

Perceptions of the community about epilepsy in rural Tamil Nadu, India

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Received: October 26, 2016; Accepted: November 14, 2016

ABSTRACT

Background: There is no qualitative research on community's perception about epilepsy available from India. However, some quantitative surveys were done among school children, local community, and patients of epilepsy. Caregivers and family members support is crucial for better compliance and care of epileptic patients. **Objectives:** The purpose was to study the perceptions of the community members of the age group 18-60 years about epilepsy in rural Villupuram, India. This can improve the quality of life of epileptic patients. **Materials and Methods:** It was a qualitative descriptive study in which four Focus Group Discussions were conducted; two among male and female group each. A vignette was used as a stimulus material to evoke discussion among participants. **Results:** The text information was coded using 22 codes which were merged into 5 major categories which were (1) perceived causes, (2) modes of spread, (3) perceived prognosis, (4) suggested treatment options, and (5) social inclusions and exclusions. Although participants felt that the epileptic patients can undergo education, earn a livelihood by employment and seek allopathic medication for treatment, there were some misconceptions about the causes of epilepsy. Patients with female gender were reported to experience more stigma and discrimination than male. **Conclusion:** The study gives insight into the variety of perceptions on different aspects of epilepsy. The misconceptions in the community about epilepsy can affect nutrition, maternal and child health, hygiene, health care seeking, compliance to treatment of the epileptic patients leading to poor quality of life. The results demonstrated a need for educational and awareness programs among family and community members about the causes, modes of spread, treatment of epilepsy. The findings of the present study can direct the future quantitative research in community settings in India.

KEY WORDS: Social Perception; Epilepsy; Qualitative Research and Focus Groups

INTRODUCTION

Epilepsy is one of the most common serious brain disorder throughout the world.^[1,2] A large cross-sectional study conducted in Kerala found the prevalence of epilepsy as 4.9/1000 population.^[3] Although 70% of people with epilepsy can live normal lives with proper treatment, more than 80% people with epilepsy, living in developing

countries, including India, do not receive appropriate treatment.^[1,4]

Misconceptions about epilepsy act as the greatest barrier to treatment of persons with epilepsy.^[5] Fear and misunderstanding about epilepsy in the community and among caregivers lead to stigma, social isolation and discrimination of epileptic patients.^[6] The stigma associated with epilepsy can be minimized by health education of the community.^[7,8] According to the World Health Organization, the first aspect of the models of epilepsy control is to assess the knowledge and attitudes of the population, correcting misinformation, and increasing awareness of epilepsy.^[6]

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Access this article online	
Website: http://www.ijmsph.com	Quick Response code
DOI: 10.5455/ijmsph.2017.1061014112016	

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quantitative surveys were done among school children, local community, and patients of epilepsy.^[3,9-15] Caregivers and family members support is crucial for better compliance and care of epileptic patients. Thus, it was decided to conduct this study in rural Villupuram among people aged 18-60 years to explore the wide variety of perceptions among the community members about epilepsy. These findings were expected to help in planning health education programs in our local community. This can improve the quality of life of epileptic patients.

MATERIALS AND METHODS

Study Area and Settings

This study was conducted in the field practice area of Urban Health Training Centre (UHTC) located in Villupuram district under the Department of Community Medicine, of a Medical College and Hospital.

Apart from the existing public and private health-care systems, the nearest central government centers for excellence for neurological and mental health disorders are Jawaharlal Institute of Postgraduate Medical Education and Research and National Institute of Mental Health and Neurosciences, which are 40 km and 263 km, respectively, away from the study area.

Study Design

It was a qualitative descriptive study in which four Focus Group Discussions (FGDs) were conducted.^[16,17]

Participants

Two FGDs were done with men and women group each. All the 42 participants in the FGD were selected by purposive sampling using the following inclusion criteria: Age group 18-60 years, willingness to participate and the ability to be vocal. We targeted the age group of 18-60 years as it was the age group which was often involved in family level decision-making. There were 10-12 participants per FGD.

Data Collection

Trained moderators conducted the FGDs. FGDs with women were facilitated by a female medical intern under the supervision of trained investigators. Since UHTC regularly conducts field clinics in the villages, there was already a good support and rapport with the local community.

The venue for three FGDs was chosen as a nearby government school, while one FGD was held at an anganwadi centre in the village (anganwadi centre is a mother and child care center under the National Health Program of India). After obtaining informed consent, all the participants were informed about the purpose of the discussion, and consent was taken for recording the discussion. The FGDs were

carried out in regional language Tamil. A pilot tested vignette describing an episode of epilepsy in a boy aged 14 years was used as a stimulus material to generate discussion among the participants on this rare condition. This was followed by a discussion to know their perceptions about epilepsy. Each FGD lasted for 60-90 min. Culture-sensitive refreshments were served to the participants after each FGD session. After each FGD, the summary of discussion was shared with the participants for member checking.

Data Analysis and Interpretation

The second author, who knew both Tamil and English language carried out the translation of FGD interview from Tamil to English. Transcripts were typed in the English language after carefully listening to the recordings and referring to the field notes. The descriptive content analysis was carried out manually.^[18] Descriptive coding of the text information was done. Later, similar codes were merged together to form the categories. The first author who was trained in qualitative research methods carried out the content analysis, and the findings were reviewed by the other two authors. Twenty-two codes emerged from the data were grouped into broad five categories. An example of the coding process is shown in Table 1.

Direct quotations or verbatim from the respondents have been indicated by - Italics. Statements in square brackets are authors' explanation of the terms used. The quotations stated, are either in support or an addition to the description of results and help to explain what respondents shared. The "Consolidated Criteria for Reporting Qualitative Research" guidelines have been followed while reporting this qualitative work.^[19]

Ethical Issues

This study was approved by the Research and Ethics Committee of Sri Manakula Vinayagar Medical College and Hospital, Pondicherry, India.

RESULTS

Background Information of the Participants

The mean age of the participants was 34.59 ± 12.32. The majority, 18 (42.9%), of the participants reported farming as their occupation. The age and occupation of the participants are as shown in Table 2.

The various local names for epilepsy in local Tamil language were Kakavalipu, Valipu, Nodipu noyi, or Illupu. The five

Table 1: Example of coding process

Categories	Codes	Statements
Perceived cause	Supernatural forces	Sin in the past Black magic Haunted by a ghost

Table 2: Age and occupation of the FGD participants

Variables	Categories	Female (n=21)	Male (n=21)	Total (n=42)
Mean age in years±SD		30.66±13.81	38.52±9.39	34.59±12.32
Occupation	Builder	0	1 (4.8)	1 (2.4)
	Company worker	0	3 (14.3)	3 (7.1)
	Coolie	1 (4.8)	0	1 (2.4)
	Driver	0	4 (19.0)	4 (9.5)
	Farmer	9 (42.9)	9 (42.9)	18 (42.9)
	Housewife	10 (47.6)	0	10 (23.8)
	Student	1 (4.8)	4 (19.0)	5 (11.9)

FGD: Focus Group Discussions, SD: Standard deviation

categories which emerged from the data were (1) perceived causes, (2) modes of spread, (3) perceived prognosis, (4) suggested treatment options, and (5) social inclusions and exclusions.

Category (A) Perceived Causes of Epilepsy

The perceived causes of epilepsy were subcategorized into hereditary, pregnancy related, diseases, human behavior, psychological factors, diet, supernatural forces, and menstrual cycle.

Code A.1 hereditary

Participants attributed epilepsy to consanguineous marriages and family history of epilepsy. A 19-year male told,

“If parents get married within relations, children born may be blind, deaf, and dumb or like this... have fits.”

Code A.2 pregnancy-related

Participants considered that illness and stress during pregnancy, excessive consumption of medicine by a pregnant mother could lead to epilepsy in the newborn child. They also attributed epilepsy to consumption of unhealthy, non-nutritious, stale food or food items such as chicken, kalavaie kerai (a local green leafy vegetable). A 28-year women said,

“The pregnant women should not eat chicken and fruits like mango, papaya, pumpkin, and jackfruit or else the child will develop epilepsy.”

Code A.3 diseases

According to participants, the diseases which lead to epilepsy were raised blood pressure, a blood clot in the brain, high fever, poor immunity, impure and less blood in the body, mental illnesses, problems in the nervous system and injury. Perceived causes in girls were less strength and different blood group.

Code A.4 human behavior

Some participants believed that human behavior like improper vaccination, inadequate nutrition, being in contact

with cold water for a long time, taking an oil bath were the causes of epilepsy.

Code A.5 psychological factors

Participants thought that hiding problems such as stress, anxiety, fear of hearing bad news, and sadness lead to the problem of epilepsy.

Code A.6 diet

Participants perceived that consumption of alcohol, sweets, ulandvadai (a local snack) and other fried food items, unhygienic food, contaminated water, and palaya satham (a recipe of rice and curd) causes epilepsy. According to participants, lack of dietary vitamins, calcium, and other nutrients also led to epilepsy.

Code A.7 supernatural forces

Few participants attributed epilepsy to the influence of ghosts, sins in past life, black magic and visiting a graveyard for the ritual of a deceased who died of epilepsy.

Code A.8 menstrual cycle

Participants perceived that girls can get seizures during the full moon day and during their menses.

Category (B) Modes of Spread

Most of the participants perceived that epilepsy was not contagious. However, few participants said that epilepsy could be contagious. Some of them said that it could even spread due to sexual intercourse and cough. They also believed that as epilepsy can spread through blood; an epileptic person should not donate blood. Many participants said that it was hereditary. A 26-year male said:

“An epileptic person can spread this disease to his wife through sexual intercourse and then through wife it spreads to their children born.”

Category (C) Prognosis

The perception on prognosis varied from good to poor.

Code C.1 factors for good prognosis

Participants perceived that epilepsy has a good prognosis with good compliance to treatment and it is curable. According to participants, in children, <6 years epilepsy is due to fever and it is curable.

A participant shared her cousin sister's experience:

"My cousin sister had epilepsy. She is taking regular medication and proper follow-up. For the last 5 years, she didn't even have a single attack. Her caregivers have forgotten her illness."

Code C.2 factors for poor prognosis

Participants perceived that the prognosis of epilepsy is poor if the age is >6 years, during pregnancy and if it is due to accidents.

Female epileptics are prone to accidents while cooking and male epileptics are prone to accidents while working. Many participants said that accidents occur near water bodies and also shared many experiences of drowning due to fits.

Some participants also believed that epilepsy can progress to mental illness, paralysis, and suicidal tendency.

Category (D) Treatment

Participants perceived that treatment is same for all genders and suggested various treatments under allopathy, Indian System of Medicine, faith healers, first aid, precautions.

Code D.1 allopathy

Many participants expressed the view that treatment should be done regularly in allopathic hospitals for a cure.

Code D.2 Indian system of medicine

Some participants perceived that Siddha and Unani was a slow but a permanent cure for epilepsy. A participant told that if Neem (scientific name: *Azadirachta indica*) oil is rubbed regularly to the foot and palm then there won't be any fits.

Code D.3 faith healers

Some participants perceived that epilepsy can be treated at temple or mosque, by a priest or by tying a sanctified thread on the wrist. Many perceived that epilepsy can be treated at home by putting an iron rod or keys in the patient's hand during seizures.

Code D.4 first aid

Many participants perceived that giving chilli currency (an iron utensil), iron key chain, iron rod/key in hand was the first aid.

Few participants were of the opinion that pouring water on the face, giving water for drinking, accompanying the patient to the hospital, giving psychological support to the patient and decreasing the fever using a moist towel if the fever was present can be the first aid required for the epileptic patient.

Code D.5 precautions

Precautions perceived necessary for persons with epilepsy included supervision at the workplace, avoiding bath in pond/river, using hot water for bathing, bathing in short time, avoid speaking harshly to such individuals, avoiding cold items, keeping iron rod/key, wearing iron bands in the hands or legs, accompanying female patients whenever they go out of home.

Category (E) Social Inclusions and Exclusions

The majority of the participants perceived that we should behave friendly with epileptic persons. The participants were very empathetic about the epileptic persons. Social inclusions and exclusions were subcategorized into family support, education and employment, reasons for allowing and disallowing their child to play with the epileptic child.

Code E.1 reasons given by participants for allowing their child to play with the epileptic child

Participants were asked if they will allow their children to play with the child described in the vignette. Most participants said that they will allow as epilepsy is not contagious. A 36-year male expressed some caution as:

"We can allow playing. But have to advise the other children to inform elders if they get fits while playing. Also, few children may make fun of them so we have to be careful."

Few participants said that they will not allow as epilepsy is contagious. Few perceived that if the epileptic child gets seizures people may blame their child.

Code E.3 family support

The majority of the participants believed that family support is very necessary for epileptic patients. Some participants perceived that the seizures are transient and so the patient can stay with family. 42 years male respondent said:

"We should support them. If I had epilepsy will my family members ignore me?"

Code E.4 education and employment

Most participants were of the opinion that education and employment should be given to them, while few participants said that it will be difficult for them to study and do the job.

Code E.5 marriage

Most participants thought that epilepsy patients can marry, but they will face difficulties. Difficulties in marriage will be much higher for female epileptic patients. Few participants had the misconception that marriage can cure epilepsy.

Code E.6 stigma and restrictions

Participants perceived that the stigma due to epilepsy was much more for females as compared to males. Females during seizures may lose consciousness, their dress may not remain in proper position or may get torn and due to this fear parents do not let their epileptic daughters go outside the home. Some participants perceived that if female epileptics want to go outside someone should accompany them.

DISCUSSION

The five categories which emerged from the data were (1) perceived causes, (2) modes of spread, (3) perceived prognosis, (4) suggested treatment options, and (5) social inclusions and exclusions. There were a variety of misconceptions for the causes of epilepsy. Female patients were found to experience more stigma and discrimination than male. On a positive note, participants felt that the epileptic patients can pursue education, earn a livelihood by employment and seek allopathic medication for treatment.

These narratives have explored a variety of perceived causes of epilepsy. The hereditary and supernatural causes for epilepsy were also reported by other quantitative studies.^[3,10-12,14,15] The additional perceived causes explored by our study are pregnancy related, human behavior, psychological factors, diet, diseases, perceptions related to full moon day, and menstrual cycle.

In ethnographic studies in China, participants attributed epilepsy to psychological causes and physical causes such as trauma, tiredness, fever and too much brain-work and dietary factors.^[20] Both India and China are ancient civilizations, and their cultural relations can be traced back to very early times.^[21] These communities were thinking on similar lines about the cause of epilepsy.

Notably, some empirically known risk factors of epilepsy are consanguinity of marriage, family history, alcohol consumption, problems in the nervous system, and hypertension.^[4,5]

There were misconceptions that eating chicken, fruits such as mango, papaya, pumpkin by pregnant women can

cause epilepsy. However, this misconception might deprive pregnant mothers of nutritious food items. The misconception that cold water can cause epilepsy can affect personal hygiene of epileptic persons predisposing them to diarrhea and skin diseases.

Most participants perceived that treatment should be done regularly at allopathic hospitals and it will cure epilepsy. Some participants had faith in Indian system of medicine and faith healers. Giving iron articles in hand for first aid and treatment of epilepsy was a common misconception. The practice of using iron rod was reported by many quantitative studies in different parts of India.^[3,10-12] However, treatment from faith healers can endanger the life of the patient. The use of iron articles can lead to injury to the patient and the caretaker. The practice of giving water for drinking to an epileptic person as a first aid during seizures should be discouraged as it can lead to choking.^[22]

In our study, participants felt that the epileptic patients can pursue education, earn a livelihood by employment. In a community-based cross-sectional study in Kerala, 38% of the respondents felt that epilepsy is a hindrance to normal education.^[3] In studies done in Uttarakhand and Kerala, majority of the school students considered epilepsy a hindrance to education, employment, and marriage.^[12,13] The difference can be due to the difference in geographic location, time and age group of participants.

Participants perceived that for epileptic females marriage was very difficult and for epileptic males marriage was less difficult. Stigma and restrictions were more for females than males. The reason given was loss of consciousness and improper dress position during seizures. In a community-based cross-sectional study in Kerala, 29% of respondents believed that an epileptic person could not have a normal married life.^[3] According to a clinicians' experience, women epileptics had to conceal their illness and secretly take medications. If epilepsy was revealed they faced abandonment, more dowries had to be given or hear derogatory remarks (dowry is the amount of property or money brought by a bride to her husband on their marriage). Men had fewer problems in the marriage but faced problems at work.^[23] According to a cross-sectional hospital based study of epileptic patients, the initiation of proper treatment for women is delayed and more wrong practices like opening mouth with keys are practiced for women than men.^[9] The reflection of the male dominance is also seen in aspects related to epilepsy.

Methodological Considerations

The strength of the study is the use of a vignette as a stimulus material to generate discussion among the participants on this rare disease of epilepsy compensating for the lack of personal experience of seeing a case of epilepsy by some participants. To maximize the methodological rigor in this study, we used

following strategies: Triangulation, credibility, transferability, dependability, and conformability.^[24] Triangulation was done using different sites and analysis by different investigators trained in qualitative research. The results of the study have been shared with the community to increase the credibility of the study. We tried to increase the transferability by providing elaborate information of the context as well as a detailed description of the phenomena of interest. Detailed descriptions of context, methods, and analysis enhance dependability and conformability. Limitation of the study was that male investigators were present and assisted the female intern in facilitating FGDs of female groups. The female participants might have hesitated in disclosing their concerns.

CONCLUSION

The study gives insight into the variety of perceptions on different aspects of epilepsy. The misconceptions in the community about epilepsy can affect nutrition, maternal and child health, hygiene, health care seeking, compliance to treatment of the epileptic patients leading to poor quality of life. The findings of this study can direct the future quantitative research in community settings in India. The results demonstrate a need for educational and awareness programs about the causes, modes of spread, treatment of epilepsy. There are positive perceptions about the education and employment of epileptic persons. Programs should address the stigma and gender issues in epilepsy.

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How to cite this article: Dhikale PT, Muruganandham R, Dongre AR. Perceptions of the community about epilepsy in rural Tamil Nadu, India. *Int J Med Sci Public Health* 2017;6(3):628-633.

Source of Support: Nil, **Conflict of Interest:** None declared.