepsy.” (female, 33, rural, TCM Doctor)

“I think parents worry about their [child with epilepsy] schooling. Other students would not like to be his deskmate. Some students are somewhat selfish nowadays; they could therefore think that a seizure in another person would bring them adverse effects. They may think a child having such a disability should not go to school at all.” (female, 25, urban, Middle School Teacher)

People with epilepsy were perceived as limited in their participation in social life, in as much as those around them were afraid of “bearing liability” for them. Many informants expressed concern that they themselves might trigger a seizure just by being in the company of a person with epilepsy and were fearful of being present when a person with epilepsy had a seizure. This resulted in people either taking on the role of scared by-stander or excluding people with epilepsy from their social circle. To mitigate this behaviour and reduce the fear

and worry experienced by others, and to reserve their rights in social communication at large, people with epilepsy were seen as concealing their condition from those in their primary social circle:

“I think people with epilepsy surely have an inferiority complex...worrying that once people see his seizure it generates bad feelings, or thinking that others would not like to be present when he is. He therefore has an inner fear, not initially telling others.” (female, 23, rural, nurse)

However, while appreciating why people with epilepsy so often chose to conceal their condition, most informants thought that they should not conceal; that they should at least tell their family and doctors, in order to get appropriate treatment and protection. They should also tell people with whom they were in close contact, to get help with their seizures. In particular, people with epilepsy should be frank when trying to find a marriage partner, since marriage was thought to be based on equality; and if a person had epilepsy, he was deemed to carry a heavy disease burden and be less likely to perform well in society, especially with regard to any expectation of having high earning capability or high social status.

Attitude differences by socio-demographic characteristics of the informants showed some patterns of informants' comments. Compared with females, male informants were more likely to support the concealment of epilepsy; female informants were more likely to think that people with epilepsy should tell others about their disease and get help from the family and society. Urban informants were more likely than their rural counterparts to disagree with the policy of concealment, although informants in both living situations who cited their disagreement with concealment offered similar reasons - namely that openness about their disease would ensure people with epilepsy got timely and proper help during a seizure, as well as appropriate and safe employment. Urban informants also often expressed the view that the misconception of epilepsy by others, as well as an unfavourable social ethos, contributed to the concealment of epilepsy by those suffering from the condition. As one informant noted:

“Society always regards epilepsy as psychosis...Considering the current social ethos, as a whole, concealing does good for people with epilepsy.” (female, 40, urban, Primary School Teacher)

Rural informants tended to be more concerned about the marriage prospects of people with epilepsy and so more often supported the concealment of epilepsy for younger patients.

While urban informants who approved of concealment were more concerned about the privacy rights of those with epilepsy, while at the same time worrying about the potential psychological harm of concealment:

“Concealment..., a person with epilepsy has to conceal carefully, bearing the pressure psychologically, and doing harm to his treatment as well as daily life.” (male, 29, urban, Neurological Doctor)

No differences in attitudes to concealment were apparent by age or professional group.

4. Discussion

The analyses reported here identify attitudes and beliefs to epilepsy among different informant groups and by different socio-demographic characteristics. Overall, most informants thought negatively about epilepsy and people with epilepsy. Noticeably, informants who held the most positive attitudes were mainly from a medical background, and cognizant of the possibilities for better diagnosis and treatment and the non-infectious

nature of epilepsy. Nonetheless, about two-thirds of health professionals thought that people with epilepsy were more likely than the general population to have other health problems, and that having epilepsy was worse than having other serious diseases. Further, males, younger informants and those living in rural communities held more negative attitudes than their female, older and urban counterparts, who offered a more balanced view.

Through mapping the reasons behind informants' attitudes and beliefs, a two-level model can be constructed. The reasons can be categorized as operating at either the practical level or at the cultural level, and as reflecting either individual considerations or cultural foci and the social value system, respectively. Practically, ideas about epilepsy focused around risk attitude and attitude towards costs associated with epilepsy; culturally, ideas about epilepsy were demarked by an urban/rural divide:

- i. Reasons at the practical level: Male informants were much more exercised by the disease burden of epilepsy and the risks involved in it, such as having to bear liability for stimulating seizures if in close contact with people with epilepsy. Females tended to focus more on the unpredictability of epilepsy. Older informants were more likely to see people with epilepsy as at greater risk of other health problems since they observed more complications than the younger. Rural informants were concerned about whether the treatment of epilepsy was more affordable, compared with treatment of other serious diseases.
- ii. Reasons at the cultural level: Rural informants tended to be pre-occupied by social-psychological problems of people with epilepsy, when they commented that having epilepsy was worse than having other serious diseases. Moreover, rural informants often mentioned the vital impacts of misconceptions of epilepsy held in rural societies and which led to support for the concealment of people with epilepsy.

Adopting a social constructionist perspective, we deemed the world experienced by people with epilepsy to be constructed by its social, historical, and individual contexts [24], no matter with symptomatic epilepsy or idiopathic epilepsy which is considered that epilepsy may be caused as a birth defect, expecting to enhance the quality of prenatal health care. This position is reflected in the comments reported here from health professionals, teachers, employers and community leaders – all potential key contributors to the meaning of epilepsy in Chinese society. Our study indicates that at a practical level, arising from attitudes to risk and risk avoidance particularly, people without epilepsy tend to keep those with epilepsy outside their intimate social circle, leaving them socially isolated. This finding echoes those relating to the experience of people with epilepsy in South Korea, a country with a similar cultural background, Confucianism, to that of China [25]. Our qualitative findings also agree with those from a recent quantitative survey in China in 2008 [12], which highlighted the worries of people with epilepsy about its medical cost [4]. These findings reflect a deficiency in the extent of coverage of current government financial support [1, 3] to people with epilepsy.

We would suggest that cultural level differences are rooted in China's 'Rural Society', a term invented to capture and portray the characteristics and rules of rural communities in China, which are heavily rite-based and where ritual is the major tool of social control [26]. In such communities, people would try concerted to protect themselves from any undesirable involvement with people with epilepsy, who would therefore suffer greatly from social-psychological pressure and social isolation. This is demonstrated in our data by rural informants' preoccupations with the impact of epilepsy for issues such as employment and marriage and the related preferences for concealment. In contrast, urban informants, divested of the impact of Chinese 'Rural Society' rules and obligations, were more concerned with individual rights issues such as personal privacy. The stigmatisation of

people with epilepsy in rural areas, together with the unmet treatment gap, almost certainly contributes to the much lower remission rate in rural China. Epilepsy is covered by the shroud of ritual in Chinese Rural Society, contributing significantly to quality-of-life reductions for those with the condition, since in this setting its stigma offers potential for greater harm than does the clinical suffering arising from seizures or medication effects [7, 20].

As described in our previous reports, the data collection methodology employed in this study, the mini-ethnography, has been acknowledged as potentially leading to production of a very limited contextual analysis [27]. Additionally, the urban area investigated was Beijing, a highly sophisticated city in terms of health care facilities and its innovative promotion of support for patients with epilepsy. This means attitudes cited urban informants may not be typical of those in other urban areas in China. Moreover, data analyses revealed that compared with the individual in-depth interviews conducted, data collected through the focus group discussions are less information-rich, maybe reducing their credibility.

Despite these limitations, by constructing a model of the causes and sources of stigma in China, our analysis has helped to uncover the social roots of the already well-documented contributors of stigma such as under-resourced medical services, poor seizure control, and inadequate knowledge of epilepsy. Epilepsy stigma in China is in part the outcome of deficiencies in government provision for people with epilepsy, and in part the product of the shroud of ritual in China's 'Rural Society'. Studies of the direct and indirect costs to the Chinese nation of failing to treat non-clinical aspects of epilepsy, including stigma, in addition to the clinical aspects, would provide further hard evidence at the internalised, interpersonal and institutional levels. Our own qualitative findings can usefully inform the development of anti-epilepsy programmes in China [1], and future strategies against stigma of epilepsy in other countries.

Research Highlights

- The analysis enriches current research on factors and sources of stigma of epilepsy.
- It constructed a hierarchical model to include: Practical Level issues related to attitudes, and Cultural Level issues in China.
- Cultural Level issues discovered contrast between rurality and tradition, and urbanization and modernity in the Chinese context.
- Thematic analysis was applied to see through the "mini-ethnographic" qualitative data, with the use of computer-assisted data analysis (NVivo 8).

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Table 1
China ethnographic study: Informants by age, gender, residence, and informant type

	Information type	Rural-urban	Gender	Age			Total
				<35	35–45)	>=45	
<u>Focus Groups</u>	Primary school teachers	Rural	Female	5	1	0	6
		Urban	Female	1	5	0	6
	Middle school teachers	Rural	Female	2	0	3	5
			Male	0	0	1	1
	Nurses	Urban	Female	3	0	3	6
		Rural	Female	5	1	0	6
	Community leaders	Urban	Female	0	0	6	6
		Rural	Female	1	0	1	2
			Male	1	2	1	4
		Urban	Female	2	0	1	3
		Male	1	1	1	3	
subtotal			21	10	17	48	
<u>Interviews</u>	Doctor of Traditional Chinese Medicine	Rural	Female	4	0	0	4
			Male	1	1	0	2
	Employer	Urban	Female	1	2	2	5
			Male	0	0	2	2
		Rural	Male	3	1	0	4
		Urban	Male	0	4	1	5
	Neurological Doctor	Urban	Female	0	0	1	1
			Male	2	1	1	4
	Paediatrician	Urban	Female	1	1	1	3
		Rural	Female	2	2	1	5
	Physician		Male	1	0	0	1
		Urban	Female	0	3	0	3
		Rural	Female	0	0	1	1
			Male	0	0	5	5

Information type	Rural-urban	Gender	Age				Total
			<35	35–45	>=45		
			15	15	15	45	
		subtotal					
		Total	36	25	32	93	

Note: The genders of primary school teachers in the urban focus group discussion (FGD), were missing in the original casebook, so were determined according to informants' names and contexts.

Table 2**Conversational Prompts in the China ethnographic study**

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- Can epilepsy be caught from another person?
 - Can people with epilepsy expect to be cured, or can epilepsy only be treated?
 - How easy is it to prevent seizures from occurring and why?
 - How likely is it that a person with epilepsy will stop having seizures?
 - What factors would contribute to a person with epilepsy becoming seizure free?
 - Do you believe epilepsy to be a frightening illness? If so, why?
 - If a person has epilepsy are they more likely to have other health problems too? If yes, what sort?
 - Is it worse to have epilepsy than to have an illness like TB or hypertension? If so, why?
 - Do you believe people with epilepsy should keep it to themselves?
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