

Knowledge gaps and uncertainties about epilepsy: findings from an ethnographic study in China

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Abstract

Epilepsy represents one of the major brain disorders worldwide. In China, research into how much people with epilepsy know about their condition appears limited. Drawing on data collected as part of a large ethnographic study, we present the experiences and views of Chinese people with epilepsy and their family members, to identify knowledge gaps and uncertainties about epilepsy within selected urban and rural communities. We also examine how respondents' demographic characteristics influence their knowledge, understanding and beliefs about epilepsy. We found knowledge and understanding of epilepsy to be uneven and context-specific. Hereditary factors were most frequently cited as a potential cause, although their impact remained unclear. Western medicalisation of epilepsy appears less evident in the reports of rural informants, where traditional beliefs continue to shape definitions and treatment. Societal differences within these communities set boundaries on knowledge acquisition. Plotted against these differences, we suggest strategies for proposed educational/psycho-social intervention programmes.

Introduction

A number of studies suggest that knowledge acquisition about epilepsy - its causation, its treatment and its prognosis and what important lifestyle changes have to be made to ameliorate its impact - results in a number of positive effects for the individual with the condition, including improved self esteem, improved self efficacy and better illness adjustment [1-3]. Within the context of the overall management of the condition, it is desirable for the individual and their family to possess a good understanding of epilepsy and its treatment for a number of important reasons. These include improving the communication between the patient and the clinician in respect of choices and treatment plans; demystifying beliefs about causation and treatment; ensuring awareness of the factors that might potentially decrease the amount and or severity of seizures; understanding the psychological and neuropsychological impact of the condition; helping educate friends, families, schools and employers; and acquiring information about external support agencies. Despite recognition of the importance of knowledge and the abundance of information on epilepsy that exists, certainly in developed countries, people with epilepsy and their families do not appear to possess sufficient knowledge about their condition [4,5]. Addressing knowledge deficits as a means of enhancing epilepsy management has led to the development of a number of psycho-educational programmes (6-8).

To date, relatively little research appears to have been undertaken on the knowledge of people with epilepsy and their families in Developing World countries. One notable exception is the psycho-educational public intervention study conducted in Tanzania by Jilek-Aall and co-workers [9]. The authors were able to show a significant improvement in attitudes towards people with epilepsy through the use of focus groups addressing knowledge and beliefs. More recently, as part of campaigns to reduce the stigma of epilepsy, emphasis has been placed not only on the need to educate people with epilepsy and their families, but also to educate the general public. For example, in Zambia Mbewe and colleagues [10] recently examined the knowledge of policemen, who are frequently called upon to manage people experiencing a seizure. Findings from the study indicated that a small but significant minority attributed epilepsy to spirit possession or witchcraft; and more than half believed epilepsy to be contagious. The authors assert that in regions of the developing world where the police provide emergency medical services, police officers need to be a target for educational and social intervention programs. A parallel survey, conducted by the same investigators with non-physician healthcare workers, found that respondents expressed both personal and professional reservations about people with epilepsy marrying. The researchers argue that in addition to improving diagnosis and treatment skills, educational programs must address underlying attitudes [11].

A cross sectional survey conducted among Government workers and the general public in Accra, Ghana, found that almost all of the 380 respondents were able to provide accurate

descriptions of epilepsy. However, 45.3% did not know the cause of epilepsy, and 37.6% did not know how it could be treated. Out of the 358 responses to a question about the cause of epilepsy, 114 (31.8%) said the condition was inherited and 100 (27.9%) attributed it to witchcraft/juju or spirits. The authors note that traditional beliefs and attitudes about epilepsy are still held firmly by the adult working population and that respondents' educational level is linked to the appropriateness of the responses. In concluding, they suggest that, in order to improve the management of persons with epilepsy, additional efforts are required to improve the knowledge of the general population through the use of social marketing strategies [12]. Similar results are reported from research conducted in Senegal [13].

In China there has been limited research into how much people with epilepsy understand about their condition. A recent face to face survey conducted by Ding and colleagues [14], in three urban communities in Shanghai, Beijing and Changsha, revealed that many patients only had a basic knowledge of epilepsy. The authors argue the need to emphasise knowledge and publicity/education as part of the management of epilepsy. Using a standard assessment tool, Lim and colleagues [15] in an earlier study conducted across Asia, reported both similarities and differences in knowledge, attitudes and perceptions of epilepsy across regions of China, Taiwan, Malaysia, Singapore, and Hong Kong. Negative attitudes towards people with epilepsy were reported by Fong and Hung [16] following the conduct of a large face to face survey of public attitudes to epilepsy in Hong Kong. Thirty two percent of respondents reported they would not allow their children to marry a person with epilepsy and 25% of employers said they would terminate the employment of a person with epilepsy. These findings emphasise the need for improved public awareness of, attitudes toward, and understanding of epilepsy - which the researchers argue could be facilitated through school education and epilepsy-related organisations in the region.

Cultural beliefs about the source of epilepsy, for example attribution of its cause to spiritual possession, may underpin health-seeking behaviour. Consequently individuals may seek support from religious leaders or traditional healers rather than from Western medical doctors [17-20]. In addition the shame and fear associated with epilepsy often deters those affected from accessing appropriate treatment. Such cultural interpretations and behaviour appear to act as major contributors to a 'treatment gap' in developing countries, estimated as between 70-90% [21]. In China specifically, between six and nine million people were identified as having active epilepsy in a recent epidemiological study; however, over 60% did not receive adequate treatment [22]. This gap in treatment has inevitable consequences for education, employment and socialisation [23-25].

As a means of addressing the clinical and social realities of epilepsy, the Global Campaign Against Epilepsy (GCAE) partnership between the International League Against Epilepsy, the International Bureau for Epilepsy and the World Health Organisation has been established.

The aim of this collaboration is to reduce the treatment gap and bring epilepsy 'out of the shadows' [26]. Demonstration projects, set up in selected regions in various developing world countries, provide the platform from which to launch a number of strategies targeted at achieving this aim. These strategies focus on the identification of people with epilepsy and the provision of appropriate treatment, the reduction of social and physical burden, the education of health care professionals, and supporting prevention and dispelling of stigma.

In collaboration with the GCAE, the authors and colleagues conducted large ethnographic studies in China and Vietnam to explore the stigma and social impact of epilepsy in these two developing world countries [27]. Our findings promote understanding of the reasons behind previously reported negative attitudes towards epilepsy within these two cultural contexts, and as such provide insight for the required direction of future intervention studies. One of the conclusions we draw from this work is that if understanding about epilepsy is to be enhanced and its negative impact on daily living reduced, then any clinical intervention aimed at bridging the treatment gap (see for example Wang et. al, [22]) needs to be conducted in parallel with culturally specific information and educational programmes.

To inform and facilitate design and development of such educational interventions within rural and urban locations of China, we have conducted further analysis of our data with specific focus on identification of issues related to knowledge gaps and uncertainties about epilepsy, from the perspective of people with epilepsy and their family members. We report only on our findings from China within this article; data from Vietnam will be the subject of a separate report.

Subjects and Methods

In brief, the ethnographic study from which these data are drawn was designed to address familiarity, or lack of it, with epilepsy across various target groups. It also focused on knowledge about causes, triggers and treatment, understanding about its manifestations, controllability and cure, perceptions of physical and psycho-social impacts, societal attitudes and beliefs and ideas about how the quality of life for people with epilepsy might be improved. Details of the methods used were previously reported in Jacoby et.al., [27].

Table 1 provides an overview of the target population for the Chinese arm of the study and details the total number of interviews and focus group discussions undertaken in both urban and rural locations of China.

Table 1
Chinese arm of ethnographic study: target population

Interviews		Focus Groups	
<i>Urban</i>	<i>Rural</i>	<i>Urban</i>	<i>Rural</i>
24 PWE	24 PWE	1 NUR	1 NUR
24 FM	24 FM	1 CL	1 CL
5 EMP	4 EMP	2 TCH	2 TCH
11 WMDR	11 WMDR	2 NBR	2 NBR
7 TMP	5 TMP		
Total = 71	Total = 68	Total = 6	Total = 6

Key to informant type: PWE=person with epilepsy; FM=family member; EMP=employer; WMDR=Western medicine dr/health worker; TMP=traditional medicine practitioner; NUR=nurse; CL=community leader; TCH=teacher; NBR=neighbour

Our current analysis is drawn from a sub-set of data extracted from 96 in-depth interviews with men and women with epilepsy and their family members^ϕ. This sub-set includes 24 people with epilepsy and 24 family members from urban Shunyi and 24 people with epilepsy and 24 family members from rural Chongwen Districts of China. Particular attention was employed to ensuring that the sampling technique allowed for maximum variation by age, gender and socioeconomic status. The demographic characteristics for this sub-set of informants are outlined in Table 2.

Table 2
Chinese Informant sub-set – demographic characteristics

Shunyi District (Urban)			Chongwen District (Rural)		
<i>Category</i>	<i>Gender</i>	<i>Age range</i>	<i>Category</i>	<i>Gender</i>	<i>Age range</i>
People with epilepsy	12 Men 12 Women	15-61	People with epilepsy	12 Men 12 Women	16-69
Family members	8 Men 16 Women	29-71	Family members	8 Men 16 Women	33-70

Data collection was undertaken by local research teams who received formal training in qualitative research methods prior to the commencement of fieldwork. This training was conducted by two of the authors (AJ;GB). All interviews were tape recorded (with the participants' permission), transcribed and subsequently translated into English.

Results

We analysed the views of Chinese people with epilepsy and their family members as a means of identifying knowledge gaps and uncertainties about epilepsy within urban and rural communities. The framework for the presentation of this descriptive account is grounded in the frequently raised issues and concerns expressed by our participants throughout the interview process, primarily in relation to: the origins of epilepsy, its prevalence, its clinical

^ϕ Interview schedules for people with epilepsy and family members are included in the appendix

course and treatment and the psycho-social impact of the condition. We also examine how the respondents' demographic characteristics influenced their knowledge, understanding and beliefs about epilepsy.

Knowledge regarding the origins of epilepsy

Our informants across both urban and rural China were able to make the distinction (either implicitly or explicitly) between epilepsy as a condition and seizures as a manifestation of the condition. However, in attributing both causes of epilepsy and triggers for seizure occurrence a somewhat complicated picture with regard to lay understanding emerges. This understanding for the most part was underpinned by either Western or traditional Chinese medicine concepts but non-scientific beliefs were also evident.

Within a Western medicine explanatory model, heredity factors were most frequently cited as the potential cause of epilepsy. However, having made this association, informants remained unclear about the impact and mechanisms of hereditary factors on this condition. For example there was speculation among informants as to whether epilepsy could only be inherited by boys; whether children only inherit epilepsy from a female with epilepsy; that girls inherit from fathers and boys inherit from mothers; and that if both partners have epilepsy the risk to a sibling inheriting the condition was increased. However, informants also drew on their own personal experiences to justify their beliefs, often referring to inconsistencies between what they had heard and what they had observed for themselves. For example, if a person with epilepsy had not been born with the condition or the offspring of a person with epilepsy remained unaffected then epilepsy was perceived as not an inheritable condition. Conversely, informants with a previous family history of epilepsy generally expressed the belief that it was.

Generally epilepsy was perceived as a neurological problem; with seizures resulting from abnormal electrical discharge – '*too much electricity*' or '*gore of the brain*' (cerebral damage). Attributions of cause cited by respondents included a number of potential factors for example, viral and bacterial infection including encephalitis or meningitis, malnutrition, hypertension, stroke, head injury, and peri-natal trauma. Febrile convulsions were commonly cited by both rural and urban respondents as a predisposing factor to the onset of both childhood and adulthood epilepsy. Less commonly cited, but evident in the expressions of both rural and urban participants, was the view that surgical intervention and/or the requirement to have a general anaesthetic had resulted in the onset of epilepsy. Several female participants expressed the view that seizure frequency and severity was related to the menstrual cycle, stating their condition became worse prior to or during menstruation, during pregnancy or since childbirth, or during the menopause.

A commonplace belief was that epilepsy was not an infectious condition; although one urban family member expressed the view that some epilepsies are contagious and others are not; and one man from rural China while apparently subscribing to the view that epilepsy is not a contagious condition, described behaviour which directly opposed this expressed belief:

“I won’t eat with others even when invited to do so in case I pass it on...the family eat together but we have separate bowls and cutlery...If I didn’t have epilepsy I wouldn’t want to mix with people with epilepsy in case I caught it.” [PWER24][∞]

Respondents only rarely acknowledged spiritual causes as predisposing to epilepsy; one man with epilepsy in rural China expressing total disbelief in a neighbour’s comment that epilepsy was related to witchcraft. Conversely, a mother in rural China believed evil spirits and moving lands (as a consequence of building a house) was the source of her child’s epilepsy and engaged a fortune teller to sacrifice a pig’s head as a means of warding off evil spirits.

A number of emotional traits were cited as precipitating seizure onset. These included stress, anger, fear, excitement, unhappiness, grief or depression. A number of informants from rural China believed that a person was more vulnerable to epilepsy if they were timid, displayed narrow mindedness or were introverted, hiding away unhappy thoughts, which led the individual to think too much and take too much to heart. Urban respondents however, more frequently linked seizure occurrence to stress inducing circumstance; for example, coping with an unhappy marriage, dealing with difficult social relationships or being over-worked or too much brainwork.

Psychological robustness was seen as key in managing seizure occurrence:

“Unlike normal people her ability to endure mental stress is very bad, if you blame or criticise her she may have a seizure.” [FAMU51]

Frequently cited activities of daily living thought to act as seizure triggers included bathing and washing clothes in cold water and wading through fields of cold water while working. Environmental factors such as feeling cold and residing in compromised living conditions were frequently expressed reasons for the cause of epilepsy from participants living in rural locations:

“People said it [epilepsy] was because we lived in a campo santo, an unsafe environment.” [FAMR42]

Other suggested causes were lack of sleep and fatigue, noisy environments, watching the television or using computer screens and seasonal climate changes.

[∞] In this and the subsequent quotations informant type is denoted by the codes in parentheses: PWE, person with epilepsy; FAM, family member; R, rural China; U, urban China.

Rural participants more often than urban participants cited dietary regimes as potential causes of epilepsy; variously cited examples included eating food that was raw, eating food that contained too much fat, and eating food that was too hot or too cold. Although respondents were not always able to provide reasons for why this might be the case, a generally held belief was that overeating would lead to vomiting and convulsions:

"It's [epilepsy] called choushifeng - fatty boys greediness." [FAMR44]

Other food intake-related triggers cited were alcohol, caffeine and tobacco.

Finally, and perhaps not surprisingly, many informants - especially in rural China - remained unclear about the causes of epilepsy. This lack of understanding arose either from contradictions and differences in information respondents had received about the condition, or because of an absence of a clear predisposing illness or specific seizure trigger:

"...she has seizures on every occasion for no reason." [FAMR54]

Knowledge regarding prevention, clinical course and cure

A number of both rural and urban respondents stated explicitly that epilepsy was impossible to cure, especially if inherited. As one urban woman with epilepsy explained:

"The disease cured completely is better than epilepsy, which is too difficult to treat. Sometimes I think I would rather have a tumour or cancer, which can be cured after operation. This epilepsy, which you can not see or touch, can not be cured."
[PWEU24]

This characteristic of epilepsy was often embedded in individuals' experience:

"...although she took the medicines and accepted treatment she could not be cured."
[FAMU51]

Viewed from this perspective, epilepsy was characterised as a chronic and often unstable condition, which required long-term treatment.

The unpredictability of seizures and their potential to place people with epilepsy at increased risk of injury led many participants to the view that effective seizure management was an essential pre-requisite to optimising and maintaining quality of life. Many people expressed the opinion that when controlled, epilepsy did not constitute anything serious because it was not contagious or fatal. Both urban and rural Chinese informants articulated a number of medical and personal interventions they considered key to maintaining good seizure control.

Of these interventions, regular long term use of Western anti-epileptic medication - cited as more effective in controlling epilepsy than Chinese medicine - was seen as crucial:

"Western medicines are better than Chinese medicine and are the only way to treat epilepsy." [FAMR35]

Importance was also placed on the need for treatment compliance and whilst some people with epilepsy acknowledged that they didn't always do as they had been instructed, the need

to 'cooperate harmoniously with the doctors' and to follow their advice in order to optimise treatment effect and reduce seizure reoccurrence was recognised by many.

Some informants viewed the potential curability of epilepsy more positively; rationalised by their beliefs that with good doctors and the continued development of both medical and surgical advancements a cure for epilepsy was a distinct future possibility. However, whilst many respondents held hope for the future, epilepsy as a reality still represented a chronic condition and raised concerns as to whether it could be radically cured or even treated effectively:

"At first I thought the illness would only be slight and cured after some treatment."

[PWEU22]

"Unlike cancer patients, people with epilepsy don't die but have to take drugs for life."

[FAMU51]

"I have lost confidence in this illness, although I have eaten much medicine and used many methods, it is no good, the illness can still attack me." [PWEU07]

Personal and lifestyle interventions used by those with epilepsy to maximise seizure control varied, reflecting beliefs about the causes of seizures and their triggers. Noise was a commonly cited trigger and one that should be avoided. Also expressed was the need to reduce social and psychological burdens by avoiding anger, excitement and stress, maintaining a good mood by trying to look on the bright side of things, and regulating one's lifestyle to ensure a balance between work, exercise and rest. Attention to one's diet was often cited as crucial in maintaining seizure control, although there were opposing beliefs as to what constituted good and bad dietary practice. While only few respondents stressed the importance of a nutritious diet, a number agreed that stimulants such as tea, coffee, alcohol and smoking should be avoided. Dietary regimes, which may reflect the influence of Chinese medicine, were more commonly cited by rural participants and included, in addition to the avoidance of hot or cold foods cited above, strictly regulating food intake and drinking plenty of water to aid digestion – this latter because indigestion was thought to be a seizure trigger. Avoidance of eating beef, mutton or spicy foods was also recommended.

For many participants, epilepsy was seen as a 'great trouble' both psychologically - often being described as 'a fate not as good as death'; and economically - families often expressed suffering financial hardship as a consequence of the cost of long-term treatment regimes. A man from rural China whose wife has epilepsy explains :

"[Epilepsy] is heavy on the economy, [wife] doesn't work and I laid off, all my family rely on the subsidy. The drug takes 100 yuans per month, and if unfortunately we should go to the hospital the subsidy will be used up." [FAMR46]

However, despite any accompanying burdens, the role of the family as caregiver was seen as central to optimising wellbeing, with the majority of family member informants expressing willingness to offer help to their relative with epilepsy. Family members were optimistic that the provision of practical, psychological and, where possible, financial assistance would not only translate into reduced seizure frequency for the person with epilepsy, but would also limit family stress in general. These findings parallel those reported in a recent phenomenological study conducted by Pei-Fan Mu [28] where ‘family resilience’, demonstrated through shared family responsibilities, including care giving, domestic and financial support, was highlighted as a key resource for facilitating individual and family coping and wellbeing.

Knowledge related to clinical manifestations

The most frequently referenced seizure manifestations were tonic-clonic movements with loss of consciousness. Other symptoms such as twitching, dizziness brief lapses in consciousness and altered mood state were also reported to a lesser extent. Participants with epilepsy, as well as family members, spoke of the apparent normality of those with epilepsy when not having a seizure:

“I would just be normal after staring.” [PWER14]

“There seems a patient in my village...he was the same to a normal one, but as a lunatic when he had seizure.” [PWER14]

“It is not possible to distinguish a person with epilepsy from a normal person if the seizure does not come.” [FAMU21]

“People with epilepsy may behave as normal if seizures can be controlled.” [PWEU14]

However, evident within the context of these descriptions was our informants’ expressed fears about the unpredictable and variable nature of seizure occurrence:

“I would fall down and lose consciousness. I could not control myself and got hurt sometimes.” [PWER14]

“Epilepsy is frightening...the accident is easy to occur because you do not know when it [seizure] will attack you.” [PWEU07]

“Sometimes it [seizure] occurs on the bus, or when shopping. I suddenly was slammed into the floor...nothing evokes it. I look for the reason all the time, but I find nothing.” [PWEU24]

Interestingly, descriptions about epilepsy and participant views with regard to the fear involved with the condition were expressed differently by urban and rural informants. Urban informants more often expressed themselves from a western biomedical viewpoint using medical terminology to classify seizure type. Commonly expressed terms included: idiopathic, grand mal, generalised tonic-clonic, secondary generalised and absence seizures. While noting that seizures did have the potential to be frightening when observed by a person not familiar with epilepsy, urban informants appeared to rationalise this fear in others by attributing it to a general lack of societal understanding:

“Before she understood about the condition my daughter would run away in fear at sight of mother’s seizure.” [FAMU33]

“It seems it is the display that makes people feel terrible.” [PWEU22]

“Sometimes they [neighbours and friends] said it was horrible because they didn’t know the disease clearly.” [PWEU24]

This medicalisation of epilepsy was less evident in the descriptive accounts of informants from rural communities where folk and traditional beliefs appear to remain strong and the use of lay terminology, derived from these beliefs, continues to shape negatively rural informants’ definitions and descriptions. Two commonly used but pejorative rural terms for seizures were *yang jiao feng*, meaning ‘making a noise like a sheep’ and *chou shi feng*, meaning literally ‘fat boys greediness’ or ‘sickness’. The first term connotes madness and engenders fear as expressed by one rural mother:

“Common people call it [seizure] yang jiao feng...it is frightening because it is similar to a mental disease both of which are difficult to cure.” [FAMR51].

While a rural woman with epilepsy explains:

“People call people with epilepsy yang jiao feng and madman” (PWEF21)

The second term *chou shi feng*, or ‘fat boys greediness’ derives from the belief that epilepsy is caused by overeating. Seizures were more frequently characterised as scary and a fearsome sight to watch among rural participants, as expressed by one respondent who described how her daughter with epilepsy:

“Suddenly fell down with a series of frightful actions.” [FAMR36]

For rural family members the presence of this fear was often articulated through the metaphor of ‘death’; one wife described how it frightened her to death when she witnessed her husband’s first seizure, whilst others observed how seizures rendered the sufferer like a dead person:

“Sometimes she seemed like a dead person when the disease seriously attacked.” [FAMR39]

“It seemed like he was dying.” [FAMR45]

Knowledge sources about epilepsy

Our analysis identified three different sources from which informants drew knowledge and information concerning epilepsy and seizures, which we have categorised as: (i) *formal knowledge*, within which we include knowledge gained from reading medical publications (books, journals, hospital information leaflets) or speaking with medical personnel, (ii) *informal knowledge*, which is gained experientially or via word of mouth, and (iii) *mass media*, which includes information provided via newspapers, radio, television or advertising campaigns. We explored these categories further and found urban participants more often reported using

formal knowledge sources and were more proactive in seeking out knowledge for themselves than their rural counterparts.

With regard to formal knowledge, respondents appeared insightfully to recognise good advice from healthcare professionals when it occurred; the sister of a person with epilepsy explains how she gained information about epilepsy mainly from the doctor at the hospital:

“...the doctor herself also suffered from epilepsy and had a friendly relationship with me...she told me how to deal with the disease and avoid the attacks.” [FAMU55]

However, respondents were equally insightful in their recognition of practice they believed had failed them. This was seen as partly attributable to the doctor’s ignorance of the condition - as a middle aged woman with epilepsy and a family history of the condition explains:

“It is difficult to find an expert in the field of epilepsy...it is because of maladjustment of positive and negative in Chinese medicine and the Western doctors will talk about primary and secondary. They often decried each other...there is no systematic theory.” [PWEU04]

but also as compounded by their heavy workloads and time constraints. Several informants reported information from doctors to be insufficient, but acknowledged that doctors were often too busy and had no time to talk:

“Some doctors can not listen to the whole thing you say, they have already prescribed the drug.” [PWEU24]

Our findings indicate that informal knowledge, the quality of which was mediated by the knowledge, experience and cultural beliefs of the teller, was often in conflict with scientific and medical knowledge. Respondents often reported feeling confused with regard to claims in support of certain treatment options and expressed disappointment when treatment regimes were found to be unsuccessful. A man from urban China explains:

“I was told by others to bury tablets in arm and belly, but ineffective...” [PWEU20]

Similarly a mother from rural China tells of how ‘others’ told her to increase her child’s medication, which resulted in her son’s condition becoming worse:

“Now his memory is slow and he stutters.” [FAMR31]

The majority of informants expressed the need for more information about epilepsy; often seeking responses to their unanswered questions throughout the course of the interview. Knowledge was viewed as a positive resource, with the view widely articulated that increased knowledge could lead to an improved lifestyle for people with epilepsy in terms of seizure prevention and control, and enable others to act appropriately when witnessing a seizure or during an emergency situation. Several of our respondents commented that not all information in newspapers, on television or in advertisements could be trusted and was often deceptive in its claims:

“Good medicine needs no advertisements and medicine by propaganda is unlikely to be good.” [FAMU51]

However, if conducted sensitively, ‘quality’ educational propaganda about epilepsy via mass media resources was perceived by many informants as having the potential to be beneficial in assisting decision making about treatment and day to day care management. Furthermore, mass media resources were viewed as a useful mechanism through which to raise general awareness about epilepsy, which many respondents believed would reduce societal misunderstanding and discrimination.

A limited number of informants expressed the opposing view that general education about epilepsy was unnecessary. The two main justifications for this belief were: firstly that as the majority of people did not have care responsibilities for a person with epilepsy, they would view this information as irrelevant; and secondly that generalised others knowing more about the condition could place too much focus on those with epilepsy, ultimately increasing their risk of being discriminated against.

At an individual level, some respondents argued that information about epilepsy was useless, since knowledge in itself could not provide a cure. Others expressed the concern that improving knowledge about the condition had the potential to increase rather than decrease psychological stress. For example, one family member from urban China described how she often went to the library to seek out knowledge about epilepsy, but was now apprehensive to do so for fear of discovering the condition to be worse than she first thought. Similarly, a young woman with epilepsy explained how she was fearful of losing her hope of a cure:

“...as time passes I gradually get my confidence to overcome the disease but I lost that confidence again after I saw a booklet bought by my aunt. I dare not read books for fear of losing confidence.” [PWEU13]

Discussion

Our analysis indicates that our informants’ knowledge and understanding of epilepsy was uneven and context-specific. While both rural and urban people with epilepsy and their family members understood that epilepsy was a condition of ill health and that seizures were a manifestation of that condition, misconceptions regarding the nature and causes of epilepsy were common. The degree of and variation in misconceptions among our informants would appear to be shaped by a number of factors: location, differing beliefs prevalent in rural and urban communities; the influence of the individuals’ ‘situated experience’, (their individual biographies and living environment) and the personal meaning people with epilepsy and their families attached to their condition (for example, psychosocial burden and the interpretation of

individual events); the associated long term cost of appropriate Western-oriented treatment regimes; and the limited availability of high quality information resources.

Our studies were confined to samples drawn from urban and rural locations close to Beijing and among Han Chinese peoples, who are the predominant ethnic group. We therefore recognise that our findings may not reflect the knowledge and understanding of epilepsy among all Chinese people and can not necessarily be generalised to other settings or contexts beyond those sampled.

Despite this limitation, a number of important messages emerge. First, in contrast to the studies in both Tanzania [29] and more recently, Pakistan [30] a commonplace belief was that epilepsy was not an infectious condition. It is clear from the reports of our informants that a key area requiring addressing is the question of genetic associations in epilepsy. While certain seizure types can be linked genetically [31,32] the role of hereditary factors was more often than not misunderstood by participants in both rural and urban locations - a finding comparable to results from other Asian-population studies [16,33,34]. These misbeliefs could, in part, be the result of limited information provision; but may also be a consequence of the influence of Chinese traditional medicine philosophies. Such cultural beliefs may create an unnecessary fear of epilepsy being transmitted to future generations as discussed in our previous paper [27]. The negative social impact of these beliefs in relation to marriage and family formation was of grave concern for both people with epilepsy and their families.

In general, Western medical concepts about epilepsy were less evident in the reports of our rural informants, where traditional beliefs continued to shape definitions and treatment of epilepsy. Consistent with the findings of Lai and colleagues [33] the use of terms such as *feng* (psychosis) to describe epilepsy and seizure occurrence continue to contribute to misunderstanding and negative connotations about the condition.

The emphasis placed by our rural informants on dietary regimes and restrictions may in part be influenced by continuing adherence to Traditional Chinese Medicine ideas. However, these beliefs and practices may also reflect the lack of appropriate public education regarding epilepsy, particularly where access to information may be limited for those living in rural locations.

Environmental and emotional stresses, although variously weighted by rural and urban participants, were explicitly cited as seizure triggers. This finding highlights the need for psycho-educational programmes that address attitudes, beliefs, knowledge and behaviours as an integral component of any implemented programme. We can conclude from our interviews that people do not always behave in a manner that reflects their beliefs. By way of example, our rural informant cited earlier [PWER24], while subscribing to the view that epilepsy was not contagious, described using separate eating utensils and a reluctance to mix

with others in case he passed epilepsy on. Education in isolation may therefore not be enough and likely requires intervention programmes which include components to promote and support behavioural change. Facilitating positive emotional and behavioural functioning through the provision of psychosocial intervention has the potential to promote coping skills and reduce the perceived burden associated with the condition for people with epilepsy and their family members [6-9].

Both Western and Traditional Chinese healthcare practitioners were perceived by many informants as a primary resource through which to seek information about epilepsy. However, our informants' responses highlight once again the tension which exists between these two philosophies, often creating confusion and uncertainty. For many respondents acquiring adequate knowledge and information from Western doctors was perceived as problematic, their role as information provider being hindered by a lack of specialist knowledge, heavy patient workload and time constraints.

Our evidence not only suggests the need to conduct training on epilepsy to improve the clinical knowledge of healthcare professionals, but prompts us to suggest additional interventions to facilitate a more 'community orientated' approach to education. Such interventions would focus on developing greater collaboration and understanding between Western and Traditional practitioners, facilitated through joint training opportunities and participation in interactive workshops. Developing knowledge capacity by identifying and training community-based support workers would not only assist in easing the workload of medical doctors, but would provide easier access for people with epilepsy and their families (especially those residing in more rural locations) to a community-based contact from whom they can receive knowledge concerning epilepsy.

Educating the general public about epilepsy was perceived by many informants to be beneficial in raising awareness and reinforcing the need for communities in general to have access to adequate information about the condition. Unfortunately several of our informants expressed the view that not all mass media coverage could be trusted and often contained inappropriate or inaccurate information. Consideration needs to be given to addressing this situation as it hinders what could potentially be an effective public resource for delivering science-based information about epilepsy, its treatment and self-care management guidance.

Conclusion

Previous research has focused on documenting percentage-based responses to quantitative surveys to assess knowledge, behaviours and beliefs about epilepsy; such documentation is, however, limited in its ability to explore the underlying meaning behind such responses. The value of this type of ethnographic study is that it enables researchers to elucidate the contextually driven meaning behind these surveys and gain understanding.

We suggest that in meeting the challenge of reducing the treatment gap our findings provide background knowledge which can be made useful for researchers and health professionals alike; it brings to the fore evidence of how social forces contribute to the experiential affects of epilepsy and its treatment. This work has enabled us to be clear about what any educational programme mounted in China about epilepsy would need to involve. From this vantage point we can shape, develop and sensitively communicate science-based psycho-educational programmes and advice directly to people with epilepsy, their families and the wider community, in a way that is responsive to the everyday realities with which they contend.

References

- [1] Commission for the Control of Epilepsy and its Consequences. Plan for Nationwide Action on Epilepsy. Vols. I and II, Part 2. Washington, DC: US Government Printing Office; 1977.
- [2] Mittan RJ. Fear of Seizures. In: Hermann B, Whitman S, editors. *Epilepsy: Social Dimensions*. Oxford: Oxford University Press; 1986. p. 90-121.
- [3] Schneider JW, Conrad P. Doctors, information and the control of epilepsy. In: Hermann B, Whitman S, editors. *Epilepsy: Social Dimensions*. Oxford: Oxford University Press; 1986. p 69-89.
- [4] Jarvie S, Espie C, Brodie MJ. The development of a questionnaire to assess the knowledge of epilepsy: 1. General Knowledge of epilepsy. *Seizure* 1993;2:179-185.
- [5] Baker GA, Jacoby A, De Boer H, Doughty J, Myon E, Taïeb C. Patients' understanding and adjustment to epilepsy: Interim findings from a European Study. *Epilepsia* 1999;40:s26-9.
- [6] Austin JK, Shafer PO, Deering JB. Epilepsy familiarity, knowledge, and perceptions of stigma: report from a survey of adolescents in the general population. *Epilepsy & Behavior* 2002;3:368-75.
- [7] Dilorio C, Shafer PO, Letz R, Henry TR, Schomer DL, Yeager K. Project EASE: a study to test a psychosocial model of epilepsy medication management. *Epilepsy & Behavior* 2004;5:926-36.
- [8] Snead K, Ackerson J, Bailey K, Schmitt MM, Madan-Swain A, Martin RC. Taking charge of epilepsy: the development of a structured psychoeducational group intervention for adolescents with epilepsy and their parents. *Epilepsy & Behavior* 2004;5:547-56.
- [9] JilekAall L, Jilek M, Kaaya J, Mkombachepa L, Hillary K. Psychosocial study of epilepsy in Africa. *Social Science & Medicine* 1997;45:783-795.
- [10] Mbewe E, Haworth A, Atadzhanov M, Chomba E, Birbeck GL. Epilepsy-related knowledge, attitudes, and practices among Zambian police officers. *Epilepsy and Behavior*. 2007;10:456-62.
- [11] Chomba EN, Haworth A, Atadzhanov M, Mbewe E, Birbeck GL. Zambian health care workers' knowledge, attitudes, beliefs, and practices regarding epilepsy. *Epilepsy and Behaviour* 2007;10:111-19.
- [12] Nyame PK, Biritwum RB. Epilepsy: knowledge, attitude and practice in literate urban population, Accra, Ghana. *West Afr J Med* 1997;16:139-45.
- [13] Ndoye NF, Sow AD, Diop AG, Sessouma B, Sène-Diouf F, Boissy L, Wone I, Touré K, Ndiaye M, Ndiaye P, de Boer H, Engel J, Mandlhate C, Meinardi H, Prilipko L, Sander JW. Prevalence of epilepsy its treatment gap and knowledge, attitude and practice of its population in sub-urban Senegal an ILAE/IBE/WHO study. *Seizure* 2005;14:106-11.
- [14] Ding D, Jiang B, Liu YH, Wang WZ, Wu JZ, Yang QD, Zhang L, Li SC, Hong Z. [Study on the diagnosis, treatment and requirement of epilepsy patients in urban communities.] *Zhonghua Liu Xing Bing Xue Za Zhi* 2006;27,11:1000-4. Chinese.
- [15] Lim SH, Pan A. Knowledge, attitudes, and perceptions of epilepsy in Asia: toward a uniform study protocol. *Epilepsia* 2005;46 Suppl 1:48-9.

- [16] Fong CY, Hung A. Public awareness, attitude, and understanding of epilepsy in Hong Kong Special Administrative Region, China. *Epilepsia* 2002;43:311-16.
- [17] Adamolekun B, Meinhardt H. Problems of drug therapy of epilepsy in developing countries. *Tropical and Geographical Medicine* 1990;42:178-81.
- [18] Feksi AT, Kaamugisha J, Sander JWAS, Gatiti S, Shorvon SD. Comprehensive primary health care antiepileptic drug treatment programme in rural and semi-urban Kenya. *Lancet* 1991;337:406-9.
- [19] Andermann LF. Epilepsy in developing countries. *Transcultural Psychiatr Res Rev* 1995;32:351-83.
- [20] Banerjee T, Banerjee G. Determinants of help-seeking behavior in cases of epilepsy attending a teaching hospital in India: An indigenous explanatory model. *International Journal of Social Psychiatry* 1995;41;3:217-30.
- [21] Global Campaign Against Epilepsy. *Epilepsy in the Western Pacific Region. A call to action.* Geneva:WHO; 2004.
- [22] Wang WZ, Wu JZ, Wang DS. The prevalence and treatment gap in epilepsy in China. An ILAE/IBE/WHO study. *Neurology* 2003;60:1544-5.
- [23] Scambler G, Hopkins A. Being epileptic: coming to terms with stigma. *Social Health and Illness* 1986;8:22-43.
- [24] Jallon P. Epilepsy in developing countries. *Epilepsia* 1997;38:1143-1151.
- [25] Birbeck GL. Barriers to care for patients with neurological disease in rural Zambia. *Archives of Neurology* 2000;57:414-17.
- [26] Global Campaign Against Epilepsy. *Epilepsy Out of the Shadows.* Geneva:WHO; 2003.
- [27] Jacoby A, Wang W, Dang Vu T, Wu J, Snape D, Aydemir N, Parr J, Reis R, Begley C, de Boer H, Prilipko L, Baker G. Meanings of epilepsy in its sociocultural context and implications for stigma: Findings from ethnographic studies in local communities in China and Vietnam. *Epilepsy & Behavior* 2008 12;2:286-297.
- [28] Pei-Fan Mu. Transition experience of parents caring of children with epilepsy: A phenomenological study. *International Journal of Nursing Studies* 2008;45:543-51.
- [29] Rwiza HT, Matuja WB, Kilonzo GP, Haule J, Mbeni P, Mwang'ombola R, Jilek-Aall L. Knowledge, attitude, and practice toward epilepsy among rural Tanzanian residents. *Epilepsia* 1993;34:1017-23.
- [30] Shafiq M, Tanwir M, Tariq A, Kasi PM, Zafar M, Saleem A, Rehman R, Zaidi SZ, Taj F, Khuwaja AA, Shaikh KS, Khuwaja AK. Epilepsy: Public knowledge and attitude in a slum area of Karachi, Pakistan. *Seizure* 2007;16:330-7.
- [31] Winawer MR, Rabinowitz D, Barker-Cummings C, Scheuer ML, Pedley TA, Allen Hauser W, Ottman R. Evidence for Distinct Genetic Influences on Generalized and Localization-related Epilepsy. *Epilepsia* 2003;44:1176-82.
- [32] Pinto D, de Haan GJ, Janssen GAMAJ, Boezeman EH, Gerard van Erp M, Westland B, Witte J, Bader A, Halley DJJ, Kasteleijn-Nolst Trenité DGA, Lindhout D, Koeleman BPC. Evidence for Linkage between Juvenile Myoclonic Epilepsy-Related Idiopathic Generalized Epilepsy and 6p11-12 in Dutch Families. *Epilepsia* 2004;45:211-17.
- [33] Lai CW, Huang XS, Lai YH, Zhang ZQ, Liu GJ, Yang MZ. Survey of public awareness, understanding and attitudes toward epilepsy in Henan province, China. *Epilepsia* 1990;31:182-7.
- [34] Chung MY, Chang YC, Lai YHC, Lai CW. Survey of Public Awareness, Understanding and Attitudes Toward Epilepsy in Taiwan. *Epilepsia* 1995;36:488-493.

APPENDIX

Rather than a structured set of formal questions, the interview(s) will follow the format of a focused conversation. The interview will begin with an introductory question, followed by the use of conversational prompts to enable further related discussion.

Person with Epilepsy

Introductory Question

'I'd like to begin by asking... *what events took place that lead you to believe you might have epilepsy...?*

Conversational Prompts

- Do you know what causes epilepsy?
- Can you catch epilepsy from another person?
- Do you believe epilepsy can be cured or just treated? If so what treatment/cures?
- What are the symptoms of your epilepsy?
- Where did you learn what you know about epilepsy?
- Do you get any treatment for your epilepsy? If not, Why not?
- How easy is it for you to get your treatment?
- Where do you go for your treatment?
- What type of treatment do you have? For how long, have you been having treatment?
- How do you feel about the treatment you have received?
- How easy is it for you to get involved with the decisions relating to your treatment?
- What does having epilepsy mean to you?
- Do you believe having epilepsy makes you 'different'? If so in what way?
- Do you think it is worse for a man to have epilepsy than for a woman? If so, why?
- How does having epilepsy affect your day-to-day life?
- How does having epilepsy affect your hopes and aspirations for the future? - Education? Marriage? Children? Employment opportunities?
- Are there things that people with epilepsy can't do within your community? If so, what and why?
- Do you know anyone else with epilepsy?
- Would you have someone with epilepsy as a friend? If not why?
- What does having epilepsy mean to your family?
- Do people in your community treat your family differently because you have epilepsy? If so, why and in what way?
- Do you believe that people perceive epilepsy as a frightening illness? If so, Why?
- Have you been able to discuss your illness with people outside your family – if not why?
- Do you believe having epilepsy has burdened your family? Your local community? If so, why and in what way?
- How do you believe people in this community behave towards a person with epilepsy? Why?
- Do the attitudes and beliefs of your family/friends affect the way in which you cope with and manage your epilepsy? In what way?
- Do you believe you have been given enough information about your illness? If not, why?
- Do you believe learning more about epilepsy would help you to understand and manage your epilepsy more effectively?
- Do you believe educating family members and friends about epilepsy would help people with epilepsy? Why?
- Do you believe educating the general public about epilepsy would help people with epilepsy? Why?
- Do you feel that more could be done within your community to help people with epilepsy and their families?
- What mechanisms need to be established in order for this help to be available? How might this be achieved?

Family Member

Introductory Question

'I'd like to begin by asking... *when did you become aware that your {relative} might have epilepsy...?*

Conversational Prompts

- Do you know what causes epilepsy?
- Do you believe that you can catch epilepsy from another person?
- Do you believe epilepsy can be cured or just treated? If so what treatment/cures?
- Where did you learn what you know about epilepsy?
- Does your {relative} receive treatment for their epilepsy? If not, why not?
- Who decided that your {relative} should receive treatment for their epilepsy?
- What type of treatment does your {relative} receive?
- How easy was it to get the treatment?
- What type and for how long, has your {relative} been receiving treatment?
- How do you feel about the treatment they are receiving?
- How easy is it for you to get involved with supporting your {relative} with their treatment?
- Do you believe epilepsy to be a frightening illness? If so, Why?
- What does having a {relative} with epilepsy mean to you?
- What does having a {relative} with epilepsy mean to your family/friends?
- Do you believe having epilepsy makes your {relative} 'different'? If so in what way?
- How does having a {relative} with epilepsy affect your day-to-day life?
- How does having a {relative} with epilepsy affect your hopes and aspirations for the future?
- Do you believe that people with epilepsy should be educated? Able to marry? Have children? Be employed?
- Are there things that people with epilepsy can't do within your community? If so, what and why?
- Within your community, do you think it is worse for a man to have epilepsy than for a woman? If so, why?
- Are there restrictions placed on you because you have a {relative} with epilepsy? If so, what and why?
- Do you know anyone else with epilepsy?
- Have you been able to discuss your {relative's} illness with others in your community – if not why?
- How do you believe people in this community behave towards a person with epilepsy? Why?
- How do you believe people in this community behave towards {relatives} of a person with epilepsy? Why?
- Do you believe that your attitudes and beliefs have affected the way in which your {relative} copes with and manages their epilepsy? In what way?
- Do you believe you have been given enough information about your {relative's} illness? If not, why?
- Do you believe learning more about epilepsy would help you to understand and support your {relative} to cope with their epilepsy more effectively?
- Do you believe educating family members and friends about epilepsy would help people with epilepsy? Why?
- Do you believe educating the general public about epilepsy would help people with epilepsy? Why?
- Who do you feel would be the best people to deliver this education?
- Do you feel that more could be done within your community to help people with epilepsy and their families?
- What mechanisms need to be established in order for this help to be available? How might this be achieved?