

Analysis on the Main Obstacle Factors of Preventing and Controlling Epilepsy in Chongqing Community

Xiao Fu¹, Lei Liu¹, Xinyi Chen¹, Anshi Wang², Bin Zhang^{1*}

¹School of Public Health and Management, Chongqing Medical University, Chongqing Research Center for Medical and Social Development, Collaborative Innovation Center for Social Risk Prediction and Governance in the Health Field, Chongqing, China

²Chongqing Medical Insurance Research Association, Chongqing, China

Email: *zhangbin_127@163.com

How to cite this paper: Fu, X., Liu, L., Chen, X.Y., Wang, A.S. and Zhang, B. (2019) Analysis on the Main Obstacle Factors of Preventing and Controlling Epilepsy in Chongqing Community. *Journal of Service Science and Management*, 12, 755-766. <https://doi.org/10.4236/jssm.2019.127051>

Received: October 1, 2019

Accepted: November 11, 2019

Published: November 14, 2019

Copyright © 2019 by author(s) and Scientific Research Publishing Inc.

This work is licensed under the Creative Commons Attribution International License (CC BY 4.0).

<http://creativecommons.org/licenses/by/4.0/>



Open Access

Abstract

Objective: Epilepsy is a serious disease in China, and its community prevention and control is a great challenge, but few studies have focused on depicting these difficulties from a broader perspective. The purpose of this study was to identify barriers to prevention and control of epilepsy in the community from the perspective of medical institution managers, health care providers, and epilepsy patients. **Methods:** A total of 6 heads of CHS centers, 16 specialists, and 270 epilepsy patients were selected through purposeful sampling, and the qualitative data from the interviews were analyzed using a thematic framework. **Results:** The main obstacles to the prevention and control of epilepsy in community were the lack of community self-service ability, imperfect inter-agency sharing mechanism, poor disease-related cognition and insufficient cognition of community health service of patients. **Conclusion:** It is suggested that the existing platform should be used to promote and guarantee the community service ability, optimize the community health management service, adjust the medical insurance compensation method, correctly publicize the first consultation at the grass-roots level, and strengthen health education, so as to improve the community prevention and control planning of epilepsy.

Keywords

Community, Epilepsy, Prevention and Control, Barrier Factors

1. Study Background

In China, epilepsy is a chronic disease of the nervous system that seriously af-

fects patients' physical and mental health and quality of life, second only to stroke. According to the epidemiological data [1] [2] [3] [4], the prevalence rate is 4‰ ~ 7‰, and the incidence rate is (40 ~ 73)/100,000. According to this, it is estimated that there are about 9 million patients with epilepsy in China, and about 650,000 ~ 700,000 patients are newly diagnosed each year. The mortality rate of epilepsy is 2 - 4 times than that of the general population [5], and patients have high suicidality, which is almost three times than that of the general population [6]. However, epilepsy can be effectively treated and controlled by taking drugs through formal treatment [7]. Community health service centers should provide basic medical services for residents. However, as far as we know, the current community "health gatekeeper" system in China is still not perfect, and there are many deficiencies and irregularities in the community prevention and control practice of epilepsy. No studies have explored issues and barriers to prevention and control of epilepsy in the community from a health system perspective. This study, to a certain extent, fills a gap in academia and provides new insights into the effective prevention and control of epilepsy in the community. Through in-depth interviews, actual needs, barriers, and recommendations were collected from the perspectives of health care facility managers, healthcare providers, and patients with epilepsy.

2. Study Methods

2.1. Qualitative Interviews

1) Qualitative interview: 10 specialists in neurology (external) medicine in the secondary and tertiary medical institutions, and 6 community general practitioners, including: conventional treatment approaches for epilepsy in our hospital (center); types and examination means of antiepileptic drugs commonly used in clinical practice in our hospital (center); diagnosis and treatment status of epilepsy patients in our hospital (center). 2) Qualitative interview with 6 leaders of community health service center, including: the measures taken by the center for epilepsy prevention and control, main difficulties; status of follow-up and management of epilepsy patients; forms of referral and cooperation with superior hospitals.

2.2. Questionnaire Survey

2.2.1. Sampling Method

According to the method of multi-stage stratified random sampling, according to the per capita GDP level of 38 districts and counties in Chongqing in 2017, the largest medical association in 3 districts and counties was selected as the survey target. Then, in combination with the specific conditions of the health institutions in Chongqing and the treatment of epilepsy, 5 tertiary hospitals and 5 secondary hospitals were selected from the 3 medical hospitals, and 6 medical cooperative community health service centers in the secondary hospitals, a total of 16 institutions. As an investigation site.

2.2.2. Object and Content

All epilepsy patients who came to the clinic within seven working days were investigated. The questionnaire included: basic sociodemographic information of patients, illness and medical treatment, the situation of antiepileptic drugs taken, the habits and reasons for choosing medical institutions, and referrals within the past year.

2.3. Quality Control

Interviews were conducted by two well-trained and experienced researchers, one male researcher (LL) for interviews and a second female researcher (FX) for recording the focus. Each interview was conducted in a private and quiet room with a detailed antecedent communication prior to the interview, ensuring that the interviewee understood every detail of the interview (objectives, content, research methods, time, location, benefits, risks). All interviews were conducted in the local language/dialect and lasted 20 - 40 minutes. Data collection and analysis lasted until the additional input of new participants no longer changed the researchers' understanding of the concept, namely the data saturation point. And strictly following the principle of information saturation, we stopped interviewing when there was no more information about the research topic.

Based on a self-made questionnaire, the questionnaire was improved on the basis of a pre-survey. The investigators trained by the unified training, with the assistance of the outpatient doctors of the Department of Divine Medicine (some hospitals), conducted investigations on epilepsy patients for seven consecutive working days. The investigators stated to the investigators the purpose of the investigation and the requirements, and after making oral informed consent, the investigators themselves filled in the investigation, and in the event of reading difficulties, the investigators asked for help to fill in. Investigators do a daily job of reviewing and proofreading questionnaires.

2.4. Data Analysis

The analysis team consisted of two researchers with experience in qualitative research, who first translated the interview recordings verbatim into Mandarin. Then, the two investigators repeatedly read and recorded the recurring themes. After group discussion, the themes highlighted in the interview were established and coded line by line according to the theme framework. The questionnaire uses EpiData 3.1 to establish a database and uses SPSS 22.0 for statistical description and analysis.

Finally, in order to ensure the quality and consistency of translation, the researcher was able to use English proficiently, first translating the illustrative quotes in the study results into English, and then translating them into Chinese separately by two other researchers for proofreading inspection. All documents were analyzed using grounded theory.

2.5. Ethical Approval

The research project was approved by the Review Committee of Chongqing

Medical University of China.

3. Results

3.1. Social Demography

Among the patients in this survey, 158 (58.52%) were males and 112 (41.48%) were females, the youngest child was 3 months old, the oldest patient was 86 years old, and the median age was 26 years, the educational level was mainly junior high school (84, 31.11%), followed by primary school and below (65, 24.07%), the proportion of agricultural population to urban population was 51.85% and 48.15% respectively, the occupation was mainly preschool or student (36.67%), followed by unemployed or unemployed (17.04%). See **Table 1**.

3.2. Disease Condition and Diagnosis and Treatment Status

3.2.1. Illness

Epilepsy patients were mainly affected during childhood and adolescence (69.63%), 127 patients (47.04%) had a disease duration of more than 5 years, the

Table 1. Basic sociodemographic status of patients with epilepsy (n = 270).

	project	Number of cases	Composition ratio (%)
Gender	Male	158	58.52
	Female	112	41.48
Type of household registration	Town account	130	48.15
	Agricultural account	140	51.85
Actual age	0~	20	7.41
	6~	48	17.78
	15~	58	21.48
	25~	91	33.70
	45~	29	10.74
	60~	24	8.89
Education level	Primary school and below	65	24.07
	Junior high school	84	31.11
	High school or technical secondary school	50	18.52
	University or College	48	17.78
	Bachelor or above	23	8.52
Job occupation	Agriculture, forestry and animal husbandry	34	12.59
	Students and preschool	99	36.67
	Government enterprises and institutions	40	14.81
	Other	51	18.89
	Unemployed or unemployed	40	14.81
	Retirement	6	2.22

shortest time since onset was 1 month, the longest was 56 years, 75.28% of patients had different degrees of seizures per year, and 17.4% of patients had concomitant diseases. See **Table 2**.

3.2.2. Current Situation of Diagnosis and Treatment

Basic information in this study, among 270 patients with epilepsy, 191 patients (70.74%) preferred tertiary care institutions while only 5 patients (1.85%) preferred primary care institutions during treatment. The purpose of treatment was to maintain drug prescription (71.85%). 89 patients (32.96%) had been hospitalized, and 38 patients (14.07%) had used or were using other treatment methods in addition to drug treatment. See **Table 3**.

3.2.3. Status of Community Epilepsy Control

The six community health service centers in this study all pointed out that the community anti-epileptic drugs are not equipped enough, only one or two traditional anti-epileptic drugs can be provided, and the clinical experience and ability to treat epilepsy are very limited, and cannot meet patients' basic needs. Studies have shown that [8] [9] [10] [11], There are still large differences in

Table 2. Related conditions of patients with epilepsy (n = 270).

project		Number of cases	Composition ratio (%)
Age at first onset	0~	59	21.85
	5~	78	28.89
	15~	51	18.89
	25~	54	20.00
	45~	17	6.30
	60~	11	4.07
Disease duration (years)	0~	143	52.96
	6~	50	18.52
	11~	25	9.26
	16~	8	2.96
	20~	44	16.30
Seizures (times/year) (Note: data are missing, n = 267)	0	66	24.72
	1 ~ 2	81	30.34
	3 ~ 5	40	14.98
	5 and above	80	29.96
Concomitant disease (Type)	0	223	82.59
	1	40	14.81
	2	5	1.85
	3 and above	2	0.74

(Note: Because three patients can not accurately recall and describe the number of annual episodes, in order to ensure the accuracy of the results, they are recorded as missing data.)

Table 3. Basic information of diagnosis and treatment of patients with epilepsy.

	project	Number of cases	Composition ratio (%)
Medical institutions preferred for treatment	Class I (township health center, village health room)	5	1.85
	Class II (county hospital)	73	27.04
	Class III (Municipal Hospital, Affiliated Hospital of University)	191	70.74
	other	1	0.37
Purpose of visit	First consultation	21	7.78
	Review (examination)	47	17.41
	Maintenance therapy (prescribed)	194	71.85
	other	8	2.96
Have you ever been hospitalized	Yes	89	32.96
	No	181	67.04
Whether it is treated by other methods except drug treatment	Yes	38	14.07
	No	232	85.93

economic levels, lifestyles and medical conditions in different regions of China, and there are large differences in the level of diagnosis and treatment of epilepsy and the management of services. There are uneven and insufficient phenomena. In particular, most epilepsy patients in rural areas have not received formal anti-epileptic treatment. Treatment gap is large, anti-epileptic drug treatment is not standard. The reason is that the community did not assume the role of “gatekeeper” and the management level of epilepsy control was not high.

4. Major Obstacle Factors Affecting Community Epilepsy Prevention and Control

4.1. The Community's Own Service Capabilities are Weak, and the Inter-Institutional Sharing Mechanism is not Sound

All six CHCs noted that antiepileptic drugs in the community were inadequately equipped to provide, only one or two conventional antiepileptic drugs, and could not meet the basic needs of patients. The person in charge also pointed out that most of the medical staff in community health service centers is general practitioners, and their clinical experience and ability to treat epilepsy are very limited. It is necessary to refer to the diagnosis and treatment results of patients in superior hospitals. Although it has signed a contract with the superior institution as a medical consortium, more patients are transferred upward than downward, two-way referral has not met the expected requirements, and the mechanism of information communication and sharing between institutions still needs to be strengthened and improved. From the patient's point of view, all 15 pa-

tients reported that they had been transferred from multiple medical institutions to seek medical treatment, but most of them were from multiple hospitals and multiple tertiary hospitals to seek medical treatment or transferred from secondary hospitals to tertiary hospitals, and only one patient had visited a community health service center to purchase drugs. Since the patients cannot get effective treatment from the community health service center, they have to spend more time, energy and economy, including treatment costs, transportation costs, direct and indirect medical expenses, such as food and accommodation costs for patients and carers, to go to the superior medical institutions for treatment.

4.2. The Current Medical Insurance Compensation Is Not Appropriate, Screening Follow-Up and Other Management Deficiencies

Similar to the results of other studies [12], the main route of diagnosis and treatment of epilepsy patients in this survey was outpatient, 92.96% of patients maintained medication in outpatient, and 67.04% of patients had no history of epilepsy hospitalization. The current medical insurance in Chongqing has basically achieved full coverage [13]. However, only 2 patients (0.27%) with epilepsy were reimbursed for outpatient treatment costs in this survey, in the form of free medical care and reimbursement by parents or other relatives. This suggests that the current medical insurance compensation for patients with epilepsy in Chongqing is not compatible with the actual utilization of medical services and cost generation, and the protection for outpatients with epilepsy is incomplete. At the same time, the six community health service centers have not screened patients with suspected epilepsy and epilepsy, and have not followed up, tracked and managed the patients with confirmed epilepsy. In addition, some of the interviewed doctors indicated that the special funds for treating epilepsy in the community were insufficient.

4.3. Patients Have a High Degree of Attention to the Disease and Poor Willingness to Make the First Consultation at the Grassroots Level

Because epilepsy is a brain disease and social stigmatization is serious [14], suffering from epilepsy makes patients easily frustrated in terms of schooling, employment, marriage, etc., and patients and their families pay more attention to the disease than common chronic diseases. In the early stage of the disease, they often seek medical treatment repeatedly due to seeking authority and worrying about delaying the illness. In this survey, 76.41% of the patients reported that they had sought medical treatment in multiple places or institutions, but none of the patients chose to visit the community. The patients often went directly to the second- and third-level medical institutions for medical treatment, and the subsequent treatment also occurred in second- and third-level hospitals, suggesting that the patients did not trust the community health service centers and had poor willingness to make the first consultation at the grassroots level. This may

be due to the fact that the community health service centers are mostly converted from the original regional level hospitals [15]. The public health service function has not been implemented, but has been slightly expanded on the basis of the past basic hospital practice, and has been less developed in general practice, community or home first aid, preventive health care, community rehabilitation, etc. and has not effectively exerted its own advantages, leading patients to regard the community health service center as a small clinic, which is considered to be the site for infusion injection and drug prescription. At the same time, domestic general medicine education starts late, many general practitioners have not received special training and assessment of general practitioners, the foundation is weak, the medical technology level is low, and it is difficult to be competent for all tasks of community health, resulting in that patients think that general practitioners are inferior to specialists and tend to visit higher-level medical institutions.

5. Recommendations

Epilepsy is not only a medical problem but also an important public health and social problem. Community as a “health gatekeeper” is essential to improve the illness and medical treatment of epilepsy patients. Solving the problems faced by community in preventing and controlling epilepsy requires the cooperation of multiple forces such as institutions, society, and government. For this reason, the following suggestions are made:

5.1. Strengthen the Linkage to Enhance and Guarantee the Community Service Capacity

Only by enabling patients to be effectively treated in the community and building trust in the grassroots can we improve the utilization of primary care services for patients with epilepsy. First of all, the upper and lower linkage should be strengthened to clarify the functional positioning of institutions at all levels, implement the “two-way referral” policy, and establish a rapid referral channel to ensure that patients with major seizures can timely and quickly reach the superior institutions for treatment, and can be transferred back to the community for further drug treatment after their condition is stable. Secondly, we should further build a fine counterpart assistance within the medical alliance. For example, a superior hospital may regularly send a specialist to a designated community health service center for consultation and attract patients to seek medical treatment while providing business guidance for general practitioners. Thirdly, improve the inter-agency information communication mode, realize the sharing of medical resources in the region with the help of “telemedicine” and other means, promote the continuous improvement of diagnosis and treatment capacity of lower level hospitals, and realize the retention of patients. Finally, to effectively solve the lack of medical and drug phenomenon in primary care institutions, to ensure that patients with conventional drug treatment.

5.2. Adjust Compensation Methods and Optimize Community Health Management Services

It is suggested that the medical insurance compensation for epilepsy should be rationally adjusted to the outpatient, so as to adapt it to the actual medical service utilization and cost generation of patients, so as to alleviate the burden on patients and families. Meanwhile, it is feasible to learn from the inpatient reimbursement policy, establish the outpatient differential medical insurance policy, guide the patients to seek medical treatment reasonably, give full play to the leverage role of the medical insurance system, and encourage the patients to seek medical treatment in the community. In addition, it is necessary to optimize the health management services for epilepsy in the primary institutions within the medical association. First, increase the investment in improving the routine treatment and follow-up management of epilepsy patients in the community; second, recruit some public health professionals to continue the professional development of in-service medical staff and improve the professional level of medical staff; and third, from the perspective of patients, grasp the balance for the treatment of diseases and economic burden and select the most beneficial diagnosis and treatment plan for patients.

5.3. Correctly Publicize the First Diagnosis at the Grass-Roots Level and Guide Patients to Seek Reasonable Medical Treatment

In addition to the meaning of the first diagnosis, the first diagnosis at the grass-roots level also has the meaning of triage [16], which means that the diagnosis is confirmed in the hospitals at the higher level in the grass-roots level, the connotation of the first diagnosis at the grass-roots level should be correctly publicized, and the first diagnosis of patients at the grass-roots level should be correctly guided. First, administrative intervention should be avoided. It is impossible to form mass changes in a short time. Patience and ambition should be maintained. Secondly, young people should be targeted to establish a new fashion of orderly medical treatment and rational use of medical resources, because most of them have received higher education and have remarkable receptivity. Finally, the use of personalized, targeted public opinion propaganda, in addition to the traditional education means, the government management department should also use of modern media, Internet, grassroots medical institutions of service object, service content, service items and standards such as extensive propaganda, the content of residents gradually corrected prejudice to the grassroots health institutions function.

5.4. Strengthen Health Education and Improve Patients' Awareness of Self-Management

First of all, strengthen disease-related health education, let patients correctly understand epilepsy and its conventional treatment, improve patients' self-management awareness, enhance their awareness of taking drugs on time and in dosage, im-

prove medication compliance, and better treat and control diseases. Secondly, strengthen social education, guide all aspects of society to give patients more attention, understanding and tolerance, provide them with daily life skills training and employment opportunities, so that patients gradually improve their self-confidence in practice, face the disease. Finally, with the rapid development of information technology and the popularity of smartphones, almost everyone has a smartphone with social applications, so applications such as We Chat can be used to convey the knowledge and routine care means to prevent and control epilepsy.

Finally, the study has several limitations that must be acknowledged. First, due to limited time, human and other resources, only a few topics were included. Secondly, the study was carried out in a limited number of IFH institutions, which were deliberately selected to reflect a range of levels of achievement and geographical areas. Thirdly, this survey is a cross-sectional survey of medical institutions based on convenient sampling. So the characteristics of patients' constitution cannot represent the overall situation of epilepsy patients, but they can reflect the characteristics of epilepsy to a certain extent. Therefore, the results may not be extended to other parts of China, but may provide some insights into the current community's challenges in preventing and controlling epilepsy.

6. Summary

Epilepsy is not only a simple medical problem, but also a serious social problem. The high incidence and prevalence of epilepsy and the long period of treatment have brought heavy psychological, economic and social burdens to individuals, families and society, indirectly constraining the country's economic construction and social progress in general. To solve the lack of community own service capacity, the imperfect mechanism of inter-agency sharing, the poor understanding of patients' diseases, the lack of awareness of community health services, and other major obstacles to community prevention and control of epilepsy, we need the cooperation of multiple forces, such as society, government, and institutions. All aspects of society should give patients more attention, understanding and tolerance, and provide them with daily life skills training and employment opportunities, so that they gradually improve their self-confidence and improve their economic situation in practice. Government departments shall establish relevant policies and systems, plan relevant medical resources in a rational manner, and, if necessary, tilt appropriately towards primary medical institutions, and guide patients to sink through the sinking of medical resources. Medical institutions at higher levels should clearly locate functions, strengthen two-way referrals, and use existing platforms to help communities continuously improve their health service capabilities, including diagnosis and treatment capabilities and service awareness. The community should formulate comprehensive prevention and treatment measures, strengthen the science education of epilepsy, raise the level of understanding of the patient and the whole society on the disease and the

standardization of diagnosis and treatment, and enhance the patient's compliance with medical behavior.

Funding

This study was supported by Chongqing Medical Insurance Research Association.

Conflicts of Interest

The authors declare no conflicts of interest regarding the publication of this paper.

References

- [1] Guo, M.H. and Zhang, J.J. (2013) Epidemiological Investigation of Epilepsy. *Chinese Journal of Brain Diseases and Rehabilitation (Electronic Edition)*, **3**, 338-340.
- [2] Tu, X.S. (2017) Epidemiological Study on Epilepsy. *Journal of Brain and Neurological Disorders*, **25**, 522-529.
- [3] Wang, X., Chou, L.N., Liu, X.J., et al. (2016) Epidemiological Survey on Epilepsy of Hui Nationality in Tongxin County, Ningxia. *Journal of Stroke and Neurological Disorders*, **33**, 27-31.
- [4] Pi, X.R., Cui, L., Liu, A.A.Z., et al. (2012) Epidemiological Survey of Epilepsy in Yueyang City, Hunan Province. *International Journal of Neurological Neurosurgery*, **39**, 103-107.
- [5] Peng, X.Y. and Wen, S.R. (2012) Research Status of Quality of Life in Patients with Epilepsy. *Medical Review*, **18**, 3609-3611.
- [6] Rohit, S., David, C., Virupakshi, J., Scott, B., et al. (2013) Sudden Unexpected Death in Epilepsy (SUDEP): Development of a Safety Checklist. *Seizure: European Journal of Epilepsy*, **22**, 812-817. <https://doi.org/10.1016/j.seizure.2013.07.014>
- [7] Chinese Medical Association (2007) Clinical Diagnosis and Treatment Guidelines. Epilepsy Volume. People's Medical Publishing House, Beijing.
- [8] Ding, D., Jiang, B., Liu, Y.H., Wang, W.Z., Wu, J.Z., Yang, Q.D., Zhang, L., Zhang, W.J.Z. and Hong, Z. (2006) 155 Cases of Urban Epilepsy Diagnosis and Treatment and Needs Investigation. *Chinese Journal of Epidemiology*, **11**, 1000-1004.
- [9] Zhang, H.Z., Yuan, C.L., Xu, J., Li, X.B., Jing, J., et al. (2005) Investigation on the Management of Epilepsy Prevention and Control in Rural Community of Touqiao, Yangzhou City, Jiangsu Province. *Journal of Practical Clinical Medicine*, **11**, 75-76 + 78.
- [10] Sun, L.X., Fen, G.R., Wu, G.F., Wang, F., Liu, T., Yao, Y.T. and Ou, Y. (2013) Investigation of Patients with Epilepsy in Rural Areas of Fenggang County, Guizhou Province. *Modern Preventive Medicine*, **40**, 855-857 + 867.
- [11] Zhang, G.J. (2018) Create a Full Management Model for Epilepsy Patients. *Chinese Medical Journal*, **53**, 233-235 + 228.
- [12] Wang, B.Y., Li, S.Y. and Guo, Y. (2015) Cost of Drug Therapy in Outpatients with Epilepsy. *China Health Economy*, **34**, 65-67.
- [13] Jiang, C.H. and Ma, J.D. (2015) Analysis of the Role of "Universal Health Insurance" in the Process of "Universal Health Coverage" in Chin. *China Health Service Management*, **32**, 108-110 + 141.

- [14] Yang, H.C., Wang, W.Z., Wu, J.Z., *et al.* (2010) A Qualitative Study on Shame of Epilepsy Patients in Urban Community. *Chinese Journal of Mental Health*, **24**, 284-288.
- [15] Li, X.B. (2012) Analysis on the Current Situation and Obstacle Factors of Community Medical Institution Construction in Henan Province. *China Health Service Management*, **29**, 330-331 + 368.
- [16] Cheng, W.J. and Zhu, Y.M. (2017) Restrictive Factors and Promoting Countermeasures for the Implementation of the First Consultation at Grassroots Level. *Health Economics Research*, **10**, 56-58.