

IN CONFIDENCE

Meanings of epilepsy in its socio-cultural context and implications for stigma: findings from ethnographic studies in local communities in China and Vietnam

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Abstract

We investigated beliefs about causes, course and treatment of epilepsy and QOL impacts in key target groups, using 'mini-ethnographies' involving 141 in-depth interviews and 12 focus groups in China, and 84 in-depth interviews and 16 focus groups in Vietnam. Data were analysed thematically, using a qualitative data analysis package.

In both countries, beliefs about causes and triggers for epilepsy and seizures were a complex interweaving of western, traditional and folk medicine concepts. Epilepsy was understood to be chronic, not curable, but controllable; and seen as enormously socially disruptive, with wide-ranging impacts for QOL. Our findings suggest a more 'embodied' and benign set of theories about epilepsy than in some other cultural contexts; nonetheless, PWE are still seen as having low social value and face social rejection.

By exploring meanings attached to epilepsy in these two cultural contexts, we have clarified reasons behind previously documented negative attitudes and foci for future intervention studies.

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Introduction

Recent studies of the incidence and prevalence of epilepsy worldwide have clarified that for the majority of people who develop it, it is a disorder with a benign clinical course and an excellent clinical prognosis (1). However, epilepsy also has a social course 'organised as much by what is at stake for participants in [*their*] local world as it is by the biology of the condition' (2) – and there is clear evidence that this social course of epilepsy may be somewhat less benign. One reason for this is the devaluation of people with epilepsy (PWE), historically and cross-culturally, which rests on 'a whole mythology' (3) about its origin and transmission, but also on the 'symbolic' threats it poses (4). While there is general agreement in the literature that the devaluation, and accompanying stigma and discrimination, of PWE are common features of their condition worldwide (5), there is also recognition that processes of devaluation and stigmatisation are relational (6) and that there is considerable cultural variation in the ways they are played out (7). Initiatives directed at defining and reducing the devaluation of PWE and so improving its social course must therefore be informed by an appreciation of such differences.

Understanding and dispelling stigma is one of the stated aims of the Global Campaign Against Epilepsy (GCAE) 'Out of the Shadows' initiative (8). Though the implications of epilepsy-related stigma for disease burden and QOL are difficult to calculate (9), they are almost certainly of great significance in low-income countries, where four-fifths of the world's 40 million PWE are located. In these countries, epilepsy represents a major public health problem (10) characterised by lack of prioritisation and infrastructural support (11) and a 'treatment gap' (ie. proportion of people with active epilepsy who are untreated) of anywhere between 60% and 98% (12). Recent calculations suggest that a significant proportion of the current disease burden of epilepsy is avertable by up-scaling availability of low-cost AEDs (13); and doing so is a major commitment of the GCAE. However, focussing on clinical aspects of epilepsy and seizure control, though important, is likely of limited value (14). Interventions are also required that recognise epilepsy's social course and the relevance and importance of epilepsy-related stigma to overall disease burden and impact on QOL. The work reported here was carried out to inform development of intervention studies aimed at reducing misinformation and misunderstanding about epilepsy and the resulting formal and informal stigma perpetrated upon PWE; and, by extension, to alter its social course and reduce its negative impacts on QOL. The research took place in two Asian countries, China and Vietnam. The choice of these

two geographically proximate but culturally unique countries was made to support the work of GCAE in the Western Pacific Region, where lack of understanding was identified as a major contributor to the burden of epilepsy, including its stigma (15). They were also seen as presenting important and potentially highly relevant contrasts with regard to their economic status and socio-historic position, despite some cultural commonalities.

Kleinman et al (2) have proposed that it is the continuous interaction between socio-cultural and biological processes in conditions of chronic ill health such as epilepsy that 'creates a local ontology of illness' and the degree of human suffering associated with it. In this paper, we report on local ontologies of epilepsy in China and Vietnam, through consideration of beliefs about its causes, course, treatment and QOL implications among its local protagonists. Earlier studies in this world region, including in our two target countries, have documented poor understanding of causes and treatment of epilepsy and negative attitudes towards those affected (16-22). These studies have been limited, however, by being almost uniformly quantitative in approach and so lacking explanatory power; and by drawing on questions developed for use in a different cultural context (23). To enhance understanding of the nature, rather than extent, of epilepsy stigma in China and Vietnam and of the mythologies and threats that underlie it inside these two cultures - and so to better inform design and focus of future stigma reduction interventions - we opted to use in-depth, ethnographic approaches, as outlined below. In presenting our findings, we aim to draw attention to both similarities and differences in social meaning between these two countries; and to consider our findings in light of parallel work undertaken in other countries in the Asian continent and further afield.

The most recent epidemiological study in China provides an epilepsy prevalence estimate of 0.7% (24), which, translated into raw numbers, equates to almost nine million people affected, of whom an estimated six million have active epilepsy (ie. two or more unprovoked seizures in the preceding 12 months). In urban areas, epilepsy care is provided through the provincial hospitals; in rural areas, it is provided largely through the three-tier (county hospital-township hospital-village clinic) Medicare system. Evidence suggests the 70% of China's population living in rural areas are disadvantaged in relation both to access and quality of healthcare (25) and with regard to health insurance coverage (26). With regard to epilepsy care specifically, though neurological provision is impressive in the large urban centres such as Beijing, neurologists and healthcare workers trained in the management of epilepsy

are in short supply within the rural Medicare system, as are Western AEDs. Phenobarbitone, phenytoin, carbamazepine and sodium valproate are all available, but are expensive; and following economic reform and the increasing dependency of the Chinese healthcare system on fee-for-service revenue (26) users, including PWE, increasingly face charges for drugs supplied by local health facilities (27). This, in part, explains the treatment gap (defined as no AEDs in the previous week) among patients with active epilepsy, which in the recent study cited above (24), ranged from 47% to 77% across five rural provinces in northern China.

In China, 'integrated medicine' was a cornerstone of national health policy during the cultural revolution (28) and Western and traditional medicine are now practiced together at every level of the healthcare system. It is estimated that around 40% of all healthcare involves traditional treatments, the proportion being higher in rural areas (29). Chinese traditional medicine (CTM) explains disease as the product of disharmony of the five basic elements – wood, fire, earth, metal and water, of the five organ systems, and of blockages in the circulation of *ch'i* (the life force)(30). The aim of treatment is therefore to restore balance through stimulation of the circulation (*khi*) using herbs, acupuncture and moxibustion, massage and diet. Deficiencies of the liver, kidney and spleen, causing internal wind, phlegm and blood stagnation, are the basis for epilepsy in CTM; and treatments are therefore aimed at reinforcing deficiencies and expelling toxins. Some clinical trials of CTM prescriptions for epilepsy have been carried out, with some evidence of their effectiveness. A recent survey found that 70% of PWE had consulted Western medical practitioners, 20% traditional Chinese medicine practitioners and 12% folk or witch doctors (Wu, *personal communication*). Common lay terminology for seizures, particularly in rural areas, is *yang jiao feng* (a derogatory term with the literal meaning 'making a noise like a sheep').

Recent estimates put the prevalence of epilepsy in Vietnam as 14 per 1000 (31). As in China, Vietnamese medical culture involves a mixture of Western biomedicine and traditional medicine. In formal traditional medicine, a range of recipes combining different ingredients is used to treat epilepsy. Folk treatments include lemon juice, cinnabar, varan (monitor lizard) meat and bile, pangolin scale, crow and cobra meat and snail. The Vertical Mental Health Program provides long-term medical care and Western AEDs free of charge to PWE, via four care levels - national, provincial, district and commune. Within the program, psychiatrists at provincial level are supported by staff employed in commune health stations, who in turn are supported

by hamlet health workers. Because epilepsy is classified as a 'social disease', treatment is funded by the state, with drugs distributed weekly, free of charge, at district-level dispensaries. However, choice of drug is limited to *Gardenan*, a locally produced form of Phenobarbitone, along with the vitamins B1 and B6. With 12,500 registered patients receiving care (32) the treatment gap is estimated as around 99.5%. Knowledge of epilepsy among doctors working in the lower levels of the health system has been reported as very limited, with little integration of the Vertical Program into primary health care (33). Terminology used to talk about epilepsy includes *dong kinh* (unstable nerve epilepsy), *phong giat* (wind-bitten seizure) and the traditional medicine term *kinh phong cap* (literally 'acute neurological wind-bitten'). In traditional medicine theory, there are two kinds of 'wind', external and internal, that in combination with excessive heat or cold can cause illness; the internal wind in association with excessive heat is thought to cause seizures. Traditional treatments for epilepsy therefore aim to address these elements. Individuals with weak or 'unstable' nerves (thought to be hereditary) are thought to be at increased risk of seizures if subject to stress, promoting a policy of 'chieu' ('treat more gently') among their family members.

In China, the work reported here was carried out in one urban district, Chongwen, and one rural district, Shunyi, of Beijing municipality. Until 2004, Shunyi was classified as a county (indicating that farming was the primary occupation), but was then re-classified as a district. It lies some 40 kilometres from Beijing city. As the centre of Government, Beijing has a highly educated workforce, with an estimated one-quarter of its population working in some form of administration. Healthcare facilities are sophisticated and Beijing is home to China's only existing epilepsy patient support organisation. The population of Beijing is largely Han Chinese, with less than three percent non-Han.

In Vietnam, the research sites were Hanoi in the north and Cantho in the south. Hanoi, capital of the Socialist Republic of Vietnam, is the most important metropolitan centre in North Vietnam and the country's largest centre of education – 62% of the science workforce lives and works there. Hanoi has the highest Development Index of all Vietnamese cities, and a strong public health network, with several large hospitals and at least one doctor for each commune. In Hanoi, informants were drawn from two districts: Dong Da, a highly urbanized district and Soc Son, a rural district. Cantho, situated in the Mekong Delta, is one of the urbanized provinces in

South West Vietnam, renamed Cantho City in 2004. Informants in Cantho came from two districts: one, Ninh Kieu is largely urban and the other, Binh Thuy, largely rural.

Methods

To explore the meanings attached to having epilepsy in the different socio-cultural contexts of interest here, we undertook 'mini-ethnographies' in each (34), involving rapid appraisals (35) to inform subsequent detailed qualitative studies (in-depth interviews and focus group discussions) with identified relevant informant groups, and review of local literature and media reports. Mini-ethnographies are proposed as focussing on and interpreting a specific set of cultural phenomena and related human experiences - in the present case, epilepsy and the medical and social practices relating to it. Detailed protocols for the qualitative work reported here specified geographical locations, types and numbers of informants and the focus of questioning.

Ethical permission to conduct the studies was obtained in China from the Institutional Review Board (IRB) of Beijing Neurosurgical Institute; and in Vietnam from Hanoi School of Public Health IRB.

Sampling procedures and data collection

Sampling for the qualitative work was purposive, major categories being informant group membership (ie. person with epilepsy, relative, community member etc) and area of residence (urban/rural in China; north/south in Vietnam). For people with epilepsy (PWE) and relatives, we also aimed for maximum variation by age and gender. Data collection began in May 2005 and was completed in November 2005 in China and December 2005 in Vietnam. In China, PWE and family members were identified in urban Beijing by hospital and community clinic doctors, and local community members by community leaders; in rural Beijing PWE and family members were identified through staff at a specialist centre for epilepsy and local community members by community leaders. In Vietnam, local commune and hamlet health workers identified PWE living in the area, regardless of the source of their healthcare. Family and local community members were also identified through commune and hamlet health workers.

Interviews were conducted in informants' homes; focus groups were conducted in local health or community facilities or places of work. All interviews and focus groups were conducted by local research teams led by two of the authors (WW, DVT) in their own languages. Details of interviews and focus groups achieved in each country are shown in Tables 1 and 2. In both countries, all encounters were tape-recorded (with permission from informants); the recordings were then transcribed and translated into English by WW, JW and DVT, then cross-checked with AJ and DS for clarity of translation and meaning of any culturally specific terminology. Though some subtleties of meaning were almost inevitably lost in the process of translation, this allowed accessibility of all the ethnographic material to the whole research team. All checked and cleaned data were stored as Word files.

Data analysis

The data were subjected to a process of thematic coding and charting, assisted by use of the qualitative data analysis package, 'Framework' (36). A subset of transcripts were coded inductively by three of the authors (AJ, RR, DS), to develop an initial set of codes representing major and sub-themes raised; application of the initial set to subsequent transcripts generated additional codes which were then incorporated following discussion and agreement by all members of the coding team. To ensure quality of the coding process, every fifth transcript was double-coded and any inconsistencies arising were discussed by the coding team and reconciled. The coded data were then charted electronically using an Excel database, to allow easy transferability of files to all team members, regardless of geographical location.

Findings

Beliefs about causes and triggers for epilepsy

In both China and Vietnam, beliefs about the causes of epilepsy and triggers for seizures were a complex interweaving of western biomedical, traditional and folk medicine concepts. Thus, epilepsy was recognised as the outcome of neurological events; but also as arising from bodily imbalances such as *feng* (wind) moving in the liver, too much fever and accumulated liver fire, disharmony of the liver and *tanya* (gathering of phlegm). Internal, psychological pre-disposition and external socio-environmental stimuli were also commonly implicated (Box 1).

There was universal agreement among both lay and professional informants in China that epilepsy was not a contagious disease, but in both groups considerable uncertainty was expressed about the role played by heredity. Where lay informants' observations were that the offspring of an affected family member were unaffected, their common-sense conclusions were that epilepsy could not be inherited; conversely, when other relatives were known to have epilepsy, this was seen as proof of its hereditary basis. Among healthcare workers, none working in urban Beijing rejected the possibility of epilepsy as hereditary, but a number (mainly traditional medicine practitioners) working in the rural district did so, on the grounds that they had never seen any identifiable cases. Healthcare workers clearly differentiated between causes of epilepsy and triggers for seizures. Cited causes of epilepsy included accidental head injuries, infection, fever, birth trauma, cerebrovascular disease or abnormalities, problems with the nervous system and mental pressure; and among urban workers particularly the distinction was often drawn between epilepsy secondary to one of these and primary or 'obstinate' epilepsy, where no cause was known. Among rural workers, seizures were more commonly described as having a psychological basis, being triggered by tiredness, nervousness, fright, excitement, anger, low mood or introversion and having 'a narrow mind'. Though the distinction between epilepsy and seizures was less clear-cut among lay informants, they too frequently endorsed psychological causes, as well as physical causes such as trauma, tiredness, fever and 'too much brainwork'; and dietary factors, including *chou-shi-feng* (literally, 'fatty boy's greediness'), eating food thought to be too fatty or the wrong temperature. Spiritual causes of epilepsy were rarely endorsed by either lay or expert informants, though one parent reported using a fortune teller to exorcise the evil spirit thought to be causing their child's epilepsy. Likewise, the link between epilepsy and insanity, commonly reported in public attitude surveys in this world region, was rarely explicitly endorsed and often actively rebuffed.

As in China, lay informants in Vietnam were clear that as a disease 'inside the body' epilepsy was not 'transmittable' to others; again, however, opinions were divided as to whether epilepsy could be inherited. The question as to the inheritability of epilepsy was linked to a lay theory that seizures often resulted from 'weak nerves' and that such weakness was itself hereditary; following from this, factors such as stressful life events and heavy or over-work were seen as exaggerating any such weakness and so acting as triggers for seizures. Other common attributions were that epilepsy was linked to fever (a common-sense interpretation of the onset of

seizures in an area where malaria, dengue fever and Japanese encephalitis are all endemic); and to exposure to the chemical 'Agent Orange'. Epilepsy was only rarely attributed to sins committed in a previous incarnation, fate or magical causes. In keeping with traditional medicine theory focussing on *phong* (wind), seizures were also commonly thought to be triggered by extremes of weather such as strong winds, or seasonal weather changes.

Vietnamese healthcare workers recognised epilepsy as a condition with multiple causes, including accidents and head injury; birth trauma; infections such as encephalitis, meningitis, tetanus and TB and accompanying high fever; hypertension and blood circulation problems. However, they also pointed to the delineation in traditional medicine of three categories of disease causation: internal psychological causes such as sadness, depression and anger; external environmental causes, in particular climate and weather changes; and other causes, including falls and food poisoning. Healthcare workers were all confident that epilepsy was not contagious but in some instances had a genetic basis, specifically with mother-to-child transmission.

Beliefs about the course and treatment of epilepsy

In China, lay informants generally accepted that epilepsy was 'a chronic disease, very pernicious' and one that could not be 'radically cured' unless through surgery, but that it could be controlled by treatment taken long-term (Box 2). With regard to treatment, the emphasis was on Western AEDs, as more effective than traditional or folk medicines. Acupuncture was seen as useful as a means to 'restrain the nerve'; and acupressure as a means of stopping seizures when they occurred, by applying pressure to the 'renzhong' (philtrum) and 'hegu' (between the base of the thumb and index finger) points. An often cited folk treatment was 'burying catgut' (catgut laid under the skin surface by means of a small incision); other folk remedies cited included cat and sheep's brain. In addition to medicine-taking, lay informants also commented on the importance of a PWE getting rest, maintaining harmonious personal relationships and 'a good mood' and avoiding 'irritant foods', environmental 'inducements' such as noise and flashing lights and psychological ones such as getting upset or angry. The financial burdens associated with adhering to prescribed medications regularly and long-term were raised by several informants, one of whom concluded that, 'they are just controlling the state of the disease, this is not worth so much money'.

Both traditional and Western medicine-based healthcare workers in China were in agreement that though epilepsy could seldom be cured, seizures could be controlled with medication and surgery. However, they were also very well aware of the lack of responsiveness of some epilepsies to drug treatment and that, 'neither prevention nor control is an easy job'. The possibility of combining both Western and traditional treatments was discussed. Some traditional medicine practitioners commented that Chinese remedies were less effective or did not work quickly enough, meaning a combination of Western and traditional treatments was desirable for 'adjusting all the organs'. Western AEDs were seen as useful for treating the seizures specifically, while Chinese medicines were useful for regulating the patient's constitution between seizures. Perhaps unsurprisingly, urban-based healthcare workers displayed a more sophisticated level of understanding of epilepsy than their rural counterparts, distinguishing between idiopathic and symptomatic epilepsies, the different foci for and types of seizures, and the possibility of seizure remission and subsequent drug withdrawal.

As in China, Vietnamese lay informants understood that, 'sometimes the disease is severe' but were confident that generally, even if not curable and a condition that 'stays with them for life', epilepsy could be treated effectively with 'modern' (western) AEDs. PWE and family members frequently noted that since taking antiepileptic medication, their/their relative's seizures were reduced in frequency or completely controlled. There was general awareness that though it could not eradicate the disease, regular and prolonged medication taking could help patients to recover from their condition, and that seizures were likely to recur if medication was stopped. Healthcare workers recognised that seizure control was attainable in the majority of affected individuals (variously estimated as between 70% and 90%) with appropriate and regular medication, initiated early after disease onset; but also that patients often failed to appreciate the long-term nature of the condition and its treatment. As in China, the cost of taking western AEDs long-term, especially where they were not completely effective in controlling seizures, called into question the virtue of taking them.

Additionally, both lay and professional informants in Vietnam endorsed the importance of regulation of mood and lifestyle, including avoidance of overwork and stress, avoidance of extremes of weather and temperature, good rest and nutrition, family care and support and being 'psychologically comfortable' – though none proposed these as independent treatment strategies, but as ones additional to drug

treatment. Some herbal treatments including lemon juice and citronella dropped on the tongue were thought useful by lay informants as temporary remedies for seizures when they occurred; and folk medicines such as snake wine and varan meat and gall were also mentioned.

Beliefs about implications of epilepsy for quality of life

In both China and Vietnam, epilepsy was represented as enormously disruptive of 'the flow of social interactions' (7) – in the words of one informant, not a terrible disease, but one that gives 'pain both to the heart and the body'. As recorded elsewhere in the world, the impacts of epilepsy were wide-reaching, encompassing all the major dimensions of QOL and also impacting significantly on the QOL of other family members (Box 3). The unpredictability of seizures, the dangers this presented both to the affected person and to those around him and the high levels of anxiety so created for both parties were presented as highly problematic by informants in both countries. Further, the embarrassment and potential loss of face arising from having seizures publicly and the resultant negative psychological impacts and 'self-contempt' felt by PWE was a common theme for discussion by Chinese informants. Though the issue of loss of face appeared less pronounced for Vietnamese informants, frequent reference was made to epilepsy causing decrements to general health that left those affected physically weaker than others and more susceptible to developing other illnesses, including 'weak nerves' and mental illness or 'instability'. In both countries, there was a clear tension between the understanding that, 'after the convulsions, people with epilepsy are like normal people' and the view that despite appearing so, a person with epilepsy was rendered somehow 'not the same as a normal person' and so less able to contribute fully to everyday social life, even when seizure-free.

The QOL domains raised by informants in both countries as impacted by epilepsy were: body-focussed; internal (both impaired cognition and psychological status); social (difficulties in making and retaining friends, and of finding a girl/boyfriend or spouse); and educational/employment (learning difficulties and school disruption; problems with job-seeking and keeping, work disruption and reduced income). With regard to the first of these, fears around the risk of death and seizure-related injury were common, but were also expressed about possible organ damage resulting from repeated seizures. The negative effects internally both for intellectual functioning and psychological status were raised frequently: PWE were described as having low intelligence; or experiencing a decline in their intellectual function over time following

the onset of seizures, sometimes attributed to medication side-effects. Negative changes in character were also often ascribed to the development of epilepsy. The impact of such intellectual and psychological decrements on school performance and disruption was an important theme. Among Chinese informants the question of whether PWE could or should continue in education was highlighted, with several PWE and parent informants reporting that they/their child had withdrawn voluntarily, been encouraged to quit or been actively barred from the education system because of them.

Another major negative impact raised was the likelihood of epilepsy leading to impaired employment prospects. The widely articulated view in both China and Vietnam was that the unpredictability of their seizures meant PWE represented a poor employment risk, that no employer would be willing or could afford to employ them, and that there were many jobs in which they could or should not be employed. Informants in both countries expressed the view that PWE needed to avoid potentially physically dangerous occupations and should be confined to doing 'simple', 'special' or 'appropriate' work only; that they should be restricted from work involving contact with the general public or media because of potential embarrassment should they experience seizures publicly; and that they should be prevented from doing any heavy physical or 'stimulating' work and discouraged from work that is 'strenuous' or 'too tiring', since this might trigger seizures. As has been noted elsewhere, PWE were represented as somehow unreliable and 'less competent' employees because of their tendency to seizures. They were also seen as physically weaker and liable to seizures particularly if undertaking heavy physical work or 'brainwork', and so as unsuited to the demands of paid employment – and family members in both countries commonly expressed the view that they therefore should not work outside the home. Thus, as in many other countries worldwide, the negative impacts of epilepsy for employment were attributable to a combination of what was largely regarded as justifiable discrimination, unjustified prejudice and familial concerns and over-protectiveness.

Finally, in both countries epilepsy was seen as having a major impact on marriage prospects. A view common among Chinese informants was that while there were no technical restrictions on marriage, the lesser desirability of a partner with epilepsy was self-evident and prospective partners would inevitably be hesitant, since 'everyone wants a healthy partner'. The logic of this argument was followed by widespread acceptance that a PWE would be well-advised to conceal their condition

from a prospective partner; and that even if able to marry without deception, such marriages were more likely to end in divorce because of the resultant burdens to the partner. It was also generally accepted that those who did marry without concealing their condition were likely to marry less well.

In both China and Vietnam, the lack of marriageability of PWE seemed to hang around two main issues, the one being the possibility that epilepsy was inheritable and so could be passed on to any offspring, the other the perceived inability of PWE to carry out everyday living tasks and contribute adequately to the family economy. With regard to this latter, a wide range of everyday living activities central to fulfilling the marital role were perceived as threatened by the possibility of seizures, including driving a car or riding a bike, working on or near water, including working in the paddy fields, cooking food and childcare. With regard to the former, as noted earlier, the issue of the inheritability of epilepsy and the process of transmission was much debated and had a clear influence on the perceived ability of a PWE to produce a healthy child. There was widespread endorsement of the comment that 'there is a lot of public pressure on people with epilepsy because people say it is hereditary and will pass from generation to generation and never stop'.

Additional to these personal impacts, epilepsy was seen as also having a major impact on the lives of other family members, in the sense that they were called upon to act as carers and so unable to pursue other life opportunities; and suffered the physical, psychological and financial burdens of caring, the latter divided into the enormous cost of providing regular and long-term antiepileptic treatment; and the loss of income because of disruptions to their own employment status.

Responses to QOL implications

How, then did PWE and family members of PWE seek to minimise the above catalogue of QOL impacts? A critical aspect of epilepsy is that its manifestation, seizures, are generally brief and transient and it is therefore a potentially highly concealable condition. Informants in both China and Vietnam commented on the fact that it is not possible 'to tell a person with epilepsy by looking at them' and that PWE are the 'same as normal people until [*they*] go into a fit' - and it was thus possible for them to keep their condition secret, especially those for whom the timing of seizures was protective. Unsurprisingly, in both countries non-disclosure of epilepsy was endorsed as an appropriate management strategy, clearly linked to the belief that to reveal it would lead to differential treatment and discrimination, and hence potentially

major impacts for QOL (Box 4). However, though a commonly reported strategy, there was clear evidence of cross-cultural variability in views about its advisability. PWE and their family members in China, particularly those living in the rural area, appeared more likely to support a policy of non- or only partial disclosure than were their protagonists living in Vietnam. This difference appeared rooted in Chinese thinking of seizures as breaching 'social etiquette' and so shameful; and the strong conviction among Chinese informants that revelation of their condition to others would lead them to be looked down on and suffer 'loss of face'. As a result, non-disclosure extended even to close relatives including prospective marriage partners, spouses, children and siblings. In contrast, in Vietnam, though there was not complete consensus, the majority view was that there was no need to conceal epilepsy as it was not a 'fearful disease' or one 'associated with social evils'; and several informants commented that others who knew about their epilepsy treated them no differently and, indeed, felt sympathy for them, actively supporting them when seizures occurred. Furthermore, the strategy of *chieu* ('treat more gently') was a commonly proffered one among family members of PWE. One Vietnamese community leader concluded that, 'people with epilepsy can be more positive about disclosing their condition these days.' Nonetheless, even Vietnamese informants outwardly supportive of a policy of openness recognised the potential negative impact in particular areas of functioning, particularly marriage; as a result, some pursued a policy of selective disclosure, revealing their condition only when asked outright, or in particular circumstances.

Health professionals in both countries overwhelmingly supported openness about the diagnosis of epilepsy, so that patients could access appropriate treatment and care and 'since people would know what to do and how to help'. In both countries, they argued that non-disclosure came at a price – for example, healthcare workers commonly reported that even though they were 'eager to be treated at heart', PWE and their families often opted to try to treat it at home rather than seeking appropriate medical help. Nonetheless, there were many professionals, particularly in China, who simultaneously concurred with their patients about the desirability of concealing their condition in non-medical encounters, given that the negative reactions of others to seeing seizures and the level of societal discrimination towards epilepsy meant the likely outcome of disclosure was that 'you would lose many chances'. Healthcare professionals in both countries also highlighted an apparent confusion on the part of lay members of the community, whereby epilepsy was sometimes aligned with

psychosis and other forms of 'psychopathy', thus increasing the risk of discrimination and supporting concealment as an appropriate strategy.

Discussion

The findings from the two ethnographic studies reported here both support and enhance those from previous surveys of attitudes among the general public in the two target countries (16,21,22). These earlier studies have documented quantitatively the size of the problem of negative public attitudes. By exploring the meanings attached to epilepsy in each country and among PWE, family members and the wider social networks with which they connect, we have begun to clarify more fully reasons behind these negative attitudes, and specific foci for education and information in intervention studies aimed at increasing knowledge and understanding of epilepsy and, as a consequence, reducing its impact.

With regard to beliefs about the causes of epilepsy, our work suggests a more 'embodied' and hence more benign set of theories of epilepsy in these two Asian countries than is documented in some other cultures, a point we will return to in more detail below. In both countries, too, there appears to be appreciation of the variability of epilepsy, and generally cautious optimism about its treatability – and the interweaving of alternative explanatory paradigms gives access to a wide range of treatment possibilities. Nonetheless, epilepsy was believed in both countries to have marked and diverse QOL impacts, such that selective or non-disclosure were commonly embraced as social management strategies. The reasons for this are apparent when specific sets of beliefs are examined. For example, our studies highlight the widespread concern among protagonists in both countries that epilepsy is inheritable, the widespread knowledge gap about the size of the inheritance risk, and the various misunderstandings about the mechanisms for transmission. Previous authors have documented high levels of prejudice in China and Vietnam against PWE marrying (16,21,22); and have hypothesised (16) that this prejudice links to beliefs about the inheritability of epilepsy. Our findings support this hypothesis. However, they also clarify that there are other highly pragmatic reasons at play, in as much as those with epilepsy are seen as unable to fulfil the obligations of marriage adequately and so as constituting a poor choice. The same authors also documented high levels of prejudice against PWE in the context of employment. Again, our findings shed light on this, highlighting the various ways in which PWE

were held to be less reliable and competent than others with regard to employability, a finding resonant of studies of attitudes to employment of PWE worldwide (37). Future intervention studies focussing on employment need therefore to address these ideas and educate the relevant communities as to what represents reasonable and unreasonable restrictions in this area of activity. In relation to treatment issues, our findings highlight that the emphasis on Western AEDs as suitable for treating the symptoms of epilepsy, seizures, and traditional medicines as suitable for regulating body system failures thought to be at the root of epilepsy contributes to a situation of short-term and/or irregular medication taking, with potential serious clinical consequences. Clinical interventions that aim to narrow the treatment gap, such as is currently underway in China (24), must therefore go include educational programmes aimed at countering such knowledge gaps. However, as noted in a different cultural context (38), such initiatives must also recognise the place of traditional medicine in the therapeutic process.

Limitations of the study

Kleinman (34) has noted the danger that clinically oriented mini-ethnographies such as those reported here, through 'examining only a relatively narrow band in the cultural spectrum of local worlds' may lead to production of a very limited contextual analysis. We have tried to be responsive to this charge, through use of rapid appraisals preliminary to our in-depth work, cross-cultural research collaboration with the research agenda set collectively, fieldwork led by local principal investigators and designed around local conditions and resources, and team consensus over the content and conclusions of the outputs. However, it goes without saying that our work was limited by the lack of familiarity of some team members with Chinese and Vietnamese cultures, including their healthcare systems; and lack of ability to speak the languages of the persons whose attitudes and beliefs were being investigated. Lack of familiarity with social science research methods was a limitation for the Chinese team members, though one we tried to address robustly through formal training and ongoing informal support.

We are conscious of the difficulties of eliciting 'private' rather than 'public' accounts (39) of the meaning of epilepsy in studies such as ours, despite their in-depth nature. We acknowledge the possibility that the deeply-embedded beliefs and lived experiences of our informants were not fully accessible to us in a research situation where resources did not allow for multiple interviews with informants, through which trust could be established. We are also cognizant of the fact that because our

samples of PWE and family members were identified through public health facilities, we have neglected the possibility that patients utilising only traditional medicine might have different beliefs and lived experience from those expressed here. More importantly, because of the obvious difficulties around their identification we have also excluded individuals who avoided treatment-seeking altogether and for whom issues of stigma and social exclusion may have been more intense. Finally, our studies were also limited ethnically and geographically. In China, our sample was drawn from one municipality only and among Han Chinese peoples, who are the predominant ethnic group. In Vietnam, we focused on one northern (Hanoi) and one southern (Cantho) province only. Thus, our findings can in no way be considered as representing the views of people in China and Vietnam beyond these highly confined conditions of place and being; replication of our work in other geographical locations and ethnic groups would clarify any important differences in each country.

Acknowledging these various limitations, what are the implications of our findings for the nature of epilepsy stigma in the two countries in question? Key among our findings is that the explanatory paradigms our informants drew upon were highly embodied ones and so relatively non-stigmatising. Andermann (40) divides theories about causes, transmission and treatment of epilepsy into four major categories - punishment for sin, possession; contagion; and disease of the brain – the first three of which clearly create the possibility of stigma. Whereas studies in Indonesia (41) and across rural Africa (42-46) largely endorse the first three categories, greatest weight was given among our informants to the fourth neurologically-focused category; and traditional medicine offered a fifth, that of epilepsy as the result of internal blockages of bodily fluids. In doing so, it did not suggest the 'ontological deficits' commonly associated with having epilepsy in Northern European cultures (47) or the 'moral transgressions' (48) proposed for people living in many of the African countries. As reported by Nguyen (49) in the context of mental illness in Vietnam, beliefs about epilepsy focused primarily on the natural rather than the supernatural, with attributions commonly made to mental stress, emotional strain and trauma, all of which were considered as weakening the nervous system and so increasing illness susceptibility. These ideas are not unique to Chinese and Vietnamese culture (50), but their dominance here and the response generated by them of treating PWE 'more gently' is important. Their effect appeared to be to render the PWE someone unable to fulfil their normal social roles and obligations and 'a person to be supported' (51). Furthermore, pluralistic explanations were the norm among our informants and the western biomedical model of disease, in which

epilepsy was seen as originating from neurological and other pathological causes, was equally familiar. This amalgam of Western biomedical and traditional Chinese medicine ideas meant that epilepsy was unanimously recognised as non-contagious and so as representing no real danger to others; and as relatively easily controllable, even if not curable.

Yet, despite these apparently benign orthodoxies, those with epilepsy were certainly marked out as having, in Goffman's words, an 'undesired difference' (52) and the possibility of stigma and discrimination was widely felt. This appeared linked both to the issue of loss of face, a profoundly important one in Chinese society, and to the threat imposed by their inability to perform normally in their social roles, which led them to be seen as of low social value (53) and so socially excluded. Notwithstanding both temporal and geographical differences, our ethnographic study in China delineated the same set of family, marriage, employment/financial and moral consequences as the one by Kleinman et al (2) conducted some 20 years earlier and in a different region. And though the issue of loss of face was less apparent for our informants in Vietnam, they nevertheless endorsed the same set of QOL impacts and the same appreciation of the possibility of stigma and rejection. The seriousness of these impacts and the level of this rejection seems likely rooted, at least in part, in the tenets of Confucian philosophy wherein, for example, being an effective homemaker is fundamental to a woman being considered 'virtuous', and providing offspring is an essential element of filial piety and obligation. Thus stigma and discrimination remain highly important concepts, central to the social meaning and course of epilepsy in these two countries, with the situation of those affected perhaps best be characterised as one of benign rejection. The commonly adopted response of concealment of a diagnosis of epilepsy was clear recognition of this on the part of PWE and family members. As noted by Allotey & Reidpath (51), interventions aimed at addressing the issue of stigma of epilepsy in these two countries need therefore to involve strategies to increase the social value of PWE, through enhancement of their ability to undertake normal social roles.

Reviewing interventions to reduce epilepsy-associated stigma, Birbeck (54) states that, 'to develop optimal stigma-reducing interventions we need better understanding of the mediators of stigma'. Unpacking the underpinning beliefs and practical realities of epilepsy stigma, as attempted here, should allow more precise definition of the required focus for future interventions aimed at reduction of epilepsy-associated burden, and of the appropriate outcomes. Despite their acknowledged limitations, we

suggest that our studies have demonstrated both the mediators and significance of stigma with regard to the meaning and lived experience of epilepsy in our two target countries and the urgent need for locally-driven, multi-faceted intervention programmes to reduce it. We are now seeking further funding to instigate such programmes.

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Dedication

The CREST Project team dedicate this paper to the memory of their colleague, Dr Leonid Prilipko, who died In March 2007.

Table 1. China Ethnographic Study – Informant type and numbers

Chongwen District		Shunyi District	
Interviews:	Focus Groups:	Interviews:	Focus Groups:
24 people with epilepsy*	1 nurses	24 people with epilepsy ⁺	1 nurses
24 family members [§]	1 community leaders	24 family members [#]	1 community leaders
-	2 school teachers	-	2 school teachers
5 employers	2 lay community members	4 employers	2 lay community members
11 western medicine doctor/health workers		12 western medicine doctors/health workers	
7 traditional medicine practitioners		6 traditional medicine practitioners	
Total = 71	Total = 6	Total = 70	Total = 6

Focus groups: involved up to six informants per group.

Key informant characteristics: *12 men, 12 women, age range 16-69; [§]8 men, 16 women, age range 33-70; ⁺12 men, 12 women, age range 15-61; [#]8 men, 16 women, age range 29-71;

Table 2. Vietnam Ethnographic Study – Informant type and numbers

Hanoi:		Cantho:	
Interviews	Focus Groups	Interviews	Focus Groups
11 people with epilepsy*	-	22 people with epilepsy ⁺	-
12 family members [§]	-	14 family members [#]	-
5 community leaders	2 school teachers	4 community leaders	3 school teachers
3 employers	1 lay community members	2 employers	2 lay community members
1 western medicine doctor	1 Women's Union members	3 western medicine doctors	3 Women's Union members
2 traditional medicine practitioners	1 community level doctors	5 traditional medicine practitioners	3 community level doctors
Total = 34	Total = 5	Total =50	Total = 11

Focus groups: involved up to seven informants per group.

Key informant characteristics: *5 men; 6 women, age range 15-77; [§]5 men; 7 women, age range 15-74; ⁺10 men; 12 women, age range 14-82; [#]3 men; 11 women, age range 32-74.

Box 1: Comments about causes and triggers for epilepsy*

'We all know it's not contagious. We have lived together for more than 20 years and she [wife] didn't pass it on to me. And our children and neighbours don't have the disease either.' (CRFAM48).

'Epilepsy is not infectious. Epilepsy is growing in the brain, the brain develops unstably somehow.' (VSFAM38).

'Other people said it can be inherited, but her father's family and my family did not have this disease . . . I felt that the child's disease has something do to with this, that there is heredity - but her elder brother did not get this disease. (CRFAM49).

'The disease of my child is related to her character – because she is an introverted girl and she always hides unhappy things in her heart – I heard this from my grandpa. He is a senior traditional Chinese doctor.' (CRFAM39).

'I don't remember if it was because of having a bath or something, but then I had a very high fever. . . I didn't get to the hospital quickly, so I had brain defects. . . They [doctors] called it the late effects of meningitis.' (VNPWE01).

'In Chinese medicine, it means that phlegm is stopped up. In western medicine, it means an abnormal discharge in the cortex of the brain. There are many reasons such as encephalitis, trauma, hydrocephalus, low blood calcium and so on. (CUHCP71)

* In this and the subsequent boxes, informant type is denoted by the codes in brackets at the end of the quotations: CR=rural China, CU= urban China, VN=North Vietnam, VS=South Vietnam; PWE=person with epilepsy, FAM=family member; HCW=healthcare worker, CL=community leader; EMP=employer; WU=Women's Union member.

Box 2: Comments on course and treatment

'We need to specify the question in each case. For example, what are the inducements of the patient's epilepsy - so as to prevent it. For instance, we need to remind patients when they reduce the amount of medicine without prescription. Some outbreaks of the illness are caused by surroundings, others may be caused by a cold or a fever, which should also be paid special attention. Patients should try to boost their constitution to prevent catching a cold. Moreover, low mood or agitation also causes problems, so patients should be put in a peaceful situation . . . what we can do is deal with each case according to the setting of the illness. . . what a patient needs to do is face reality and follow the prescription; while a doctor needs to set down reasonable treatments and find the proper dosage for the patient so as to achieve an effective treatment.' (CUHCW80)

'I think it [treatment] must be combined. For example, Eastern medicine is used to preserve the patient's health, say to treat the disease from the root. And Western medicine is used to treat the patient's fits or, we can say, to treat the patient from the top. I mean, patients should be prepared to take the medicine and have themselves acupunctured each week. Combining the two methods will help them be better.' (VSHCW73)

'I can see she [child] has recovered, but [she is] not completely cured. . . If she takes medicine regularly, she only has a seizure once a week or two weeks. Without the medicines, she would not be recovered and would have seizures more frequently' (VSFAM31)

'I'm fine as long as I don't get angry. I got the disease because of my mother-in-law – she kept bullying me. The latest seizure was triggered by anger with her. I'm all fine as long as I'm not with her' (PWER21)

'I think it can be cured by taking medicines and obeying the doctors. She [daughter] took Chinese herbal medicines and they were useful at first, but invalid at last. I think Western medicine is better. (CRFAM39).

'He still works. But it is said that we should not let him do heavy work, because if his brain had to work hard, fits of convulsion would happen. This disease is relating to the brain, so let him do light work. Hard work is not good for him.' (VSFAM38)

Box 3: Comments on QOL impacts

'Before I had enough passion to do anything. I think as if there was a wall before me and I was disqualified to do anything after I had the epilepsy.' (CUPWE24).

'If I were the head of the office, I wouldn't admit such an epileptic person, no matter how well qualified he might be for the job. It would be difficult if he should fall into an epileptic fit at an improper time, or in an important situation.' (VNCL58)

'I won't consider hiring him [pwe] if he behaves as normal persons. Only if he has obvious higher abilities than others and a high level of speciality will I hire him. Also if the attack frequency is low, such as once a year – it's intolerable for us that the attack comes once a month. . . Epileptics are not capable of administration or logistics management, nor are they suitable to get in touch with the public or media. . . The key departments of our country such as security and secret departments are not suitable areas for them since they can't control themselves sometimes. . . It's OK during the remission time – but I surely will not hire epileptics' (CUEMP63)

'The patients in our village are self-contemptuous, so they generally do not go out. And there are many things they cannot do. The pressure of the public voice is great to them. (CRHCW70)

'It's harder for women, because no one wants to get married with such women [with epilepsy], because women have to do housework and give birth. Those women cannot do such functions. Therefore men with this disease can still get married, while the women will have much difficulty.' (VNFAM40)

'I cannot act like a healthy person, doing fierce movements, as I am afraid fatigue will result in a seizure' (CUPWE09)

'I always think of myself as an unhealthy person and I am inferior to others in every aspect. I'm gradually distant with others – I felt we were equal together in former times, but now I feel I'm inferior to others. The spiritual burden is great to me because I have had to give up a lot of aspirations and leave my fate to chance. In fact, I want to work, which can make me feel better – but no-one would like to employ me as I have the disease. Look – my hand is very strong, but it is difficult to find a job.' (CRPWE04)

'Suppose my son is falling in love with an epileptic girl, I would not allow them to get married. That's an issue. For example, if my son said, 'I'd like to marry that girl' I would ask, 'Is she healthy?' And if then he said 'she has epileptic seizures sometimes, then that's the end, no more discussion, just a big no.' (NVWU01)

Box 4: Comments on disclosure

'PWE see it as a disgrace and are reluctant to tell others about this condition.' (CRPWE06)

'I think patients should hide it [epilepsy] from other people because discrimination still exists. People don't know much about epilepsy and their cognition is not correct now in China. It will bring a severe burden on patients' minds, which does harm to their treatment and patients' daily life.' (CUHCW79)

'I think it is better to tell – but if I am a person with epilepsy I won't tell other people. This is where the paradox lies – if I tell, I'm afraid of being looked down on. If I don't tell, I'm afraid of danger to myself.' (CRHCW67)

'I've seen from my experience that there were families with members just starting epilepsy, but they didn't let other people know, they just tried to treat it at home. They didn't want to show their child was under treatment . . . People are still thinking that way, they are confused between epilepsy and mental disorder . . . the majority of the community. about ninety percent of the people, are confused with the two.' (VNCL54)

'Yes, I did [talk about it], there is nothing to hide. My disease is not a social disease, so I'm not afraid of it.' (VNPWE01)

'No, never [talks about daughter's epilepsy to others] – I mainly wonder if my daughter' sense of self-respect will be hurt and if some insensible person will laugh and tease her, so that she thinks she is worse than other people. Secondly, I wonder whether others will look down on me and say we bore and brought up an idiot child.' (CUFAM34)

'Gosh! After I knew this [the diagnosis], the child [son] became my secret trouble. . . as a mother, I would not like others to know that my son has epilepsy. . . I'm afraid that this disease would affect the whole of his life, especially looking for a girlfriend and marriage.' (CRFAM31)

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