

Lives of Women with Seizures in Malabar, South India

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Abstract

Epilepsy affects the everyday lives of individuals and their families in multifaceted ways, and the challenges associated with this chronic disease are increased when it is not appropriately treated. The conditions are worse in developing countries such as India, where resources are few and ignorance and misconceptions about the disease prevail. Although there are no gender-based differences in the mechanisms through which the disease affects people, women in India with epilepsy suffer more than men. Little is known about the experiences of women living with epilepsy and its treatment gap in India. The phenomenon referred to as the epilepsy treatment gap is the number of people in a given population (expressed in percentage) who require treatment but do not receive it at a given point in time. Thus, the purpose of this qualitative descriptive study was to describe the lives of women living with epilepsy in the outskirts of Kozhikode district in the Malabar Coast of Kerala, South India, where the epilepsy treatment gap is extensive. The study examined (a) the customs, traditions, and beliefs of the Indian women who are living with seizures, (b) how these women actually live their lives day in and day out; and (c) their thoughts and perceptions about their seizures. Six participants (ages 20-63) who were recruited through purposive and snowball sampling completed the study. Data that were collected through in-depth semi-structured interviews and field notes were analyzed using thematic analysis to understand meaning of these participants' experience of living with epilepsy. The themes that emerged from the analysis included: (a) Amulets, "English" medicine and traditional medicine; (b) "money is tight"; (c) scarring and stigmatization; (d) "adjust accordingly and live"; (e) "have to suffer"; and (f) "live my life." The findings of this study could lay the foundation for future qualitative and quantitative research studies and for developing culturally appropriate interventions.

Dedication

To the women living under the challenging consequences of living with epilepsy in developing nations.

To my beloved father, Charles Victor Job who was the gentlest, positive spirited and godly man I have ever known.

To my husband, Albrecht von Gaudecker, and my daughter, Anna Karunya von Gaudecker, for their unending support and unconditional love.

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Preface

Much has changed in the past century in the field of epilepsy research and advancement. From being perceived as a disorder associated with magical and supernatural causes, today epilepsy is understood to be a scientifically diagnosable and treatable problem of the brain. However, in the resource-challenged developing world, epilepsy continues to be shrouded with ignorance, myths, and misconception. This results in people with epilepsy seeking inadequate or inappropriate treatment for the disease and thus are within the treatment gap. Although active discussions continue on issues related to epilepsy awareness and eradication of treatment gap, we are not close to eradicating the epilepsy treatment gap in many of these resource-challenged locations, including India.

Because epilepsy is a medical disease with a large social component, it needs a multi-disciplinary team approach to care in order to meet the complex and multi-faceted needs of people with epilepsy (PWE) and their families. Nurses, along with other health care professionals, should come to the forefront and stand together to fight the disease in the developing countries. My passion and research interest is in the field of epilepsy and seizures. I have first-hand information on the struggles PWE and their care-givers face even here in the United States, in spite of excellent care and treatment. While working as the epilepsy nurse coordinator at the F. E. Dreifuss Epilepsy Center at the University of Virginia Medical Center, I obtained significant in-depth information while initiating and reviewing patient education and staff education about epilepsy care at the University of Virginia. Improving the quality of life among people with epilepsy, especially among the most vulnerable, led me to decide upon my dissertation research.

Many quantitative research studies have been conducted in India to understand the quality of life, knowledge, attitude and perception of PWE as well as those in general public. However, in order to understand the uniqueness of the situation in which PWE live and the meaning they give to living with epilepsy and its treatment gap in India, it is important to use the method of descriptive qualitative research. This understanding is also important to develop culturally appropriate interventions in this population and to identify areas of further research.

Born and brought up in Kozhikode, in the Malabar Coast of Kerala, South India, I bring to this dissertation research an understanding of the cultural nuances in this developing culture. My experiences working as a public health nurse in India prior to coming to the United States have helped immensely with the fieldwork during the data collection phase of this project. The familiarity of getting around in Kozhikode district and my ability to fluently speak in the local language/dialect, Malayalam (my first language), was an added benefit.

Through this dissertation, I have described the lives of six women living within the epilepsy treatment gap in the outskirts of Kozhikode district. This work describes these participants' everyday struggles of living with epilepsy. The study also describes their, attitudes, perceptions, beliefs, and life aspirations about the disease. This dissertation may be of interest to scholars who focus on transcultural women's health, and to health care professionals and policy makers interested in introducing culturally appropriate interventions to eradicate the epilepsy treatment gap and improve the quality of life of women with epilepsy living in Kerala, India.

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CHAPTER ONE: INTRODUCTION

Epilepsy – The disease

Epilepsy is the most important, chronic, non-communicable neurological disease and can affect an individual in many ways. It is one of the most common neurological disorders, with incidence similar to lung cancer in men and breast cancer in women (Perucca & Tomson, 2011). It is not only a medical condition as it is also associated with social and public health issues that needs a multidisciplinary approach for its management. It can hijack the lives of people of any age, race, gender, social class or country (de Boer, Moshe, Korey, & Purpura, 2013). The disease can manifest as seizures that affect the lifestyle of individuals, although most people with epilepsy (PWE) could lead a normal life with the right treatment. While safety is everyone's concern, people with epilepsy have to be extra-cautious about their physical safety. They live a life of uncertainties because of the unpredictability of seizures and the complications these could bring. Depending on the severity and nature of the seizures, the disease can affect every aspect of one's life. Severe burns, fractures, drowning, other seizure - related trauma are some of the injuries and complications associated with seizures (Nei & Bagla, 2007; Wirrell, 2006). The disease can cause considerable psychological and emotional trauma to the individuals affected.

Living with the burden of epilepsy is not just about living with seizures and its uncertainties alone. The disease is associated with increased morbidity and mortality. According to 2010 global burden of diseases report, epilepsy ranked 36th among the 291 diseases and injuries studied and severe epilepsy contributed 0.657% of disability (Murray et al., 2012; Salomon et al., 2012). This is even higher than untreated AIDS without anti-retroviral medications (Birbeck, 2013). Along with the physical constraints, there is an enormous burden on the social, psychological, and economical aspects of individuals affected (World Health

Organization (WHO), 2005). Notwithstanding this burden and despite the fact that cost-effective treatments are available for the disorder, a vast majority of people, especially in the developing world, still do not receive adequate or appropriate treatment (Meyer et al., 2012).

Epilepsy- The Treatment Gap

The consequences and burden of living with epilepsy are far worse when left untreated. These negatively affect the individual's self- concept and quality of life. Although cost-effective treatment is available, a vast majority of individuals with epilepsy in resource-poor regions do not receive appropriate and adequate treatment, a phenomenon called "treatment gap" (TG) (Meyer, Dua, Ma, Saxena, & Birbeck, 2010; Neligan & Sander, 2013; Newton & Garcia, 2012). Treatment gap is defined as the number of people with a condition or disease who need medical treatment for it but who do not get it (Kale, 2002). Untreated epilepsy is a critical public health issue, as people with untreated epilepsy face potentially devastating social consequences and poor health outcomes (Meyer et al., 2010). The International League against Epilepsy (ILAE), World Health Organization (WHO) and the International Bureau for Epilepsy's (IBE) "Global Campaign against Epilepsy: out of the Shadows" reports that 85% of people with epilepsy worldwide receive inadequate treatment or none at all (Neligan,A., & Sander, J.W. 2013).

Epilepsy - India

The WHO estimates that epilepsy affects nearly 50 million people worldwide, of which 80% live in the developing world (Bartolini, Bell, & Sander, 2011; Mbuba, Ngugi, Newton, & Carter, 2008; Meyer, Dua, Ma, Saxena, & Birbeck, 2010; Neligan & Sander, 2013). With India and China, being the most populous countries in the world, contribute to approximately 20% of the world's epilepsy population (Radhakrishnan, 2010). Next to vascular headache, epilepsy is

found to be the second leading neurologic problem in both urban and rural populations in India (Gourie-Devi, Satishchandra, & Gururaj, 2003). Based on a prevalence rate of 5 per 1000, it is estimated that there are approximately 10 million PWE living in India (Radhakrishnan, 2009). As many as 22 % from the urban population and more than 90% from the rural population live without adequate treatment (Meyer et al., 2010; Radhakrishnan, 2010; Santhosh, Sinha, & Satishchandra, 2014). In India, along with the burden of the disease, persons with epilepsy have to contend with severe stigma, lower employment, lower education levels, and lower socioeconomic status. Studies have shown consistently that there is a huge epilepsy treatment gap in India (Meyer et al., 2010). Meanwhile, the economic burden of epilepsy in the developing world has not been thoroughly examined. In their study in India, Thomas and colleagues (2001) described significant economic implications associated with epilepsy: health care burden, mortality, and lost work productivity. The total cost per person for epilepsy amounted to \$344 (US) per year (the equivalent of 88% of average income per capita in India). The total cost for the estimated 5.5 million cases in India was equivalent to 0.5% of its gross national product (Thomas et al., 2001).

From time immemorial, epilepsy has been considered a highly stigmatized and misunderstood disease. It continues to be so even today in many parts of the world. Many ancient manuscripts, including the Bible, mention epilepsy. Some of the beliefs about the disease continue to be similar to that of '*miqtu*,' described in the ancient Babylonian cuneiform tablets of seventh century BCE (York III, 2005) or to that of '*Apasmara*' in the ancient medicine system, Ayurveda of India (Tripathi, Maheshwari, Jain, & Padma, 2000). References to different aspects of epilepsy, which include symptomatology, etiology, diagnosis, and treatment were found in age-old Ayurvedic literature. The eighth chapter of Nidanasthana (diagnosis) and tenth chapter of

Chikitsasthana (treatment) of the Charakasamhitha, written between 1,000 -800 BC are devoted exclusively to epilepsy (Jain & Tandon, 2004). Despite the long and revered history, myths, and misconceptions about epilepsy prevail and are deep rooted, resulting in considerable stigma and discrimination (Gourie Devi, Singh, & Bala, 2010).

Everyone undergoes a certain amount of unfair treatment in the course of a lifetime but there are major hurdles of multifaceted discrimination that individuals with epilepsy have to face in India. Until December 1999, according to The Hindu Marriage Act of 1955 (which applies to Hindus, Buddhists, Jains, Sikhs) and the Special Marriage Act of 1954, epilepsy was considered a legitimate reason for marriage annulment. It still continues to be a reason for contentious discussion in family courts (D'Souza, 2004; Satishchandra, Gururaj, Mohammed, Senanayake, & Silpakit, 2001). Several years of legal struggle by the Indian Epilepsy Association resulted in the removal of epilepsy as a criterion for marriage annulment at the end of the twentieth century (D'Souza, 2004). The unfortunate but common practice of concealment of epilepsy from spouses is often constructed as fraud and cruelty, and offers spurious evidence that people with epilepsy are incapable of sustaining marital lives (Thomas & Nair, 2011; Thomas, 2011).

Epilepsy - Kerala

The state of Kerala in the south-west border of India has a population of more than 30 million people. With a literacy rate of 93.91%, Kerala is ranked as the most literate state in the country (Census of India, 2013). The health indicators are equally impressive. Cysticercosis is practically non-existent (Radhakrishnan et al., 2000). Nonetheless, epilepsy continues to be highly stigmatized and people try their best to conceal it. Although Kerala has some of the best medical facilities in the country to treat epilepsy, there is a reported treatment gap of 35-41% in

the state (Radhakrishnan, 2010) yet the services for epilepsy are reportedly under-utilized (Thomas et al., 2001).

Though there are several contributing factors that impact the living experience of those with epilepsy in India, gender emerged as a crucial factor with women suffer more than men (Ashwin et al., 2013; Nehra et al., 2014; Shetty, Naik, Saroja, & Punith, 2011). Women with epilepsy (WWE) face additional burdens involving pregnancy and childrearing. A study done in Kerala demonstrated that 55% of women studied preferred to conceal the history of epilepsy prior to marriage. A majority of those marriages resulted in separation, divorce, or other unsatisfactory outcome (Santosh, Kumar, Sarma, & Radhakrishnan, 2007). In their study in Kerala, Gopinath et al (2011) suggested that WWE had more difficulty finding life partners compared to men. It was also reported that WWE were at increased risk of divorce and have more problems with, marriage, mood, and employment compared with men (Gopinath, Sarma, & Thomas, 2011). In their study, Thomas et al (2006), showed the fewer WWE, particularly from the lower socio-economic background, received tertiary care in Kerala (Thomas, Deetha, Nair, & Sarma, 2006).

Study purpose and objectives

Because little research has been done to aid in understanding the perceptions of this chronic disease in India, there is need to explore the experience of women living in rural India with epilepsy treatment gap. This qualitative descriptive study on women with epilepsy/seizures is first of its kind in India. The purpose of this focused ethnographic study was to gain a perspective of lives of women living in the epilepsy treatment gap in Kerala, through participant observation and in-depth, semi-structured interviews. Understanding the subtleness and complexity of the response to their disease allows researchers and clinicians to construct

effective, developmentally, and culturally sensitive interventions. The specific aim of this study was to describe the lives of women with epilepsy living in the outskirts of Kozhikode (a district in Kerala) receiving treatment from traditional Indian healers and who are either (a) not receiving allopathic medications (antiepileptic drugs) at all or (b) receiving allopathic medications only intermittently. The objectives of this study were to:

1. Describe the customs, traditions, and beliefs of the Indian women who are living with seizures;
2. Describe how these Indian women actually live their lives day in and day out; and
3. Describe the thoughts and perceptions of Indian women about their seizures.

A description of their experiences through participant observation and interviews, analyzed using standard qualitative methods, has led to an understanding of patients' perspectives on treating, managing, and living with epilepsy/seizures. This systematic, thorough, and qualitative research project focusing on the cultural/societal aspects of living with seizures has provided insight into possible reasons for the treatment gap among women in South India. It also serves as a foundation for future studies.

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CHAPTER TWO

Review of Literature: Current Status of Epilepsy in India

Background and Significance

Epilepsy is the oldest and most common, non-communicable neurological disease. It can affect individuals of all ages, gender, race, and ethnicity in multifaceted ways (World Health Organization, 2012). Depending on the type of epilepsy, the manifestations of the disease vary from person to person. These includes altered consciousness, behavioral changes, convulsions or other altered motor or sensory activities. Because of the unpredictable nature of their seizures and the associated potential complications, people with epilepsy (PWE) live a life of uncertainty and fear. People with epilepsy have to take special precautions to remain safe. This life style results in considerable anxiety and frustration. The recurrent seizures can affect the individual's physical, emotional, and behavioral functions. PWE often develop complications, including fractures, burns and bruising, and other psychosocial issues and conditions such as anxiety and depression (World Health Organization, 2012).

Apart from the unpredictability of the seizures, epilepsy is also associated with many misconceptions, fears, and misunderstandings resulting in social stigma. Stigma related to epilepsy is a major concern throughout the world, especially in the resource poor countries. Stigma has an impact on both individuals and families. In some cases, PWE stay isolated, thereby affecting their social life (de Boer, 2010). In developing countries, many of the issues result from the lack of public understanding and negative attitudes towards the disorder. Most of these countries have sub-optimal services towards epilepsy care. In fact, very few governments are involved in plans for people with epilepsy (Reynolds, 2002). In Asia, stigma in epilepsy is

more pronounced among people living in rural areas, those with lower educational level, who are old age, females, and those who are single and ignorant about the disease (Kheng-Seang Lim & Chong-Tin Tan, 2014). All these variables contribute to the way stigma affects the quality of their lives.

Although medication cannot cure epilepsy, antiepileptic drugs (AEDs) are the mainstay of treatment for epilepsy in that they control the recurrence of seizures (Marson et al., 2005; Perucca & Tomson, 2011). Studies in both developing and developed countries suggest that 70% of newly diagnosed adults and children can be successfully treated (with complete control of their epilepsy) with AEDs (World Health Organization, 2004). The first line AED recommended by World Health Organization (WHO) for epilepsy is Phenobarbital (Yasiry & Shorvon, 2012).

Epilepsy affects 50 million people world-wide, of which 80% live in developing countries. In some these areas 80 – 90% of PWE live without any appropriate treatment. This phenomenon is called “treatment gap” (TG). (Meyer et al., 2010; World Health Organization, 2004; World Health Organization, 2005). By definition, treatment gap is the number of people with an illness, disease, or disorder who need treatment but do not get it (expressed as a percentage) (Kale, 2002). According to International League against Epilepsy (ILAE), seizure treatment gap is defined as “the difference between the number of people with active epilepsy and the number whose seizures are being appropriately treated in a given population at a given point of time, expressed as percentage” (Meinardi, Scott, Reis, Sander, & ILAE Commission on the Developing World, 2001). In 1997, the WHO along with ILAE and the International Bureau for Epilepsy (IBE) established a joint project called “Global campaign against epilepsy: Out of the Shadows,” to improve acceptability, treatment, services, awareness, education and prevention of epilepsy worldwide (World Health Organization, 2005).

Living with epilepsy is challenging especially in resource poor developing countries. India, the second most populous country in the world, is home to approximately 6-10 million people living with epilepsy (Radhakrishnan, 2010). More than 70% of people in India live in rural communities and have a low socio-economic and educational background (Mani, K. S, 2001). The country is also home to many myths and misconceptions regarding chronic diseases such as epilepsy. Moreover, the status of women in India is below average (Gurung, 2015; Shukla, 2015) and as a result, women with epilepsy struggle more than men as they cope with their illness.

Purpose

The purpose of this integrative literature review is to summarize the burden of epilepsy and the quality of life of PWE in India to provide an understanding of the current status of epilepsy in the country. Such an understanding lays the ground work for this dissertation study. This review is divided into two parts. The first part examines the epidemiological details to understand the burden of the disease, in particular the incidence, prevalence, and treatment gap related to epilepsy. The second part of this review focuses on studies assessing the quality of life (QOL) of PWE. This literature review examines the research published since 1997, the year that WHO launched the “Global Campaign against Epilepsy: out of the shadow,” until February 2015.

Method

This review of literature was conducted on studies related to epidemiological details of epilepsy and its treatment gap in India and the quality of life (QOL) of PWE living there. Only studies conducted within India among adults (above the age of 18 years) were included. Articles

were peer - reviewed, full text available, and published in English between January 1997 and February 2015. Comments, narrative, and opinions were not included. Searches were done using databases PubMed, EBSCO - host, and Web of Science or identified through a manual search of reference lists. The search terms for literature relevant to epidemiology included: *prevalence, incidence, treatment gap, epidemiology, epilepsy, seizure*. To identify studies related to QOL, the search terms used were: *psychosocial, quality of life, and epilepsy*. After reviewing the abstracts from different databases, studies were narrowed to those that match the purpose and inclusion criteria. Thirteen (13) articles, two of which were reviews, focusing on the epidemiological details of epilepsy in India are included. Thirteen (13) articles were included for the review of quality of life among PWE in India.

Results

Incidence

Incidence is the number of people who developed the disease in a specific period of time by the total number of people at risk during that specific time, and is expressed as the number of cases per 100,000 people in the population (Sander, 2003). Four epidemiological studies that reported the incidence of epilepsy (published since 1997) were identified (Table 1), of which two were conducted in Kolkata, North India (Banerjee et al., 2010; Banerjee et al., 2015). The lowest incidence of epilepsy was reported in Kolkata: 27.27 per 100,000 person-years (95% Confidence Interval (CI): 21.03 – 34.80) and highest in Yelandur: 49.3 per 100,000 person-years. All four studies gave gender - based incidence rates. All ages were included in all three studies and the reported incidence of epilepsy was greater among men than women (50.7 and 24.34 respectively). Based on the four studies currently reviewed, there is an average epilepsy incidence rate of 39.25 per 100,000 person-years in India.

Prevalence

Prevalence is the number of people with the disease in a defined population at one point of time by the number of persons in that population (Sander, 2003). Epilepsy is the second most common neurological disorder (after vascular headache) in India (Gourie-Devi, Gururaj, Satishchandra, & Subbakrishna, 2004). Two epidemiological reviews were identified. In their meta-analysis of data reviewed from 20 articles from 1964 to 1998, Sridharan and Murthy (1999) estimated the prevalence of epilepsy in India to be 5.3 per 1000 population (95% CI: 4.25 – 6.41) (Sridharan & Murthy, 1999). In their review, Gourie-Devi et al (2014) included 14 surveys from 1968 to 2008. They reported a mean crude prevalence rate of 5.7 per 1000 population (range 2.5 -11.9) (Gourie-Devi, 2014). Four of the surveys in the second review included both urban and rural populations and seven included only rural populations. There was a slightly higher prevalence rate in the rural population. The reported mean crude prevalence in the rural population was 5.8 per 1000 population (range: 2.5-11.9) and that of urban population, 5.2 per 1000 population (range 2.5 – 7.5) (Gourie-Devi, 2014).

Eleven (11) studies published since 1997 are included in this review (Table 2). Figure 1 shows the demographic location of these epidemiological studies. Five surveys were conducted among the rural population. Five surveys covered a mix of urban and rural population, and one survey used a semi-urban population. The total population surveyed was 7, 35,318. Surveys included people from all age groups except in two that surveyed people >60 years of age and one study that surveyed people <60 years of age. Seven surveys were conducted in North and North – East India. The highest prevalence was seen in the rural areas, 11.93 per 1000 population (Gourie-Devi et al., 2004). The mean crude epilepsy prevalence based on the population of these eleven surveys is 5.15 per 1000 population (range: 2.57 – 8.26 per 1000 population) and the

average prevalence rate in the rural population is 6 per 1000 population (3.04-11.93 per 1000 population). The prevalence rate was slightly higher among women (4.62 per 1000 population) than men (4.33 per 1000 population).

Treatment gap

All surveys except one on treatment gap were part of the prevalence studies (Table 3). One of the studies to estimate treatment gap was an intervention study (Nizamie, Akthar, Banerjee, & Goyal, 2009). The studies were conducted between 1990 and 2006 (published after 1997). The four studies covered a variety of populations including urban, semi-urban, rural and tribal population. Case-control studies were not included in this review. The treatment gap was lowest in semi-urban central Kerala, 38% and highest in a predominantly tribal population, 95% in Ranchi. The epidemiological review conducted by Gourie-Devi and colleagues (2014) reported a treatment gap between 29% and 78%. Yet another systematic review found that the treatment gap is 22% in the urban population and above 90% in the rural community (Meyer et al., 2010).

Quality of life among people with epilepsy in India

Thirteen (13) articles focusing on investigation of QOL in adults with epilepsy were retrieved through literature search, of which, 10 were on health - related quality of life (HRQoL), and one on stigma (Kumari, Ram, Nizamie, & Goyal, 2009; Nehra et al., 2014b). Two discussed both QOL and stigma (Joseph, Ray, Bhat, Herady, & Kumar, 2011; Kumari et al., 2009). One article described QOL and depression (Mehta, S., Tyagi, A., Tripathi, R., & Kumar, M, 2014) while another discussed QOL, depression and anxiety (Rakesh et al., 2012; S, R. P et al., 2012). One article discussed QOL of both PWE and their caregivers (Mehndiratta, Alam, Pandey, &

Singh, 2015). A few of the studies that were conducted among adults also included children. These were not excluded from this review. However, studies conducted only among children were not included in this review. All studies excluded people with co-morbidities such as psychiatric disorders, mental handicap that could confound the findings of the study. All the studies used quantitative methodology. No qualitative studies were found.

All except six articles reported that the instruments were duly validated for use in the local language. The majority of the researchers used the Quality of Life Inventory for Epilepsy (QOLIE) as the assessment instrument for QOL. The instrument has been field tested worldwide. Depending on the number of questions, the instrument is named QOLIE-89, QOLIE-31 and QOLIE-10. The studies also used other age appropriate instruments to assess QOL. Other assessments that were done in a few studies along with QOL were to quantify stigma, disabilities, depression, anxiety, and functionality of PWE. Table 4 provides a summary of the characteristics of the instruments used in the studies included in this review.

Of the five studies reported gender-based comparison, three studies reported that men with epilepsy had better QOL than women with epilepsy while two reported that women have better QOL than men. The other major factors that affected the QOL were increasing age (Ashwin et al., 2013a; Shetty et al., 2011b), lower educational status (Ashwin et al., 2013a; Mehndiratta et al., 2015), new diagnosis (Kumari et al., 2009), lower socio-economic status (Mehndiratta et al., 2015; Ranjana, Dwajani, Kulkarni, & Sarma, 2014), poly-therapy (Mehndiratta et al., 2015; Ranjana et al., 2014; Sinha, Sanyal, Mallik, Sengupta, & Dasgupta, 2011; Thomas, Koshy, Nair, & Sarma, 2005), frequency of seizures (Jadhav, Bodke, Sanap, & Gogtay, 2013; Mehta, S., Tyagi, A., Tripathi, R., & Kumar, M, 2014; S. V. Thomas et al., 2005), focal epilepsy (Ranjana et al., 2014), seizure worry (Mehta, S., Tyagi, A., Tripathi, R., & Kumar,

M, 2014) and depression (Mehta, S., Tyagi, A., Tripathi, R., & Kumar, M, 2014; Rakesh et al., 2012). Table 5 summarizes the studies included in this review.

Of the three studies that quantitatively assessed stigma, one reported that stigma was highest among patients newly diagnosed compared to patients who had been living with epilepsy for few years, and control group ($p < 0.05$) (Kumari et al., 2009). In one study, about 42.3% (women more than men) (Nehra et al., 2014b) and in another study, 66.1% of PWE (predominantly older age group, men, students and semi-professionals) reported that they felt stigmatized (Joseph et al., 2011).

Discussion

The gender-based incidence rates for epilepsy in India are comparable to those of developed countries where there is a reported incidence rate of 50.7 per 100,000 person-years among men and 46.2 per 100,000 person-years among women (Kotsopoulos, Van Merode, Kessels, De Krom, & Knottnerus, 2002). The mean incidence rate of epilepsy in India is also comparable to that of developed countries. Yet another meta-analysis reported the median incidence of epilepsy in developed countries as 45.0 per 100,000 person-years and that of developing countries as 81.7 per 100,000 person-years (Ngugi et al., 2011). In general, the prevalence of epilepsy is reported as 40-70 per 100,000 person-years in developed countries and above 120 per 100,000 person-years in developing countries (De Boer, Mula, & Sander, 2008). The prevalence rate of epilepsy in India is also comparable to that of developed countries where there is a reported prevalence rate between 4 and 10 per 1000 population. A few studies from developing countries have reported a prevalence of 6 – 10 per 1000 population (De Boer et al., 2008).

The epilepsy treatment gap of 38% was estimated from a highly literate semi-urban population in South India and the pre-intervention treatment gap of 95% was found among a tribal population in North India. Of the four studies identified, the study conducted in Kerala suggested the potential reasons for treatment gap as lack of diagnosis of epilepsy, reluctance on the part of the patient and care givers to accept the diagnosis, lack of knowledge about treatment, social prejudice against allopathic medicines, and non-availability and non-affordability of the AEDs (Radhakrishnan et al., 2000b; Santhosh, Sinha, & Satishchandra, 2014). In their report about epilepsy treatment gap in India, Santhosh and colleagues suggested that the reasons could be because of lack of access to or knowledge of AEDs, poverty, cultural beliefs, stigma, poor health delivery infrastructure, and shortage of trained professionals (Santhosh et al., 2014). While there are possibly many reasons for the treatment gap, in a personal interview, one of the neurologists who treats PWE in rural North India suggested that inaccessibility to appropriate medical care is the major reason for the treatment gap there. The treatment gap of 95% in Ranchi, North India, was estimated during the initial assessment of an intervention study. At the end of the four stage intervention study, (which included training of traditional workers and health workers, awareness sessions, diagnosis and treatment, and follow-up), more than 75% of PWE were seizure free (Nizamie et al., 2009).

Based on all the studies in this review, it is evident that epilepsy negatively affects quality of life. Based on two studies, it shows that the disease can influence the anxiety and depressive state of PWE. A few of the important factors that affect the QOL of PWE are discussed below.

India is one of the countries where there is high inequity in health care (Balarajan, Selvaraj, & Subramanian, 2011). Throughout the country, those with the lowest social and economic status suffer poor health. However, medical treatment available for rich patients in the

larger cities of India is comparable to that of developed countries (Connell, 2006). Along with inadequate health care, there are high levels of illiteracy, gender inequality and extremely limited access to social services among the poor rural people are of which increase the burden of the diseases (Reddy et al., 2011). The socioeconomic situation of the individual is an important predictor in PWE getting treated and continuing with the treatment. Two studies in this review emphasize the negative effect of low socio-economic background on the QOL of PWE. In India, more often than not, the patient and family are responsible for health care expenses (Thomas et al., 2005). In their study on the accessibility of health care in India, Balarajan and colleagues suggest that the inequalities are because of the socioeconomic status, geography, and gender. These are intensified by high out-of-pocket expenditures, with more than three-quarters of the increasing financial burden of health care being met by households (Balarajan et al., 2011). To worsen the situation, PWE have difficulty finding employment and remaining employed. They are either unemployed or underemployed (Varma, Sylaja, George, Sankara Sarma, & Radhakrishnan, 2007).

While the cost of treatment for epilepsy can be overwhelming for PWE, the four studies that assessed the QOL of PWE based on their pharmacotherapy profile reported that people on polytherapy had lower QOL scores than others on monotherapy. Thomas and colleagues reported that monotherapy was underutilized in many parts of Kerala (Thomas et al., 2005). In a study conducted by Krishnan and colleagues in North India, the researchers estimated that the average outpatient cost for treatment of outpatient epilepsy in a secondary level hospital was USD \$47 per patient, considering the cost of Phenobarbital to be approximately USD\$11. These authors also reported that the total annual treatment cost for patients admitted to the hospital was USD\$ 11,470 and the annual productivity loss for the same patients was USD\$ 20,475 (Krishnan,

Sahariah, & Kapoor, 2004). Based on a multi-center study involving six states in India, to estimate the economic burden of epilepsy Thomas and colleagues reported that the annual cost per person was USD \$ 344 (Thomas et al., 2001).

As mentioned earlier, the stigma associated with epilepsy is one of the major hurdles that PWE has to face in their day to day lives. In India, it affects PWE at the individual, familial, social and structural levels (Thomas & Nair, 2011) From the current review it is evident that stigma is a major contributor to negative QOL and treatment gap among PWE. Furthermore, the knowledge, attitude and practice (KAP) surveys conducted as part of the epidemiological study to assess the general attitude regarding epilepsy from a highly literate semi-urban community in Kerala, it was reported that epilepsy was considered contagious by 11.5%, a mental disorder by 27.3%, hereditary by 31.4% (significant among women $p < 0.002$). In addition, 29.6% of the people surveyed felt that society discriminated against PWE (Radhakrishnan et al., 2000c). Many existing misconceptions about the cause and care of epilepsy and the outcomes of its treatment increase the social stigma that prevails in the society regarding the disease. This stigmatization of the disease often leads to poor self-esteem and negative QOL among PWE.

Although epilepsy can affect people of all age, sex, race, and ethnic groups, women struggle more than men in all domains of the epilepsy profile. Women, especially of child-bearing age face unique challenges related to epilepsy throughout the world. In certain communities, depending on their status, women have more psychosocial consequences than men. Studies have reported that women have more struggles related to seizure recurrence, higher rates of hospitalization, and higher rates of depression. They also experience child-bearing and rearing issues (Szaflarski, 2014). In the three of the studies reviewed, the authors reported that women had lower QOL scores than men. Compared to men with epilepsy, there was a greater divorce

rate with epilepsy among women with epilepsy, there are also “withheld marriages.” Moreover, fewer women than men attend an epilepsy clinic for treatment (Agarwal et al., 2006; Santhosh et al., 2014; Thomas et al., 2006), and women with epilepsy face additional medical and safety issues involving pregnancy and childrearing. The current review also support the evidence that a major contributing factor for negative quality of life is the seizure frequency and seizure worry itself. As mentioned earlier, seizure frequency and severity can be effectively controlled using AEDs.

Conclusion

From the current literature review, it is evident that although the prevalence and pattern of epilepsy in India is comparable to that of developed countries, the treatment gap remains alarming in different parts of the country. The burden of living with epilepsy increases when the disease is not well treated. While many studies have quantified the QOL of people living with epilepsy on medical treatment, no study was identified that qualitatively described the lives of PWE who are either receiving adequate treatment or within the treatment gap. This dissertation research aims to bring that investigation.

Limitation

This review included articles available through international database. It is possible that articles that are not available for international circulation are not included in this review.

Figure 1: Map of India showing epidemiological study sites

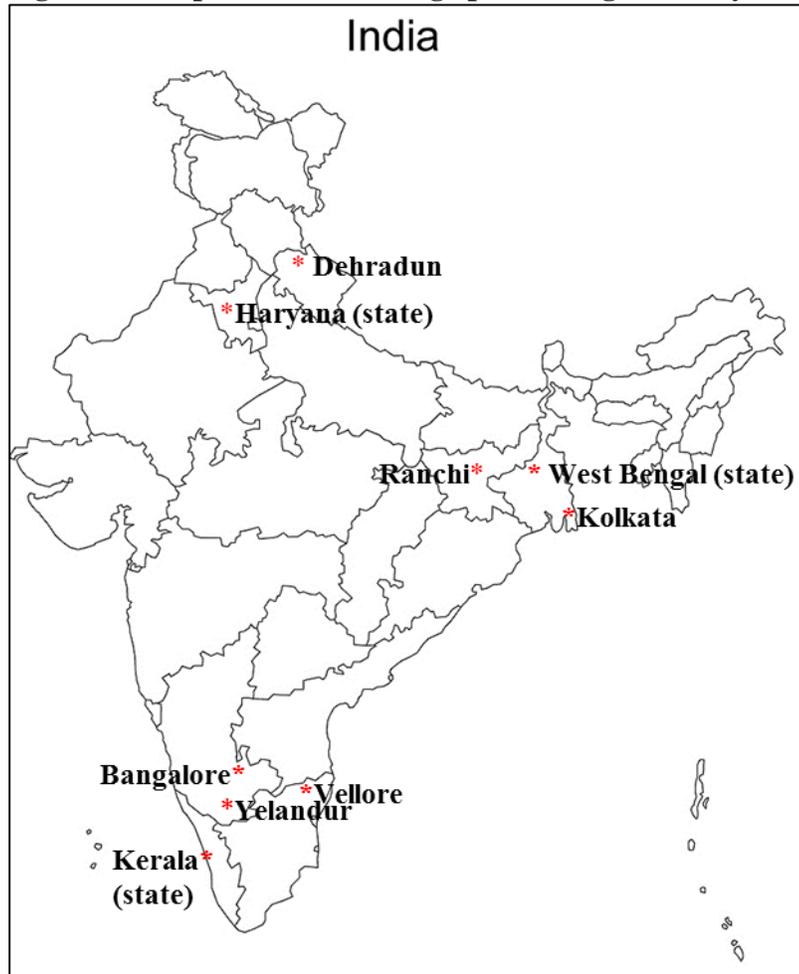


Table 1: Incidence per 100,000 person-years

Author (Year published)	Year of survey	Population size (N)	Population type	Place	No: of cases	Incidence	Male	Female
Mani et al., (1998)	1990-1991	64,963	Rural	Yelandur	32	49.3	50.7	47.7
Saha et al., (2008)	Not mentioned	20,966	Rural	West Bengal	38	42.08	38.25	34.88
Banerjee et al., (2010)	2003-2008	52,377	Urban and rural	Kolkata	66	27.27	30.54	24.34
Banerjee et al., (2015)	2003-2008	100,802	Urban and rural	Kolkata	197	38.37	44.35	33.19

Table 2: Prevalence of epilepsy 1000 population

Author (year published)	Year of Survey	Place	Population type	Age group	Population size (N)	Prevalence	Male	Female	Urban	Rural
Singh & Kaur, (1997)	1992-1994	North India	Rural	All ages	30,000	4.2	4.96	3.32	-	
Mani et al., (1998)	1990-1991	Yelandur	Rural	All ages	64,963	4.63	4.38	3.40	-	
Kokkat & Verma, (1998)	NM	Haryana	Rural	>60 years	8,595	8.03	2.56	3.02	-	
Radhakrishnan et al., (2000c)	1997	Central Kerala	Semi-urban	All ages	2,38,102	4.7	4.94	4.37	-	-
Saha et al., (2003)	1992-1993	West Bengal	Rural	All ages	20,842	3.6	4.44	8.16	-	
S. Das et al., (2008)	2003-2004	Kolkata	Urban & Rural	>60 years	52,377	2.57	1.2	5.8	-	-
Gourie-Devi et al., (2004)	1993-1995	Bangalore	Urban & Rural	All ages	102,557	8.26	-	-	5.77	11.93
Rajshekhar et al.,(2006)	2003-2004	Vellore	Urban & Rural	<60 years	50,617	3.83	3.26 [‡] 6.31* (4.8)	2.82 [‡] -- 6.16* (4.5)	6.23	3.04
Banerjee et al., (2010)	2003-2008	Kolkata	Urban & Rural	All ages	52,377	5.7	6.27	5.09		
Goel et al., (2011)	NM	Dehradun	Rural	All ages	14,086	6.5	-	-	-	
Banerjee et al., (2015)	2003-2008	Kolkata	Urban & Rural	All ages	100,802	4.71	5.41	3.95	-	-

‡ = Urban; * = Rural; NM = Not mentioned

Table 3: Epilepsy treatment gap in India

Author (Year published)	Year of survey	Place	Population type	Population size	Treatment gap
Mani et al., (1998)	1990-1991	Yelandur	Rural	64,963	78%
Radhakrishnan et al., (2000b)	1997	Central Kerala	Semi-Urban	2,38,102	38%
Gourie-Devi et al., (2004)	1993-1995	Bangalore	Urban and Rural	1,02,557	50%
Nizamie et al., (2009)	Intervention study: 2005-2006	Ranchi	Predominantly tribal	114,068	95% (pre-intervention)

Table 4: Summary of instruments used for the studies

Instrument	Expansion	Characteristics
QOLIE – 10	QOLIE: Quality of life inventory for epilepsy	10 items in 3 distinct topic (a) medication effects, (b) mental health, (c) role functioning and seizure worry (Cramer, Perrine, Devinsky, & Meador, 1996)
QOLIE-31		31 item questionnaire. Subscale grouped into two factors: (a) Emotional/ Psychological effects (seizure worry, Overall QOL, emotional well-being, energy/fatigue subscales) and (b) Medical/ Social Effects (medication effects, working – driving-social limits, cognitive function subscales) (Cramer et al., 1998)
QOLIE-89		89 items with 17 sub-scales representing four dimensions of Health related quality of life (a) severity of seizure frequency, (b) physical health, (c) mental health, (b) cognitive health. (Devinsky et al., 1995)
WHOQOL-BREF	WHO-BREF: World Health Organization quality of life short version	26 items. Shorter version of the original instrument measures broad domains: Physical health, psychological health, social relationships, and environment. (World Health Organization, 1996)
WHOQOL-26		Same as above

GHQ-12	GHQ: General Health Questionnaire	12 items questionnaire. To assess risk of developing psychiatric disorders. (Goldberg, D. & Williams, P., 1988)
SSE-24	SSE: Stigma scale of epilepsy	24 item questionnaire. Helps quantification of stigma in epilepsy (Fernandes, Salgado, Noronha, Sander, & Li, 2007)
IDEAS	IDEAS: Indian Disability Evaluation Assessment Scale	Scale for measuring and quantifying disability in mental disorders. 4 items (a) self-care, (b) interpersonal activities (social relationships, (c) communication and understanding (d) Work. (Grover, Shah, Kulhara, & Malhotra, 2014)
DAQ	DAQ: Dysfunctional Analysis Questionnaire	50 items questionnaire developed and standardized in India. Measures dysfunction in 5 areas of activity: (a) social, (b) vocational, (c) personal, (d) familial and (e) cognitive. Ten items in each section. (Chadda, 1995)
SF-36	SF: Short Form Health Survey	36 items. Measures health on 8 multi-item dimensions, covering functional status, well-being, and overall evaluation of health. (Brazier et al., 1992)
NDDI-E	NDDI-E: Neurological Disorders Depression Inventory for Epilepsy	6 items questionnaire. Measures depression symptom severity, health status and toxic effects of medications. (Gilliam et al., 2006)
PHQ-2	PHQ: Patient Health Questionnaire	2 items questionnaire. Used to measure the diagnosis and monitoring of depression (Löwe, Kroenke, & Gräfe, 2005)
GAD-7	GAD: Generalized Anxiety Disorder	7 item anxiety scale for self-report screening of generalized anxiety disorder (Spitzer, Kroenke, Williams, & Löwe, 2006)

Table 5: Summary of QOL studies from India

Author (year of publication)	Year of study	Sample size (male/female)	Sample type	Study Design	Instrument	Exclusion criteria	Summary of findings
Thomas et al., (2005)	2003	112 (59/53)	Tertiary care epilepsy center	Cross-sectional	QOLIE-31	Pregnant women; co-morbidities; language/visual / hearing disabilities	Poor QOL score among PWE on polytherapy ($p < 0.002$). Total QOL score was better for women (68.5 ± 15.5) than men (67.7 ± 16.3)
Shetty et al., 2011a	2005-2007	60 (37/23)	PWE attending Neurology clinic	Cross-sectional prospective	QOLIE-89	<18 years; other co-morbidities	Women lower QOLIE score (72.16 ± 18.58) than men (76.39 ± 16.64). Married PWE had lesser overall score ($p < 0.05$). Increasing age had negative correlation with bodily pain, seizure worry, and social support QOL scores – ($p < 0.05$).
Kumari et al., 2009	NM	45 (26/19)	Outpatient epilepsy clinic	Cross-sectional	GHQ-12 SSE-24 WHOQOL-26 QOLIE-89	co-morbid medical or psychiatric diagnosis	The sample divided into three groups: new patients; old patients and control. Stigma total score was higher among new patients ($P < 0.05$). Overall WHOQoL score best for control group and worst among new patients ($p < 0.01$). Similar pattern seen in overall QOLIE score ($P < 0.01$).
Sinha et al., 2011	NM	204 (141/63)	Outpatient clinic neuro-medicine (tertiary care hospital)	Cross-sectional	QOLIE-9	Co-morbidities that may affect the results or evaluation of QOLIE	Poor QOL associated with polytherapy ($p < 0.001$); higher frequency of seizures ($p = 0.001$); workdays lost due to epilepsy in the last 3 months ($p = 0.001$)
Jadhav et al., 2013	NM	80 (59/21)	Drug monitoring OPD	Cross-sectional	QOLIE-31	Patients with secondary epilepsy	Conducted among patients who are on first-line AEDs. Comparison of seizure free vs seizure frequency once per month. Overall QOL higher among

							seizure free group ($p < 0.0001$). Scores of women higher than men.
Ashwin et al., 2013a	NM	100(55/45)	Outpatient clinic, secondary level hospital	Cross-sectional	WHOQOL-BREF	Not mentioned	Poorer QOL score among: women (adjusted OR: 2.90, 95% CI:1.16 - 7.28); education $< 5^{\text{th}}$ grade (adjusted OR: 2.45, 95% CI0.68-8.86); > 30 years ($p < 0.001$); currently married (adjusted OR 3.82, 95% CI 1.21-12.11)
Nehra et al., 2014a	2010-2011	208 (73/135)	Tertiary care outpatient epilepsy clinic	Prospective observational	IDEAS; DAQ	Non-consenting; history of epilepsy surgery; Hearing and visual impairment	Low esteem among 18.71% patients. 42.30% felt stigmatized(women outnumbered men)
Mehndiratta et al., 2015	2010-2011	160 (92/68)	Department of Neurology	Cross-sectional	QOLIE-31 SF-36	Co-morbid conditions-neurological/psychiatric illness, motor, visual, hearing disabilities, pregnant women.	Poor QOLIE total score among PWE on polytherapy ($p < 0.05$). QOL of caregivers had a highly significant correlation with QOL of PWE ($p < 0.01$). Educational status and socioeconomic status was directly proportional to the QOL scores.
Joseph et al., 2011	2011	56 (31/25)	Tertiary care hospitals	Cross-sectional	QOLCE; Quality of life in epilepsy inventory for adolescents; QOLIE-31	$< \text{age} 7$; mental handicap or with severe psychiatric disturbances	QOL better for men (31%) than women (25%). Educational status inversely proportional to QOL ($p = 0.031$). Stigmatization reported by 66.1% PWE - mainly PWE between the age group 30-50 years ($p = 0.043$), men, students and semi-professionals.
Rakesh et al., 2012	NM	91 (39/52)	Community health department	Cross-sectional	WHOQOL-BREF PHQ-2	Mental retardation	Poor QOL among: Single, separated and widowed people than married ($p < 0.01$); below primary education

					GAD-7		(P<0.05) and unemployed people (p<0.01). Depression had correlation with low QOL (p<0.01). Generalized anxiety correlated with low QOL (p<0.01)
Ranjana et al., 2014	2012-2013	451 (251/191)	Outpatient and inpatient Neurology	Cross-sectional	QOLIE-10	Pregnant/lactating women; co-morbidities that could be confounding factor in QOL assessment	Poor QOL among PWE with monthly income <INR 5000(overall p<0.01); PWE with focal epilepsy - lower scores for emotional well-being (p=0.007), medication effects (p=0.005), and social functioning (p=0.01). PWE on poly-therapy reported lower QOL.
Nagarathnam et al., 2014)	NM	400 (17/229)	Outpatient neurology clinic	Cross-sectional	QOLIE-89	Co-morbidities, visual/hearing disabilities, drug regimen other than AEDs	Lower QOL scores among: Rural compared to urban (p<0.010; married compared to unmarried (p<0.01); lower education status compared to professional course (p<0.01).
Mehta, S et al., 2014	NM	31 (23/8)	Epilepsy patients in psychiatry outpatient department	Cross-sectional	NDDI-E QOLIE-31	Psychotic disorders, stroke, head injury, brain tumors, mental retardation, brain surgery, co-morbid chronic medical disorders	Seizure frequency significantly correlated with seizure worry (p=0.002), emotional wellbeing (p=0.026), social functions (p=0.013). NDDI-E showed negative co-relation with all subscales of QOLIE-31, except medication effects suggesting depression's effect on PWE's QOL.

NM: Not mentioned; PWE: people with epilepsy; OR: Odds ratio; CI: confidence interval; IDEAS: Indian Disability Evaluation Assessment Scale; DAQ: Dysfunctional Analysis Questionnaire; QOLIE: Quality of Life Epilepsy Inventory; GHQ: General Health Questionnaire; SSE: Stigma Scale for epilepsy; WHOQoL: World Health Organization Quality of Life; SF: Short form (survey); QOLCE: Quality of life in childhood epilepsy; NDDI-E: Neurological Disorders Depression Inventory in Epilepsy.

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CHAPTER THREE

Research Design and Methods

Purpose and Aims

The purpose of this ethnographic study was to describe the lives of women with epilepsy living in the outskirts of Kozhikode (district in Kerala, South India) who were identified as receiving treatment from traditional Indian healers and who were either (a) not receiving allopathic medications (antiepileptic drugs) at all or (b) receiving allopathic medications only intermittently. The study describes:

1. the customs, traditions, and beliefs of the Indian women who are living with seizures;
2. How these Indian women actually live their lives day in and day out; and
3. Indian women's typical thoughts and perceptions about their seizures which are rooted in Indian culture

A description of their experiences through participant observation, formal and informal interviews, analyzed using standard qualitative methods, has led to an understanding of patients' perspectives on treating, managing, and living with epilepsy/seizures. The study serves as a foundation for future studies to reduce the treatment gap and improve the quality of life among people with epilepsy (PWE) in India.

Design and Approach

Ethnography emerged in the 1960s as a research method used in health care studies to provide humanism in describing and explaining culturally specific phenomenon (Allen, Chapman, Francis, & O'Connor, 2008). In the tradition of Geertz (1973), Agar (1986), and Silverman (2007), this study as an ethnography focused on specific aspects of culture and illness

experience. The underlying questions which led to designing of this dissertation study were: what are the underpinnings of patients' beliefs about epilepsy and its treatment? What needs to be known about women with seizures and its treatment gap to improve or design culturally appropriate health care interventions? Ethnography in nursing research helps to unravel such questions (Ghebrehiwet, 2000).

Ethnography provides a truthful account of people's stories in their own words and local context as researchers immerse themselves in the social world of the participants to grasp better the meanings behind participants' social behavior in their culture (Fetterman, 1998; Roper & Shapira, 2000). Denzin & Lincoln (2011) explain that firsthand interaction with people in their everyday lives can help ethnographers attain a better understanding of their beliefs, motivations, and behaviors than can be done using any other method. Although other qualitative approaches could be used, ethnography was used in this study to take advantage of the relative immersion needed to obtain a thick description (Goodson & Vassar, 2011). Thick description refers to the detailed description of field experiences through which the investigator puts cultural and social relationships into context (Holloway, 1997)

This focused ethnography used a descriptive qualitative design. Focused ethnography, similar to classical ethnography uses participant observation activities in a natural setting, in relatively short-term field visits, asking questions to learn what is happening. It also uses other available sources of information to gain a thorough understanding of people, places, and events (Roper & Shapira, 2000). The focus of this study was to answer very specific questions regarding the experience of women living in the epilepsy treatment gap in Kerala, India. Living with a chronic stigmatized disease in a patriarchal society such as India, women especially those living in rural/semi-urban areas, bear many psychosocial consequences. These women have limited

opportunity to express the precarious situation in which they live and make every effort to conceal their seizures from family and friends (Santosh et al., 2007). This focused ethnography study allowed for data collection in a realistic setting in which people act naturally while the investigator focuses on both verbal and non-verbal behaviors (Sangasubana, 2011). Women were interviewed in their home setting.

Setting and Sample

Prior to data collection, Human Subject Committee approval was obtained from the Institutional ethics review board (IRB- HSR# 16858) of a major US medical center and the Indian Human Ethical Committee (#001/CUEC/CR/2013-14-CU). The study took place in the outskirts of Kozhikode district, South India. In preparation for the study, investigator travelled to this area between July and August 2012 to build a rapport with the traditional healers there and understand the modalities they use to treat people with seizures. In the data collection phase, the investigator lived in the study area from August through October 2014. Because the investigator was born and raised in the local townships where the data were collected, she was knowledgeable of the areas and was able to collect sufficient updated information about the rural/semi-urban area to be able to converse fully with the participants. She spoke the local language, Malayalam fluently (her first language). The investigator immersed herself in the community and setting. This in turn led to developing a thick description for the study (Creswell & Miller, 2000).

During the data collection phase, the investigator reconnected with the traditional healers in Kozhikode district, whom she had contacted earlier. Participants were initially identified by the traditional healers and through word of mouth, among the women. Recruitment was done

through purposive and snowball convenience sampling. The potential participant was contacted prior to the initial visit to ascertain that it was appropriate to visit them without disrupting any of their daily activities.

Interviews were conducted with women ($n=6$), ages 20 to 63 years, who were diagnosed with epilepsy and were not on any anti-epileptic drugs or were not taking these medications as prescribed. This sample size was chosen based on the article by Sandelowski (1995), regarding type of qualitative design and length of time in the field. According to Sandelowski, sample size varies depending on the purpose of the qualitative study. The six women were the key informants. Additional data were gathered from each participant's family and through participant observation. One participant had a graduate degree, one participant was illiterate, two of them had high-school education, and two of them had elementary school education. The women lived in several neighborhoods throughout the Kozhikode district.

Inclusion criteria for participation were the following: (a) women between the ages of 18 and 65 years of age; (b) living with seizures for the past 2 years, with a diagnosis of epilepsy by qualified medical practitioner; (c) on treatment under traditional healers for seizures/epilepsy and not on any antiepileptic medications; (d) not adhering to any antiepileptic drug protocol for at least one year prior to enrolling in this study; and (e) willing and able to give informed consent. Exclusion criteria were the following: (a) other comorbidities that compromise the ability of participants to participate in an interview such as mental retardation or autism; (b) prior medical diagnosis of non-epileptic spells or pseudo-seizures; (c) pregnant and nursing.

If a woman did not meet the criteria or was not willing to sign the informed consent, she was thanked for her time and enquired of any other women she might know who might meet the

inclusion criteria. If the woman was reluctant to sign the informed consent and participate in the study, she was asked to contact the investigator if she changed her mind. If the women requested time to discuss participation with members of her family before deciding, it was so done she was granted that time.

To ensure participant observation and an insider role, the investigator, who can fluently converse in the local dialect (her first language), lived in the city of Kozhikode and dressed and conducted herself like any other local person, spending as much time as possible with each participant. During the initial visit with the potential participant, the investigator gave a brief description about the study and at the same time made an assessment of their ability to meet the inclusion criteria. Once found eligible, the investigator briefly described the informed consent, gave the informed consent in local language for the woman to read (in three cases, read for each) and asked if the potential participant still wished to participate. Of the 21 women contacted, six (n=6) participants enrolled and completed the study. All the participants agreed to the terms of consent. The initial interview was conducted on the same day.

The investigator developed a one-page, nine item, multiple choice, short answer demographic form (Appendix C) that included information regarding socio-economic status, marital status, education, religious belief, and basic family information of the participant. The completion time was 5 minutes or less by the participants. The investigator read this form and completed it in their presence for three of the participants.

The investigator developed 20 semi-structured open-ended questions to be used as an interview guide. This guide included an introduction and brief description of the study, followed by semi-structured open-ended questions. The investigator guided the interview to keep the

participant on topic and by asking the participant to be as specific as possible in details rather than generalizing information. Additional questions were asked formally and informally as new questions emerged during the interview. All interviews were audio recorded. Field notes were collected during participant observations and interviews.

Interviews were planned to occur at any safe, quiet place where it was both convenient for the investigator and the participant. All the interviews occurred in the participants' homes where they felt most comfortable in opening up. The investigator felt safe to conduct the interviews there. All interviews lasted between 15 minutes to 100 minutes. The investigator then translated all interviews verbatim from Malayalam to English. The participants were encouraged not to mention any identifying details about themselves during the interview to maintain confidentiality throughout the data collection, transcription, and data analysis.

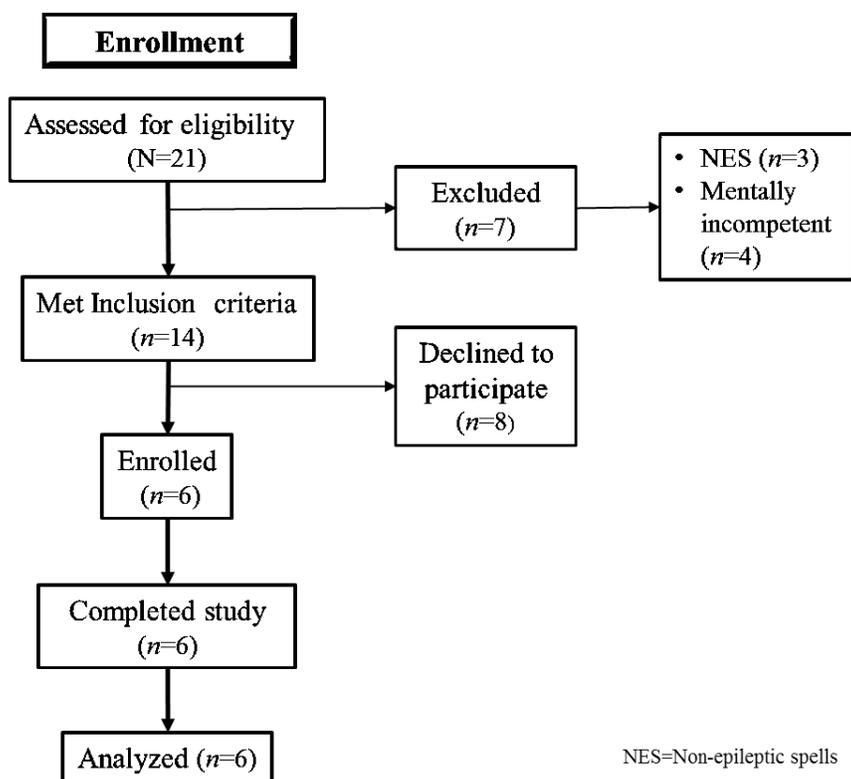
Challenges faced in recruiting participants:

The investigator approached 14 traditional healers from different parts of the district to identify women with epilepsy. The majority of them reported that they primarily treated children with epilepsy. Few even reported that epilepsy affects only children. Most of the women with epilepsy were identified through two traditional healers. About the time of this study, two homicides alleged to be related to epilepsy treatment through black-magic were reported in the neighboring district of Kozhikode. The two *religious* healers who were known to people in the community as healers for seizures, refused to accept that they treated people with seizures when the investigator approached them for help identify possible participants.

Epilepsy is a stigmatized disease in Kozhikode. Although confidentiality of information and privacy were assured, many potential participants, especially women of marriage age,

refused to be part of this ‘epilepsy research’ as they did not want to ‘open up chances’ for members in the community to know about their seizures. Arranged marriage is a common practice in this community and a few family members of these women verbalized that they worried that if the community came to know about the history of epilepsy, that knowledge might affect marriage negotiations. Of the 21 women with epilepsy identified, 6 women enrolled and completed the study. Figure 1 shows the consort flow diagram for enrollment.

Figure 1: Consort diagram



Procedure:

Women living with seizures for the past 2 years and fit into the inclusion/exclusion criteria were enrolled in the study under voluntary basis after receiving information about the study. Purposive and snowball convenience sampling was used for recruiting participants.

Informed consent (Appendix B) was obtained in the local language and a brief demographic form (Appendix C) was completed for demographic descriptors of the study population. During the process of obtaining informed consent and completing the demographic data, the investigator built a rapport with the participant. This was followed by a face to face semi-structured interview based on both specific and open-ended questions (Appendix D). The interview included questions regarding the participant's medical history, to discern whether the participant had epilepsy versus pseudo-seizures. No individuals were excluded from the study unless they had previously had a clinical diagnosis of non-epileptic spells or pseudo seizures. Participants were interviewed up to 3 times as time permitted and as new questions emerged. Interviews were conducted in a private location that was safe for both the participant and the investigator. Most of these women stayed at home and interviews were conducted in the home setting. All interviews were audiotaped. The initial interview lasted a maximum of 100 minutes. Subsequent interviews lasted between 15 and 30 minutes each. All the interviews took place over a two-week period.

The majority of the participants stayed at home and participated in minimal activities outside of the home. Time was spent with them, as participant observation, to understand their activities at home. The investigator also visited the work place of one of the participants. The investigator visited the participant every day for two weeks unless the participant requested time off from the observation. Approximately, a total of 80 hours was spent with all the participants together. Data were collected through interviews, participant observation field notes and analytic memo journals (Berg, Lune, & Lune, 2004; Mulhall, 2003).

Data Analysis

Prior to data collection, the investigator bracketed her preconceived ideas and judgments about the research phenomenon to control for bias. An ongoing reflective journal was maintained throughout the data collection and analysis phases. All interviews were translated and transcribed verbatim immediately after these were completed. Interview transcriptions were checked for accuracy by reviewing the audio-recording with the transcript. Each data component included field notes that included participant observation, audio recordings, and transcripts of interviews were reviewed multiple times so as to immerse and become familiar with all aspects of the data.

Data analysis and development of themes was done using NVivo 10. The transcripts and field notes were read again and nodes were identified that capture important aspects of each participant's narrative. The nodes were organized into categories according to similarities. The texts were read again as a validity check of identified categories. Further, categories were arranged by similarities to form themes. Once again, the complete text was re-read to determine presence of representation of the overall data. Memo of thoughts and ideas were attached throughout this process.

Trustworthiness and Rigor

According to Lincoln and Guba (1985), in qualitative research the concepts credibility, dependability, and transferability have been used to describe various aspects of trustworthiness (Graneheim & Lundman, 2004; Lincoln, Y & Guba, E, 1985). The methods of establishing trustworthiness were followed in this research. During follow-up interviews, the investigator ensured respondent validation (Harper & Cole, 2012; Lincoln, Y & Guba, E, 1985). The investigator spoke fluently in the local language, Malayalam. A clear and distinct description of

culture and context, selection and characteristics of participants, data collection, and process of analysis were detailed to facilitate thick description and transferability (Graneheim & Lundman, 2004). The investigator maintained a reflective diary and field notes during data collection. Qualitative data analysis was done throughout the entire data collection process beginning immediately after the first interview. Interview transcripts and field observations were used for triangulation of information (Creswell & Miller, 2000; Lincoln, Y & Guba, E, 1985). The investigator used the stepwise approach described in Cohen et al., 2000 (Cohen, Kahn, & & Steeves, 2000). Development of codes and themes were discussed with members of the dissertation committee during regular meetings. Credibility, which is internal validity was ensured through member checking, field journal, de-briefing with members of the dissertation committee (Krefting, 1991). Dependability and conformability was ensured through triangulation and de-briefing. Rigor was ensured using triangulation, briefing and member checking (Sandelowski, 1986).

Study limitation and benefits:

The study represents the findings of a small community in South India and cannot be generalized to the greater population, but will provide foundation to future larger, robust qualitative and quantitative studies that will have broader implications.

Selection bias was a potential limitation of the study because the women who chose to participate may have represented a certain subset of the population. Because epilepsy is a stigmatized disease, women were reluctant to participating in the study. Confidentiality was assured throughout the study and the women were given time to discuss the study with their family and decide about participating. During the consent process, participants were assured they could withdraw at any time or chose not to answer some questions.

Yet another potential limitation is that the majority of the participants were recruited through traditional healer's consultation area ($n=4$) and therefore interviewees may have censored their opinions about traditional remedies.

There were no known direct benefits to the participants in this study. However, participants may have benefitted from the opportunity to talk about their experiences and thus reflect on how they are living with their seizures. Benefits to society may include helping health care providers elsewhere to understand what it means to live with seizures in the given community.

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CHAPTER FOUR

Manuscript one

“I just want a cure for this”: Ethnography among women with epilepsy in Kerala,

South India

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Abstract:

Many studies done on epilepsy in India have shown gender-based discrimination towards women and the problem of treatment gap. This study used “mini-ethnography” to explore the experience of six women living with epilepsy (WWE) in South India. The participants were recruited through purposive and snow-ball sampling. This paper highlights participants’ beliefs and perceptions about their treatment for epilepsy. Epilepsy was understood to be the effects of “evil doings”. It was also seen as a challenge to control. ‘Finding a cure’ for seizures was the main catalyst in seeking different types of treatment. WWE reported that barriers to treatment were financial constraints, the stigma of epilepsy, medication side-effects, medicine non-availability, and dependence on family members. They also reported that traditional healers could reduce their need for allopathic medications, thereby reducing the cost. The study reveals the need for culturally appropriate intervention to reduce the treatment gap and improve quality of life of those afflicted.

Highlights

- The women in this study had initially sought treatment with anti-epilepsy drugs (AEDs).
- Ethnography exploring perceptions and experience of women living with epilepsy and its treatment gap in South India, reveal the burden of epilepsy for women in this region.
- Cultural factors affecting the treatment for epilepsy included poverty, access issues, dependence, and the social stigma of the disease.

Abbreviations

PWE, People with epilepsy; ETG, epilepsy treatment gap; AEDs, anti-epilepsy drugs; WWE, women with epilepsy; “English medicine, “western/scientific medicine; *apasmaram*, epilepsy

Key words

Ethnography, qualitative research, treatment-gap, anti-epileptic drugs, amulets, traditional medicine, India

1. Introduction

According to the World Health Organization (WHO), 80% of the 50 million people living with epilepsy live in developing countries where resources are limited and the disease remains unrecognized and undertreated [1]. Although cost effective treatment is available through anti-epileptic drugs (AEDs), 80 – 90% of the people with epilepsy (PWE) in developing countries live without appropriate and adequate treatment, a phenomenon called “treatment gap” [2-4]. The epilepsy treatment gap worsens the burden of living with the disease and thereby negatively affects the quality of life of those afflicted.

India and China, the most populous countries in the world, contribute to approximately 20% of the total epilepsy population in the world [5]. Epidemiological studies have shown that epilepsy is the most common neurological disorder in India, second only to vascular headache [6]. Based on a prevalence rate of 5 per 1000 and an incidence rate of 50 per 100,000 per year, at any time, with over a billion inhabitants, India has at least 5 million people with active epilepsy with nearly 500,000 added annually [5,7,8].

For many years, there have been active discussions about epilepsy and its treatment gap among PWE in resource poor countries. Studies have consistently shown that the epilepsy treatment gap in India is between 22 -50% (urban - suburban) to 40-90% (rural) [2]. In the state of Kerala, where some of the first world technology and treatment options are available for PWE, there is a reported epilepsy treatment gap of 35-41% [5]. In a 2007 study, Das and colleagues [9] reported that 43% of PWE in India discontinue AEDs within one year.

People with epilepsy and their families often experience prejudice, discrimination, isolation, and exclusion [13]. In India, persons with epilepsy must also contend with severe

stigma, lower education and employment levels, and a lower socioeconomic status. In Kerala, the disease continues to be highly stigmatized and is associated with myths and misconceptions, particularly for women. Two homicides of women with epilepsy (WWE), a teenager and a young pregnant woman who sought black-magic treatment [14, 15], were reported in the state during the year this study was conducted. In a 2011 study conducted in Kerala, Gopinath and colleagues [16] found that the psychosocial outcomes that WWE had to face were worse than those for men with epilepsy. These women had more difficulty finding a life partner, an increased risk of divorce, problems within their marriages, and difficulties with both mood and employment as compared with men. In a 2007 epilepsy study conducted in Kerala, Santosh and colleagues [17] reported that 55% of women concealed their history of epilepsy during marriage negotiations [17]. In an earlier study [18] within Kerala, researchers reported that fewer WWE receive tertiary care, particularly those from lower socio-economic groups.

Culture, defined as the “integrated pattern of human behavior that includes thoughts, communication, actions, customs, beliefs, values and institutions of a racial, ethnic, religious or social group” has much relevance to the health of the people living in a given cultural setting [10,11]. Much research on the topic emphasizes the importance of understanding social and cultural factors to improve health outcomes. Understanding the values, customs and norms of individuals from different cultures is crucial to the promotion of better health care. India is one of the most culturally diverse countries in the world. The different cultures, ethnicity, and traditions of which the individual is part contribute to the treatment-seeking behavior. When an individual has a chronic stigmatized disease such as epilepsy, cultural factors and the nature of their experiences of living with the disease affect their perceptions and responses to the disease and the treatment decisions they make. Therefore, a clear understanding of cultural factors is

important for health care providers. This study describes the social and cultural atmosphere that prevails in Kerala, the most literate state in India, and one in which the epilepsy prevalence rate of epilepsy is 5 per 1000 population [12].

Kerala is characterized by medical pluralism with biomedicine being the state's dominant medical system there. This can be likely attributed to the tropical-like weather with heavy rainfall contributing to the proliferation of vegetation and medicinal plants [19]. Medical practice in Kerala is complex and includes Ayurveda, the age-old, traditional and trusted form of treatment [20]. Although there are trained Ayurvedic physicians who treat people with different ailments and diseases, there is also another group of indigenous healers who are not professionally trained. These healers use both Ayurvedic medicine and their own 'secret' herbal formula to treat different diseases. The other indigenous medicine systems in this region include Siddha, Unani and Homeopathy. People with epilepsy often consult traditional healers, religious healers qualified, and unqualified private practitioners, sometimes after they are seen at a western medicine clinic and at other times instead of seeking western professional care. For the purpose of this paper, all healers other than allopathic physicians will be referred to as 'traditional healers' unless otherwise specified.

The purpose of this descriptive qualitative ethnography was to depict the experience of women living with epilepsy in the outskirts of Kozhikode (a district in Kerala, on the western coast of South India) who were identified as receiving treatment from traditional Indian healers and who were either (a) not receiving any allopathic medications (AEDs) or (b) receiving allopathic medications only intermittently. This article reports part of a larger study that explored the customs, traditions, and beliefs of the Indian women who are living with seizures; how these women live their lives day in and out; and way these women think and feel about their seizures.

Methods

1.1 Study setting

No one, to the researchers' knowledge, has done a qualitative descriptive study among women with epilepsy and its treatment gap in India. This study was carried out in the outskirts of Kozhikode district in Kerala along the south-western coast of India ([Figure 1](#)). The state of Kerala is noted for its overall social development, including its high development in Gender-related Development Index [21]. Kozhikode district, the third largest in the state, is multi-ethnic and multi-religious [22]. The language spoken is Malayalam. The demographic characteristics are given in Table 1 below.

There are 1100 qualified neurologists in India for a population of over a billion [23] and 130 qualified neurologists in Kerala [24]. According to the Kozhikode chapter of the Indian Medical Association (the national organization of doctors of modern scientific system of medicine) there are approximately 18 neurologists in the district or 1 neurologist for every 171,641 persons in the area. While there are 342 registered health care institutions [25] in the district, many healers practice in their home setting or local clinics.

Figure 1: Map of India, Kerala and Kozhikode

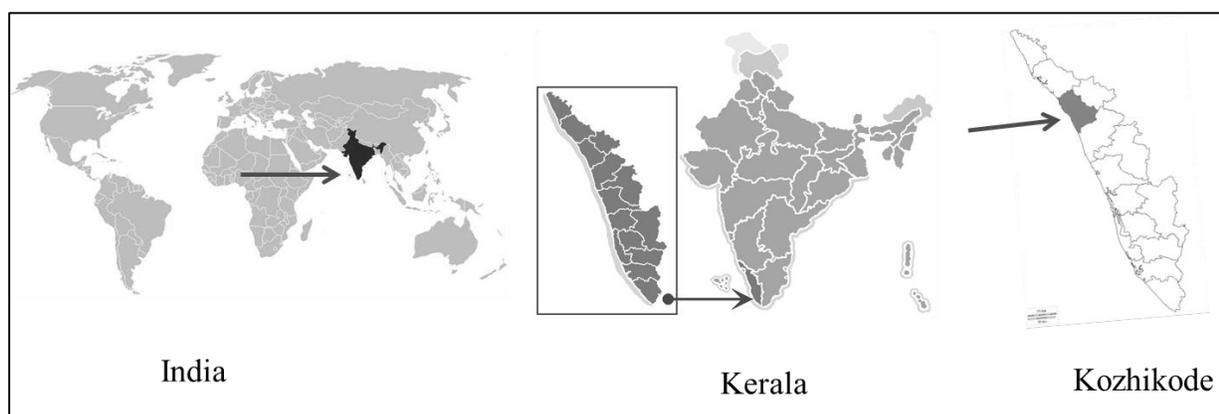


Table 1: Demographic characteristics of Kozhikode [23-26]

	India	Kerala	Kozhikode
Population	1.2 billion	33,387,677	3,089,543
Hindus	79.6%	56.2%	58.9%
Muslims	14.2%	24.3%	37.52%
Christians	2.34%	19%	4.43%
Literacy rate	74.03%	93.91%	96.8%
Number of Neurologists	1,110	130	18

1.2 Inclusion and Exclusion Criteria

The inclusion criteria for participants in the study were: women between the ages of 18 and 65 years of age who (a) were willing and able to give informed consent; (b) living with seizures for the past two years, (c) had a diagnosis of epilepsy made by a qualified medical practitioner, (d) were on treatment under traditional healers for seizures/epilepsy and not on any AEDs, and (e) those not adhering to AED protocol. Those excluded were women who had a diagnosis of non-epileptic spells, pregnant or lactating and those who were mentally incompetent to participate.

1.3 Recruitment

The study was approved by the institutional Internal Review Board (IRB- HSR# 16858) of a major mid- Atlantic academic medical center and the Indian University Human Ethical Committee (#001/CUEC/CR/2013-14-CU). Women with epilepsy were recruited between August and October 2014 through purposive and snowball convenience sampling having been identified from the traditional healer's consultation area or through word-of-mouth. Informed consent was obtained from all participants. Care was taken to ensure confidentiality of participant information.

1.4 Data collection

This ethnographic study was conducted among six women living with epilepsy. Data were collected using participant observation, field notes and in-depth semi-structured interviews with WWE (key informants) regarding their experience of living with this chronic disease. The questions in the 20-item semi-structured interview focused on understanding the cultural aspect of living with epilepsy, beliefs, treatment options, and opinions. The first author, who conducted the ethnography, is a native of Kozhikode district and understands the cultural nuances of the region which helped develop a thick description for the study. The procedures followed were in compliance with ethical standards of both IRB-HSR and CUEC. After obtaining written informed consent, the participants were asked to complete a brief demographic form. The first author guided the interview to keep the participant on topic asking the participant to be as specific as possible in details rather than generalizing information. Additional questions were asked formally and informally as new questions emerged during the interview. The first author also informally interviewed two traditional healers who treated four of the participants. Because the majority of the participants had seizures with loss of awareness or consciousness, family members served as general informants. All interviews were conducted by the first author in the participants' own language, Malayalam, and were tape recorded. In keeping with participants' preferences, the interviews were conducted at their homes. The initial interview lasted a maximum of 100 minutes. Subsequent interviews lasted between 15 and 30 minutes each. All the interviews took place over a two-week period. The first author visited the participants every day for two weeks to observe their day-to-day lives unless the participants requested time off from observation. Field notes of the interview were maintained as well as a recording.

1.5 Data Analysis

For ease of management, the interview data were analyzed and themes were developed using QSR NVivo 10 computer software package. Data were reread at each stage of analysis process while developing categories and themes [27]. The developing codes and themes were discussed during regular meetings with members of the study team. Rigor was addressed through extended contact, triangulation of information through different sources (key informants, general informants and field notes), briefing (repeated consultation with members of the study team who had impartial views), respondent validation during interviews, and audit of data analysis done by members of the study team [28].

2. Findings

The demographic descriptors and seizure details of participants are explained in Table 2. All participants lived in different areas of the outskirts of Kozhikode district in Kerala. The annual income of the household was reported by three participants to be between Rs10,000 and Rs. 25,000 (~ \$161 - \$416). Other participants did not mention their annual income.

Table2: Demographic descriptors and seizure details of participants

N=6		Average age: 37.8 Range: 20 – 63 years	
Marital status	<i>n</i>	Educational qualification:	<i>n</i>
Unmarried	1	Illiterate:	1
Married	3	Elementary education:	2
Divorced	1	High School and above	3
Widow	1		
Religion		Occupation	
Hindu:	5	Employed	2
Muslim:	1	Unemployed	4
Type of seizures		Current treatment:	

Generalized:	4	Allopathy & Amulets:	1
Complex partial	2	Allopathy, Amulets & traditional medicine:	2
		Allopathy & traditional medicine	1
		Amulet & self-treatment:	1
		No treatment	1

Particularly in the outskirts of Kozhikode, close family ties, traditional beliefs, practices and communal living situations contribute to the experience of living with this stigmatized disease.

3.1 Amulets, “English Medicine” and Traditional medicine

Although Western medicine, known as “English Medicine,” is the main-stream treatment in Kozhikode, traditional and non- biomedical treatment options also flourish in the district. The general trend of mixing Western, traditional, and religious prescriptions are also considered common. Remedies from faith healers can include rituals, offerings, prayers, and tying of amulets. Depending on the type of traditional healers WWE consult, medicines can vary according to the healer’s indigenous system of practice. The strategies that people use to manage and treat seizures depend on the cultural beliefs regarding the disease.

For all six participants, achieving seizure control was the major impetus for seeking different types of treatment. During the interviews, it was evident that family members had a major role in the treatment decisions made by the participants given that different treatment options are available for PWE in Kozhikode.

All six participants had previously had amulets or were still wearing these. An amulet is a thick, long black string with a metal capsule in the center and is worn around the neck, waist, or arm. The amulets had been given by faith healers to protect them from evil forces and difficult

situations. Most of the informants did not know the contents inside the capsule. But according to participant #1: “the verses of Koran is written in a paper and put inside the capsule.” Participant #2 said: “There are certain herbs inside that [capsule].” Participant #4 explained: “my grandfather does black-magic and he gave it to me. I am not sure what it contains. He is not allowed to say that.”

Western medicine (“English medicine”) is sought initially by almost all PWE. Of the six participants, four of them initially consulted neurologists and took AEDs but discontinued the AEDS or did not take the prescribed dose of the medications. The other two participants decided not to seek any treatment or did self-treatment.

According to a traditional healer who has been treating PWE for more than 30 years,

They [adults with epilepsy] don’t come to us initially... they come only when English medicine stops working and then we have to slowly reduce those medicines and increase this medicine as both together can cause interactions....

Participant #2, a shy young woman who completed the 12th grade stated that she avoids group interactions and prefers staying at home always. She married a year ago and lives with her husband’s family. At the time of the marriage, her husband and his family were unaware of her seizures. She is taking traditional medicine and AEDs. Her AED dose was reduced by the traditional healer. She also has amulets tied around her body. She stated the following:

I have been taking English medicine for a very long time now... I am taking my medicines and still it [seizures] happens. It really became worse and that is why I am going to this healer now... Those medicines [English medicine] were reduced by my healer... I have not stopped that completely... You know, I have tried many things....

There was a time when I had so many amulets tied on my body that I found it hard to sleep...my family would bring something or the other and I will tie it and when I have a seizure, I get angry and I just pull it off....

3.1.1. Belief about cause of the seizures:

Myths and misconceptions about the disease continue to prevail in this society. All the participants were asked about their understanding of the cause of epilepsy. All the participants did not know the real cause of epilepsy. The belief that emerged as the most important factor in the cause of epilepsy is that it is the result of “evil doing” or a “divine curse.” Their responses about the cause for epilepsy were as follows.

Participant #1, a middle aged woman with elementary school education (4th grade), lives alone but her family who lives in the neighboring house, within the same compound, is very supportive and helpful. Her family restricts her from going for any functions or anywhere alone. When she was 13 years old, she had accompanied her younger sister to the hospital where she got lost looking for her father there. Her first seizure was on that day. She says:

They say I got scared that day.... They also say I am possessed.... They [family] have done various types of treatments for me. Mother has taken me many places. Everyone says it is hard to cure. I just want a cure for this.

Her mother who is 65 years old, and illiterate says:

This is possession. We have tried everything for her. They say she has two kinds [of evil spirits] in her and they are both joined. Now it is hard to separate those two and [make them] leave her. That is why it is so hard to cure this.

Participant #2:

I don't know. I want to know the same, what is the reason? We have done everything, all offerings, everything.... All the tests done have come out normal. Then what is this?

Although she says that the reports of her diagnostic tests are normal, a note written by her neurologist on her prescription reads that her EEG was 'abnormal'. No such details were available from any other participant.

Participant #3, a vibrant, outgoing young lady with a 12th grade education, is very strong in her religious faith and rituals. She and her family believe that a deity resides in their house. The family practices strict rituals to please this deity. According to her family, her first seizure, which occurred at age 10, was 'very long'. They explained that she 'woke up from death' after 23 days in the intensive care unit. Her father is mentally ill and has been unemployed for over 22 years leaving her brothers to work for daily wages to be the bread winners in the family. The construction of their house is half completed with the family having lived at minimal living standards for many years. Her response was:

I used to have a playmate from my childhood. That family does not like anything good happening to anyone. I am not sure if they did something. You know, they can do black magic. We know that something like that was done to my father. We think that they did something to me.

Participant #4 has a Master's of Business Administration degree and has generalized seizures during sleep. She and her family have concealed the history of epilepsy from her fiancé during marriage negotiation. She is now the mother of a two year old child and lives in her husband's

house along with her brother-in-law and his family, who are unaware of her seizures. She has seizures in her sleep and is currently on treatment from traditional healers.

If it is really a physical problem, there should be problems from childhood itself. Usually kids have this. I never had any problem as a child... I don't know if this is a possession, but I think I believe in that.... If there is God, there should also be an opposite force in this world. There is reason for everything that happens in this universe.

Participant #5, a 63 year old strong-willed, thin, frail lady grew up with a difficult childhood. She is illiterate and has worked hard all her life. She became a widow at an early age and brought up her children (who are adults now) all by herself, working for daily wages in the area where she lives. Because of her seizures, she has fallen in many places on multiple occasions, had multiple injuries, and the people for whom she works help her during these events. However, she refuses any treatment and says,

“They say I got scared about something.... There was a temple there and they thought it was something related to that temple... not really the temple, but its ruins... the person who tied the amulet on me said I was possessed with ‘*brahmarakhshas*’... I don't know what to believe.” (Brahmarakshas are evil spirits according to Hindu mythology).

Participant #6 has a fifth grade education and lives in a remote area of the district. A shy home maker, mother of four girls and grandmother of 5 children, she has generalized seizures and wears amulets and uses herbs and ghee (clarified butter) from a holy place. Her husband has had a stroke in the past and was on herbal medicines prescribed by tribal medicine healer. She said: “I don't know... Some people say it is because my blood pressure is low. But I know that my pressure is normal... They have checked that.”

Overall, the participants' ignorance and belief about the supernatural cause of epilepsy can directly affect the help-seeking behavior and the treatment they choose. The family member's understanding about the disease also plays an important role as the family members have a significant influence on treatment decisions.

3.1.2. Approaches to diagnosis:

The initial diagnosis of epilepsy in the participants was generally made by a primary physician in a local hospital where family members had taken the participants after witnessing the initial seizure. Later the participants were referred to the neurologist in a tertiary care government hospital within the district where the physician confirmed the diagnosis of epilepsy primarily through history taking. One participant had had an EEG and an MRI.

The participants approached the traditional healers and religious healers while they were still taking the AEDs that had been prescribed by neurologists given the goal of these women was to find a cure for their disease. Recounting one of the participant's first visits to the traditional healer, she said:

He asked many questions, looked into my eyes and mouth. He also checked my pulse and then he told me I had *Apasmaram* [epilepsy] and then he started me on his medicines... when I go again [repeat visit], he will do the same [examination].

When discussing how the participants access the traditional healers, one of the traditional healers noted, "These [adult] patients come to us with a diagnosis [of epilepsy]... They do not come to us with new onset seizures..." This particular healer usually accepts the diagnosis of epilepsy made by the allopathic physicians. He also added that there were times when he had sent his patients to the local clinic for tests such as EEG to confirm the diagnosis of epilepsy. Regarding

consultations with religious healers, all participants related that these healers listen to an account of the symptoms manifested by the patient, accept the diagnosis made by the allopathic physicians or healers, and conduct astrological calculations based on the patient's horoscope before suggesting remedies.

3.1.3. Seizure management and treatment:

Four of the participants reported that they had generalized convulsions. The family members who spoke as general informants for these participants provided the information regarding the care during seizure. Participant #1's mother said,

... I used to keep pieces of coconut husk here [in the house). During (her) seizure, we just insert one piece into her mouth, so that she won't bite her tongue.... Nowadays, I don't get enough of coconut husk and you see, I cannot put anything hard, like spoon in her mouth... that is dangerous because it may break her teeth....

Participant #6's husband reported:

... [During a seizure] what we do is, if we have keys with us, we will place that [keys] in her palm and make her hold these. And then, there is this ghee [which is clarified butter] from [a] holy place. We smear that on her forehead and then... my daughter will burn certain herbs and make her [the participant]) smell that [the fumes]....

Placing an iron key in the palm of a convulsing patient is a usual practice that is done in this community based upon the belief that iron can shackle the evil spirit that causes the person to have seizures, and thus gripping the iron keys can stop the seizures.

Despite such beliefs and practices, the majority of participants chose English medicine, AEDs as their initial treatment. The majority of participants had been prescribed Lamotrigine and Sodium Valproate. At the time of the study interviews, these participants were receiving concurrent treatment from the traditional healers who tapered down the dose of ‘English medicine’ so that they could increase the dose of traditional medicine (a mixture of Ayurvedic medicines and their ‘secret’ herbal formula for treatment). None of these participants had completely discontinued their AEDs although they were not taking the prescribed dose. Their physicians were unaware of the changes that the traditional healers had made to prescribed dosage of AEDs.

All participants, irrespective of religious beliefs and faith had conducted rituals, prayers, and offerings as suggested by the faith healers as well as those that were in accordance with their convictions. In conversations with the traditional healers, they related the importance of understanding the connection between psychological stress and seizures and of accepting the participants’ ritualistic practices as part of their treatment. One healer said:

“If they believe in doing any kind of rituals, we encourage them to do so, because that is the first step in stress relief. If not, that [stress] will always stay in their minds and the treatment we do will not be effective. As you know, if stress is increased, they can have seizures.”

All the participants were asked about the most effective treatment for their seizures. Their responses were as follows:

Participant #1: “Oh, I will never completely stop these medicines [English medicine]....” She has also received treatment from traditional and religious healers in the past and she says: “he

[religious healer] did give me pills along with this [English medicine] but he asked me not to stop my medicine. They all [healers] say I should not stop this medicine [AEDs].”

Participant #2: “...it is this one [English Medicine].”

Participant #3: “he [traditional healer] is my God now....”

Participant #4: “I am not sure [what is most effective]. I had this amulet even when I was on that [English medicine] and I think it became worse when I removed it [amulet].... Until I went to this healer, I was having (seizures) twice or thrice a month and now it is once a month.”

Participant: #6: “probably placing keys....”

3.1.4. Perceived barriers in continuing allopathic treatment

The majority of the participants had been prescribed allopathic medical treatment (AEDs) and had been taking these drugs for several years. Four of the participants were on combination of Lamotrigine and Sodium Valproate, two effective but expensive AEDs. Many of the participants had had trouble continuing with AEDs even before they began seeing the traditional healers who reduced the dosages. The issues that the participants encounter in continuing their treatment with AEDs included financial constraints, medication side effects, stigma, ready availability of the medication, dependence on family members to obtain these medications and lack of prioritization.

Generally, the most discussed barrier to continuing treatment related to the cost of the AEDs. However, most of the participants managed to obtain the medicines through their family members who provided the money and facilitated the logistics associated with getting these

drugs. Participant #1 noted: “I don’t know if this (seizures) will be cured... we’ve been spending money on this for a very long time now.”

To deal with the cost of the AEDs and lessen the burden on the family, another participant resorted to drastic measures. She says:

[My] brother buys that [AEDs] for me... I have medicines which I have to take in the morning and night. I skip the morning dose and keep it for the following night...no one here [at home] knows about it. Mother doesn’t know that I am doing this. I hope it will be less trouble for them. And then, everything is in God’s hands. She continues: “I was supposed to see my doctors after 6 months. I told mother, ‘it was not 6 months, he told 12 months.’ And when my doctor asks, I just tell him I was away... I was in my relative’s house.

The participant had discontinued her studies to reduce the financial burden on her family members who were supporting both her schooling and her treatment.

Regarding the availability of the AEDs, Participant #1 related:

“...it is hard to get this one it seems [Lamictal]. I have had to stop it because of that [unavailability of the AED]. I went to the doctor again and he told me I should not be stopping it [Lamictal]... I have to go to [the next town] to get this one [pointing to Lamictal]. They [pharmacy in the neighboring town] get it for me. But I have to go [to get the medicine]...sometimes my brother will go and get it for me”

A similar response came from Participant #2’s mother who continues to take her daughter to the doctors although she has been married for a year now. “We won’t get these medicines [AEDs] here [at the place they live]. So I usually get it for her from there itself [near the

hospital].” The hospital is approximately 25 km from where the participant lives and requires a long trip that involves taking two buses.

Another of the participants who had generalized seizures had reduced her AED dose herself because of the side effects of the drug. Her medication dose had been increased because of the increase in her seizure frequency but she says the increased dose makes her sleep long periods of time causing her to be non- functional during the day. Multiple injuries, including scars on her face and burn marks on her forearm, were related to falls associated with her seizures. When asked if she spoke with her physician about the side effects of the medications, she said:

“...even if I go again, they will say the same thing [to continue]. I will have pay for the consultation fee. It will be around Rupees. 200.* Where is the money for that?”(*USD \$1 = ~ Indian Rupees 60). The financial constraints for this participant had forced her to not make a trip to the hospital, which led her to adjust her medications on her own.

Participant #4 talked too, about the side effects of AEDs and her aspirations in-spite of living with seizures “... [Life] without allopathic medicines... when I was on it, I was sleep-walking....” She was asked if she spoke with her doctor about the side-effects and to which she replied: “...my healer knows about it [the side-effects of AEDs] and he gave me medicine to help and I feel much better now...” The neurologist who prescribed this medication remains unaware of the medication side-effects that this participant was experiencing.

Dealing with the stigma related to treatment-seeking is another issue that these participants face. Fear of stigmatization reverberated in all the conversations with the informants.

Although the participants do everything to hide from others that they are living with seizures, they take extra precautions when they seek any type of treatment. Participant #3 recounted:

“My brothers have a lot of friends. So if we see them [during doctor’s visit], I tell them some of my relatives are there.... We will walk a little farther and come back a little later.... If I am getting hospitalized, my father’s sister will come along with me and ask us to tell everyone that she was hospitalized, not me...”

Participant #5 who has been living with seizures for many years and has refused to seek any kind of treatment says:

“I never had such thoughts [of getting treatment for seizures] at that time. What is there to think of me? For me, my children were most important... my eldest son was always sick.... We took him everywhere [for treatment]... How could I think of myself or my sickness then... and, we [would] need someone with us [accompaniment] if we should go for any treatment. If there is no one, where will I go? What will I do? I cannot always depend on my neighbors... If I have to die with this, it’s fine. I am 63 now. Why should I worry about this now? I think only about my second son now. He should have a good life...”

3. Discussion:

Six women with epilepsy living in the Kozhikode district, Kerala, South India, completed in-depth interviews about living with epilepsy and its treatment. To the best of our knowledge, this is the first study to describe the lives of women living with epilepsy in India, the treatment that they have, and their perceptions of epilepsy and its treatment. Our study findings are congruent with studies done in other developing countries where misconceptions and ignorance

prevail about the cause and management of epilepsy [4,29,30]. Our study also provides a foundation from which to develop future robust and culturally appropriate interventions to reduce the epilepsy treatment gap in Kerala, and improve the quality of life of those afflicted there.

Based on the findings of this ethnographic study, a number of factors can contribute to the treatment-seeking behavior of Indian women diagnosed with epilepsy and their response to treatment. First, the perceived cause of the disease and the traditional beliefs can affect the treatment the women seek. The cause of the disease was attributed to supernatural influences suggesting an educational gap among the six participants and their families in our study. The interviews also reveal a lack of understanding of expectations and outcomes of appropriate treatment. The treatment decisions were made based upon their perceptions about the disease and the advice given by others, especially family members, rather than from health care professionals. Educational intervention tailored to the needs of these women and their families is of the highest priority if they are to be helped to make appropriate treatment decisions. Second, because of the nature of the disease, these women and their families had trouble with the label of epilepsy and the stigma associated with this chronic disease. The participants' responses reflect the beliefs about the disease and the stigma that exists in the community, suggesting the need for community-based educational intervention to improve public awareness and understanding of epilepsy and its treatment.

Another barrier to receiving appropriate treatment among women in our study was the incidence of side-effects from the AEDs. Instead of discussing with the neurologists their concerns and issues related to the side effects of the drugs, the women either switched treatment or reduced their AED dosage on their own. During the initiation of treatment and often

thereafter, health care workers, including physicians and nurses, should create an atmosphere in which these patients are encouraged to discuss any problems they face related to taking their AEDs. Empowering these women by giving appropriate information and counseling about the common side effects associated with AEDs would help them take responsibility for their own health and improve medication adherence and treatment outcomes.

Poverty and poor health are inextricably linked. Although the Government of Kerala has taken steps to eradicate poverty among women [31], the cost of doctor's fee, drugs, and transportation can be devastating to this vulnerable population and can exacerbate the poverty given the annual cost of epilepsy per patient in India is approximately USD \$344[32]. The health care system and policy-makers could consider re-visiting the health care policies and take measures to reduce the expenses related to treatment for epilepsy. Furthermore, a study conducted in Kozhikode among primary care physicians from 14 districts for the purpose of understanding epilepsy management behavior revealed that the most common AEDs used are Valproate and Carbamazepine. These are comparatively the more expensive AEDs [24]. The majority of the participants in this study were on Valproate. Thus a goal for the treatment for epilepsy should be treatment that is economically sustainable and easily accessible.

A major factor in ensuring positive outcomes and improving the health of individuals in a community is by empowering members in that community. Although there are many factors that act as barriers to effective treatment, utilization of available community resources can play a vital role in reducing the epilepsy treatment gap. Strategies may include involving traditional and religious healers who share a good rapport with the patients. Grass root health care workers through organizations such as the Accredited Social Health Activists (ASHA) are voluntary female workers who ensure that primary health care is accessed by the rural poor. They play an

important role in Kozhikode and the entirety of Kerala to promote immunization, smoking cessation and mental health [33-35]. However, none of the participants in this study reported any interactions with these health care workers. Training given to these women to identify women with seizures, creating awareness, educating women and their families on seizure management, and referring them to an appropriate epilepsy clinic might help. Nizamie et al (2009), in a study done among tribal communities in Ranchi, India, where the treatment gap was 95%, found that educating and involving traditional healers and other community health care workers in referring patients with epilepsy to appropriate treatment, reduced the treatment gap considerably[36].

Cultural awareness and sensitivity is important for all health care professionals who provide care to people with epilepsy. It is important that these professionals understand the culture and take into consideration the person's belief system when treating a disease like epilepsy. The traditional healers in Kozhikode acknowledged the people's belief and encouraged them to complete religious rituals and prayers prior to commencing with the healer's treatment. This, they believed, reduced the psychological stress in the patients, leading to a reduction in seizure frequency in many people and improving their adherence to their treatment. All participants seemed to have a more personal connection with the traditional healers than with main stream health care providers. Cultural sensitivity and competency of the health care professional can facilitate their ability to address most of the problems faced by these women, including those related to compliance. Understanding and accepting peoples' beliefs and customs regarding the disease and providing culturally appropriate education and guidance may lead to effective and sustainable health outcomes. Explanations that consider the patient's perception and their thinking may make them feel satisfied and empowered to be more responsible for their

health. These measures might reduce the treatment gap, decrease seizure frequency, and thereby improve quality of their life.

Previous studies from Kerala have reported gender-based disparity towards women with epilepsy [17, 18, 37]. In this paper, the authors have detailed how six women with epilepsy and the treatment gap in Kerala, perceive the disease and its treatment. In addition the researchers found that there are other factors, including societal, financial, and personal issues related to living with epilepsy that contribute to the epilepsy treatment gap. Those findings are reported elsewhere (von Gaudecker et al.,(xxxx), *Journal of Transcultural Nursing; Journal of Nursing Scholarship*).

Conclusion

This study, the first of its kind in India, has explored the beliefs and perceptions of WWE and their families regarding epilepsy and its treatment. There is a need for culturally appropriate, individual and community-based interventions to educate and treat women with epilepsy in Kerala, India.

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Running Head: WOMEN WITH EPILEPSY IN SOUTH INDIA

CHAPTER FIVE

Manuscript Two

A Struggle to Balance: The burden of epilepsy for women living in Kerala, South India

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Abstract

Purpose: The burden of living with epilepsy worsens when this chronic disease is inadequately treated, especially in the developing countries where resources are few. This study describes the experience of women living within the epilepsy treatment gap in rural South India. **Design:** This qualitative ethnographic study was conducted using participant observation and in-depth interviews with six participants. Data were analyzed using thematic analysis. **Findings:** The findings shed light on the physical and emotional scars related to living with epilepsy and the coping mechanisms the participants adapted. The participants believed the disease was caused by evil spirit, their fate, or God's will, and that they considered epilepsy to be something that had to be accepted quietly and concealed except to a limited few. **Conclusion:** The paper offers insights into transcultural health practice among women living with epilepsy in South India that may be useful in providing these women holistic care.

Key words: transcultural health, focused ethnography, South India, epilepsy, treatment gap, struggles, coping

Introduction

Epilepsy with recurrent unprovoked seizures is the most common chronic neurological disease affecting individuals worldwide (World Health Organization, 2012). In addition to living with the uncertainty of seizures, epilepsy causes significant psychological, social, and economic burden for patients and their families. The International League Against Epilepsy (ILAE) and the World Health Organization (WHO) estimate that about 50 million people are affected worldwide, with 80% of them living in developing countries (World Health Organization, 2012). Although effective treatment with anti-epilepsy drugs (AEDs) is available and long-term remission or freedom from seizures is possible, many people with epilepsy (PWE) in the developing world live without adequate and appropriate treatment (Meyer et al., 2010). This phenomenon, referred to as the epilepsy treatment gap (ETG), is the number of people in a given population (expressed in percentage) who require medical treatment but do not receive it at a given point of time (Kale, 2002; Meyer et al., 2010; Satishchandra et al., 2001; World Health Organization, 2012).

Background

Epilepsy in global context

Epilepsy is one of the oldest diseases known to have afflicted mankind and throughout the ages different faith and belief systems have given different meanings to the disease. The disease, once referred to as the 'Sacred Disease,' although often anything but sacred in nature, was reasoned by Hippocrates in fourth century BC as not caused by supernatural causes (Eadie & Bladin, 2001; Ricotti & Delanty, 2006). In contrast, the Bible includes verses that specifically name faith and prayers as the only way to treat epilepsy (Mark 19: 14-29). In his book "The

Falling Sickness” describing the history of epilepsy in the Western world, Temkin points out that the disease was closely related to the history of neurology and the history of magic ((Temkin, 1971).

Given the advances that have been made in the treatment of epilepsy and the changes that have occurred in the perceptions of those with epilepsy, the experience of living with epilepsy is different today than in the past. The experience of living with epilepsy is closely associated with one’s culture. Examples follow: In China and Vietnam, the disease is considered as an outcome of neurological events and bodily imbalance of the five elements in the major organs. Thus, the disease places major restrictions on marriage prospects for women in these countries (Jacoby et al., 2008). In Haiti, where Voodoo is a popular religion, epilepsy is considered to be the possession of Voodoo spirits (Carrazana et al., 1999). In the Maya Tzeltal community in Central America, epilepsy is believed to result from animal spirits that serve the forces of good and evil and people with chronic epilepsy are considered witches (Carod-Artal & Vázquez-Cabrera, 2007). In Bolivia, the disease is considered a result of the failure to observe a period of fasting. (Bruno et al., 2011). In Ghana, epilepsy is thought to be contagious, leading to PWE being highly ostracized (Adjei et al., 2013). Based on a study conducted among university students, in Jordan, men are discouraged from marrying women with epilepsy as the disease is considered to be caused by an evil spirit and is considered to be a punishment from God (Hijazeen et al., 2014).

Epilepsy in India

The Indian equivalent for epilepsy is *apasmara* and was described by Charaka, an Ayurvedic physician in the ancient (around 1000 BC) Vedic literature as: “Epilepsy is a disease

characterized by derangements of the mind and memory. Victims of the disease experience disturbance of loss of consciousness and undergo all kinds of ugly scenes (convulsive movements).” (Tripathi, Maheshwari, Jain, & Padma, 2000b) A person with epilepsy was treated similarly to a person with insanity (Manyam, 1992; Somasundaram, 2001; Tripathi et al., 2000b). According to Ayurveda, epilepsy is thought to be caused by imbalance or disturbances of the ‘*doshas*’ or humors (Saxena & Nadkarni, 2011; Tripathi et al., 2000b).

In India, untreated epilepsy is a major public health concern because of the sheer numbers of the population, the devastating social consequences and poor health outcomes (A. Meyer et al., 2010). Based on a prevalence rate of 5 per 1000 and an incidence rate of 50 per 100,000 per year, India, with over 1 billion inhabitants, has at least 5 million people with active epilepsy at any time (Radhakrishnan, 2009; Radhakrishnan, 2010). Moreover, India has an estimated epilepsy treatment gap (ETG) of 22-90% (Meyer et al., 2010).

In addition to poor health outcomes, epilepsy causes a significant economic burden. In their study, Thomas and colleagues (2001) described significant economic implications: health care burden, mortality, and lost work productivity. The treatment of epilepsy also results in both direct and indirect costs. These investigators reported that the total cost per case of epilepsy amounted to U.S. \$344 per year (equivalent to 88% of the average income per capita in India), and the total cost for the estimated 5.5 million cases resident in India was equivalent to 0.5% of its gross national product (Thomas et al., 2001).

Women with epilepsy in Kerala

Kerala, located on the southwestern coast of India, is often showcased as the model of development for the rest of the country, primarily because of the high social achievements

despite the weak economic base (Eapen & Kodoth, 2003). The state has the highest literacy rate in the country (94%), low infant mortality rate, (12 per 1000 compared to 50 per 1000 in India overall), and high levels of health and nutritional status of women and children (Kerala State Council for Science, Technology and Environment, 2014). Neurocysticercosis, caused by tapeworm infestation, which is the most common cause for acquired epileptic seizures in the country, is considered rare in Kerala (Cherian et al., 2014; Radhakrishnan & Satishchandra, 2005). In spite of these positive developments in Kerala, there is an ETG of up to 41% in this state (Radhakrishnan, 2010).

Stigma and discrimination associated with the disease can cause social disgrace and influence the way people deal with epilepsy. Furthermore, with pluralistic religious beliefs, social disparities and gender bias in India the ETG can be wider and struggles related to the disease even more pronounced, especially among women. In one study, Gopinath and colleagues (Gopinath et al., 2011b) reported that women with epilepsy (WWE) in Kerala have difficulty finding life partners and if these women do marry, they are at increased risk for divorce. In another study from Kerala, it was reported that fewer WWE, especially from the lower socio-economic background received treatment from tertiary care centers compared to men (Thomas et al., 2006)

Until 1999, epilepsy in India was equated with insanity under the Hindu Marriage Act of 1955 and the Special Marriages Act of 1958 (D'Souza, 2004). The Hindu Marriage Act applies to Hindus, Buddhists, Jains, and Sikhs. According to this Act, a person subject to recurrent attacks of insanity or epilepsy could not have a legally valid marriage because such a marriage could be declared null and void (D'Souza, 2004; Santhosh et al., 2014). In India, women continue to struggle because of these outdated laws. A study conducted in Kerala revealed that

55% of women in the study concealed the history of their epilepsy prior to marriage. A majority of those marriages resulted in separation, divorce, or another unsatisfactory outcome (Santosh, Kumar, Sarma, & Radhakrishnan, 2007).

Purpose

Given the challenges that WWE in India face, the purpose of this study was to describe the lives of WWE living in the outskirts of Kozhikode (a district in Kerala) who either receive treatment from traditional Indian healers, are not on any AEDs or who do not regularly take the AEDs as prescribed for them.

Methods

Design

This was a qualitative, descriptive, focused ethnographic study. Experiences of six participants were collected through participant observation and in-depth interviews, and analyzed using thematic analysis as described by Cohen and colleagues (Cohen et al., 2000).

Setting

Kozhikode (formerly known as Calicut) has a population of approximately 4 million people and is the third largest district in Kerala (Census of India, 2013; Osella & Osella, 2007). A majority of the district's population are Hindus, but people from different cultural and religious background, including Muslims, Christians, and Jains, live in Kozhikode. Although Muslims are not the majority here, the district is referred to as the Muslim capital of Kerala (Osella & Osella, 2007). More than 500 years ago, the Portuguese, Arabs, Jews, Chinese, and the Dutch traded with the rulers, making Kozhikode a historically important town (Kozhikode Corporation, 2014). The language spoken is Malayalam.

Ethical consideration

Approval was obtained from the university's Institutional Internal Review Board for Health Sciences Research (IRB-HSR 16858) of a major mid-Atlantic academic medical center and the Indian human ethics committee (#001/CUEC/CR/2013-14-CU). All participants were consented using the IRB-approved informed consent form. Participant confidentiality was maintained throughout the study.

Sample

Six WWE were recruited through purposive and snowball sampling to voluntarily participate in this study. All participants spoke Malayalam and lived in different parts of Kozhikode district. They were identified from two local traditional healer's practice or through word of mouth. All the participants were above the age of 18 years, had a diagnosis of epilepsy made by a qualified medical practitioner, and had been living with seizures for the past 2 years. They were either not on any anti-epilepsy drugs (AEDs) or not taking the AED as prescribed. Women who were unable or not willing to give informed consent or had a diagnosis of non-epileptic spells were not included in the study. All participants were from the lower socio-economic background and based on daily observations, it was evident that they lived under minimal living conditions.

Data collection

Data were collected from August to October 2014. Following informed consent, participants completed a basic demographic questionnaire that included information regarding age, family structure, and socio-economic background. During the consenting process, the first author began to build a rapport with each of the participants. The dialogue moved towards in-

depth semi-structured interviews conducted at each participant's home in the local language, Malayalam. The first author's primary language is Malayalam. She is a native of Kerala. All interviews were audio-recorded. All questions were open ended and elicited experiences of living with epilepsy. The initial interview lasted for a maximum of 100 minutes and follow up interviews lasted for 15-30 minutes. Each participant was interviewed up to 2- 3 times and over a 2-week period. Rigor and trustworthiness was ensured by respondent validation during the follow-up interviews (Barbour, 2001). Participant observation was conducted for a maximum of 2 weeks to understand the daily activities of each participant. The first author dressed in the local garments to avoid attracting attention. Sometimes, these visits consisted of social interaction such as tea with a participant, a general discussion with participant and her family, accompanying a participant to a local clinic for her father's health care needs, and visiting a participant at her place of work. No seizures were observed during the time of these interactions with the participants. The observations were recorded as field notes and triangulated with data from the interviews.

Data analysis

Participant demographics were summarized using descriptive statistics. To control for bias, all preconceived assumptions were written and discussed with members of the study team (Cohen et al., 2000). All interviews were transcribed verbatim and translated into English by the first author immediately after the interview. The data components for analysis were the field notes and interviews. The first author (JvG) reviewed the transcript and audio-recording multiple times to check for accuracy. For the ease of handling data and coding, analysis was conducted using NVivo 10 qualitative analysis software. The English transcript was re-read multiple times, moving between parts and the whole of data, in an iterative interpretive way throughout the

analysis process. Data were coded and grouped according to similarity and meanings to form categories and overarching themes (Agar, 1986; Cohen et al., 2000; Gadamer, 2004). The initial coding conducted by the first author was discussed with the remaining authors.

Findings

The six women who participated in the study lived in the outskirts of Kozhikode district and their ages ranged from 20 to 63 years (mean: 37.8 years). Five participants were Hindu and one was Muslim. Three were married, one unmarried, one divorced, and one widowed. One participant was illiterate, one had a graduate degree, two had elementary school education and others had high school education.

All the participants believed that the cause of their epilepsy was supernatural/doing of evil forces (possession), and their fate. Participants initially opted for allopathic medication and later switched to other types of treatment. Financial constraints, medication side-effects, and the desire to find a complete cure for the disease were a few of the reasons for changing treatment plans. They sought treatment and remedies from religious/faith healers and/or other local healers who prescribed a mix of Ayurveda and other 'secret herbal formulas.' Religious healing was an adjunct therapy combined with other forms of treatment. One participant was not on any treatment and one practiced self-treatment with herbs and special ghee (clarified butter) obtained from a holy place. At the time of this study, four of the participants wore amulets, given by faith healers to protect them from danger and/ or to reduce their seizures.

Six inter-related themes emerged from the data. They were: (a) Amulets, 'English' medicine and traditional medicine; (b) money is tight; (c) scarring and stigmatization; (d) adjust accordingly and live; (e) have to suffer; (f) live my life. This article elaborates on two of these

themes and describes the physical and psychological struggles of these participants living with epilepsy and the coping mechanisms adapted by them. The remaining four themes are described elsewhere (references: *Epilepsy & Behavior*; *Journal of Nursing Scholarship*).

Scarring and Stigmatization

Epilepsy is a disease that can affect an individual in multifaceted ways. The burden of living with this disease is complex. The theme ‘scarring and stigmatization’ that emerged from the data reveal the struggles the participants faced because of their seizures. Apart from the physical struggles related to the seizures, the disease can also cause psychological, social, and financial difficulties. Although a majority of the participants reported having an aura prior to the ictal phase (time of seizure activity), four participants had seizures that caused them to fall. They had sustained several scars and burns as a result of these incidents.

Participant # 2, a 20-year-old married woman who reported having both generalized and complex partial seizures said “Once I fell off from the bed and hit the corner of the cupboard and hurt myself...” With her complex partial seizures, she would wander and get lost. “I didn’t know what I was doing [during seizure]. They started looking for me. There is a place where many bicycles are kept for repair. I was sitting inside that place.” Regarding her injuries, another participant (#1) who has generalized seizures said:

Once my hand got burnt [shows a scar on her left wrist]... I fell near the [outdoor firewood] stove and the hot stick was on the floor. I fell on it and got burnt... All this [points to the scars on the left side of her face] is because of falls...I have hurt myself many times biting my tongue [during the seizure]... and then for few days, I find it difficult to eat...

Participant # 6, a middle aged woman has generalized seizures, described her experiences as: “I fall down... I don’t remember anything. You know, I have passed urine on myself... I lose consciousness. And then when I wake up they [family] tell me [about the event].” Although physical trauma during seizures was a concern for her, it was evident from her conversation that being incontinent caused her the greatest difficulty.

The impact of epilepsy goes beyond the physical injuries the seizures cause. Because of the uncertainty of their seizures in terms of the nature, timing and severity, all the participants reported that they lived a restricted life, which they contribute to the psychological impact the disease brings. Social interaction remained a taboo for all the participants and it had major impact on their social relations. Most of these women preferred staying at home, avoiding even family functions. Family members also restricted them from engaging in social activities for fear that they would have a seizure in front of everyone. Participant #5, a 63-year-old widow, is an illiterate and works as a daily wage laborer in the community where she lives. The sole bread winner for the family, she gave priority to her children’s’ education and health, ignoring her own health. She was not on any treatment for her seizures. Although she falls in her work place often because of her seizures, she refuses to accept that the disease affects her life negatively. About going to other places, she said: “I can’t go anywhere with this [seizures]... I don’t have the courage to go alone. No one knows when it [seizures] will happen...” Participant #1 lives alone but has a supportive family who helps her during her seizures and her activities of daily life: “They [her mother, brothers and two daughters] tell me not to go anywhere... I don’t go for any work... I cannot go for any function... nothing... And even if I go, I come back quickly...” The limitations in socialization and related frustration echoed in their responses.

Economic costs of treating epilepsy impose a considerable burden on these participants who are from lower socio-economic background. The financial burden was a major psychological stressor and cause for many inappropriate treatment decisions. While one participant decided not to seek any type of treatment, two other participants switched to less costly treatment options for their seizures because of financial constraints. Participant #3 verbalized that she would skip medications or delay doctor's appointments to save her family from spending money on her treatment. She commented:

My brother buys that [AEDs] for me... I have medicines which I have to take in the morning. I am not taking that. I keep it for the following night...no one here [at home] knows about it. I hope it will be less trouble for them [family]. And then, everything is in God's hands....I was supposed to see my doctors after 6 months. I told mother, 'it was not 6 months, he told 12 months.' And when my doctor asks, I just tell him I was away... I was in my relative's house....

Furthermore, none of these participants had health insurance and medical costs were paid out-of-pocket. All the participants and families lived under minimal living conditions, for example, in small houses or even unfinished house with mud floor, and with little or no furniture.

Evidently, the physical and emotional struggles the women experience created hidden scars that negatively affected their self-esteem. Two of the young participants verbalized their regret in getting married. Although participant #2 had good family support in her husband's house, had an understanding and supportive husband, and had completed her high-school education she still regretted her marriage saying,

It's [seizures] a burden for others... I wish I didn't get married... I think of my husband and wish so. Isn't it sad for him? He would have had a lot of dreams and it's all gone because he married me.

Participant #4, who had completed graduate education and has an office job, also spoke about her marriage stating:

What I really am upset or regretting now is that I am married, I wish I was not. Many people live unmarried. I am educated and could have lived with a small job... Even if someone physically hurts me, that's fine. But harsh words, it hurts me the most... Why can't he understand this [the disease] is not my mistake?

Arranged marriages, where elders in the family find appropriate matches for their children who are of marriage age, are customary in this community. Participant #3 who was engaged and was preparing for her wedding, verbalized that her only wish was that her fiancé and family would not come to know about her seizures. Her mother related that the reason for concealing the seizures was because they had lost count of the number of marriage proposals that had been called off because of her daughter's history of epilepsy. Participant #3 considers her seizures shameful and a burden for others and said: "...after it [seizure] happens, I feel ashamed to look at anyone..." Most of these responses from the women experiencing seizures reflect on their low self-esteem and the hidden emotional struggles that they undergo.

Another psychosocial impact of living with epilepsy in Kerala is the stigma that exists in the community. Field notes and the interview data show that the younger women have more struggles with stigma related to their disease than the older participants. One of the biggest concerns of WWE and their families was the worry of people in the community knowing about

the disease. Although many of the potential participants who were of marriage age refused to participate in this study ($n=8$), all the women who participated preferred referring to the interviewer (first author JvG), as their friend or distant relative when curious neighbors inquired about who the interviewer was. (The first author is native of Kerala and blended into the community). All the participants who were experiencing seizures at the time of their marriage concealed the history of epilepsy from their husband-to-be and waited until it was later discovered. Upon witnessing participant #1 having a seizure, her husband who was angry with her family for concealing the disease from him, took her to a physician but then divorced her after a few years.

Among the cultural practices in India, especially in the rural areas, is that after marriage the wife lives in the husband's home with his family. From observation and conversations, it was apparent to the interviewer that the husband of participant #2 along with his parents were understanding and supportive of the participant, although both the husband and his family also had been unaware of her seizures prior to the marriage. The understanding and support that participant #2 perceived may have been related to the fact that this participant's sister-in-law had started having fainting spells after marriage, which was a relief to participant #2. According to participant #2: "I was very scared in the beginning [when they found out about her seizures] and then I realized I am not alone...."

Participant #4, who also had an arranged marriage, had seizures during her sleep. Her family had also concealed her seizures during the marriage negotiations. She and her husband share the house with her brother-in-law and his family. Given this living arrangement, participant #4 requested that the interviewer avoid visiting her in her husband's house, where she lives as no one other than her husband had witnessed her seizures. Instead, she met the interviewer in her

parent's house, which was not far from her husband's house, and at her work place. Regarding her husband's attitude after he became aware of the participant's seizures, she explained:

[He] is very angry with my family [for concealing my disease] and often shows his anger on me... he tells me that my family cheated him.... Most of his relatives live far. I don't go there because I don't stay anywhere overnight... I don't want them to know [about the seizures]... He [husband] tells me that because of me he is not able to visit his relatives...

The forgoing reports from the participants clearly reveal the restrictions and psychological stress these women have in married life because of their seizures.

“Have to Suffer”

Coping with chronic diseases is stressful, especially when it is a stigmatized disease such as epilepsy. All participants considered the disease as their fate and as something they had to live with. Participant #1 related:

... Everything will happen according to our fate... It [seizures] doesn't happen every day, once in a while... Let everything happen according to my fate...its God's will... I say this and comfort myself... I have gone to all [healers]. They all say it is a difficult disease to find cure... We just have to suffer....

Because of the history of this participant's epilepsy, her daughter's marriage was delayed, which the participant attributes to her fate. Participant #6, who is a “stay-at-home” mother and does self-treatment for her seizures, piggybacked on the same sentiment when she commented: “This [seizure] does not happen every day... We have to live with what God has allowed in our life...”

Participant 4, who has nighttime seizures was more distressed by her husband's attitude towards her and believed that she had to suffer silently. She commented:

...he knows that I will not tell anyone about it [he being upset with her], because if I do, I will have to tell them about my seizures as well and I don't want that... We did not tell him before marriage [about seizures] and what right do I have to say anything now? I just have to silently face this...

Five of the six women reported that they had never spoken with anyone about their struggles with the disease. One participant commented: "this [seizures] is a burden for them [family], why should I worry them even more [by talking about it]? I have severe headache and heaviness of head after seizure and I try not to trouble them [family] even by saying that...." One of these participants occasionally spoke with her friend about her struggles with her seizures and noted that she often found relief in doing so.

Discussion

The struggles and coping mechanisms adapted by these women living in the epilepsy treatment gap in Kozhikode represent the cultural adaptive strategies relevant to this community. Interview data from women with epilepsy who are on effective treatment and living in the urban parts of the city may be different than that from the participants interviewed for this study who were living in a rural community.

Epilepsy is unpredictable and depending on the type and nature of seizures, living with the disease can be challenging. The logical first step in reducing the burden is to facilitate them in achieving seizure control. Seizure reduction can considerably improve the quality of their life (Birbeck, Hays, Cui, & Vickrey, 2002). At the conclusion of a health care delivery model study

to reduce epilepsy treatment gap in a tribal population at Ranchi, India, where there was a treatment gap of 95%, the simple involvement of community health workers, revealed that more than 75% of those experiencing seizures became seizure free (Nizamie et al., 2009). A similar intervention, involving an educational program by community health care workers about the causes of epilepsy and the treatments available to control seizures could reduce the treatment gap among these women.

Coping with a chronic stigmatized disease is always challenging. Myths and misconceptions about the disease and associated stigmas, that devalue and demean the condition, can negatively affect any efforts towards successful coping and thereby negatively affect the quality of life of those afflicted. Individuals' understanding about their disease is equally important. Involving community health workers who share the same life experience and are from the same society to serve as bridge between the health care providers and the patients, may help in promoting better health outcomes for women with epilepsy in India.

Living with epilepsy for women in Kerala, India means dealing with stigma, societal restrictions, worry about recurrent seizures, and low self-esteem. The influence of cultural health beliefs of individuals and those within the community can affect the way in which an individual copes with epilepsy. Concealing the history of epilepsy was the participants' way of coping with the fear of stigma related to the disease. Additionally, to conceal the disease because of its unpredictability, most of the participants practiced social isolation – a practice that was encouraged by their families. The primary reason for concealing the disease relates to the negative attitudes towards the disease that prevail in this community. These in turn contribute to the societal restrictions and low self-esteem among these women.

The major hurdle for the women in this study was the financial burden related to treatment with AEDs. The participants were from lower socio-economic background and had to cover the cost of treatment out-of-pocket, which posed an enormous burden for them and their families. The Government of Kerala has initiated a commendable program to eradicate poverty and women empowerment in the rural areas. The program promotes self-help groups and micro-financing (Kadiyala, 2004a). Similar strategies to make treatment affordable (for example: the use of generic or low cost AEDs) and accessible could be considered for women living in this community thus empowering these women to seek appropriate treatment.

Conclusion and implications for practice:

This study has implications for designing culturally appropriate clinical interventions to reduce the epilepsy treatment gap in Kozhikode and to promote educational interventions to create awareness about epilepsy there and eradicate stigma. Educating WWE in Kozhikode that epilepsy is a physiologic condition of neuronal outbursts has the potential to allay the notion that the disease results from evil spirits. Such an educational program could help to de-stigmatize the disease in this community. Health care administration and social support organizations could facilitate this intervention. Making care affordable, accessible and confidential could also help the WWE in Kozhikode to come forward for appropriate treatment. Furthermore, empowering these women to take responsibility for their own health, to speak for their rights, and to use AEDs could improve their health outcomes.

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CHAPTER SIX**Manuscript Three**

Living in the Shadows - Women with epilepsy and its treatment gap in Kerala, South India

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Abstract:

Purpose: To describe the lives of women with seizures living in the outskirts of Kozhikode (a district in Kerala, South India), who either receive treatment from traditional Indian healers, are not taking any allopathic medications (anti-epilepsy drugs), or who do not regularly take allopathic medications as prescribed for them. **Design:** A qualitative descriptive focused ethnography was conducted with six participants recruited through purposive and snowball convenience sampling. **Methods:** In-depth semi-structured interviews, participant observation, and field notes were used to understand the phenomena studied. Data were analyzed using thematic analysis. **Findings:** Six interrelated themes emerged, although this paper focuses on the social and family struggles related to living within the “epilepsy treatment gap” and the participants’ aspirations. The three themes discussed are ‘money is tight,’ ‘adjust and live accordingly,’ and ‘live my life.’ **Conclusions:** Ethnography was an effective way to understand the cultural context in which the study participants live with the epilepsy. Educating women with epilepsy and their families about its cause and appropriate treatment requires that nurses and other health care providers work together and empower these women to overcome the hurdles of living with this chronic disease in resource poor countries.

Clinical Relevance: It is important to understand the health beliefs and meaning/understanding that women give in their experiences of living with the chronic stigmatizing disease of epilepsy, particularly in developing countries like India where epilepsy is a major problem. Such an understanding could help develop culturally appropriate interventions.

Key words: Focused ethnography, epilepsy treatment gap, women, South India

Introduction

For centuries the lives and treatment of people with epilepsy (PWE) have been shrouded in ignorance, myths, and superstitions. It has been often cited that “the history of epilepsy can be summarized as 4000 years of ignorance, superstition, and stigma followed by 100 years of knowledge, superstition, and stigma” (Kale, 1997). Today epilepsy remains a stigmatized disease, affecting the quality of lives of PWE and their families. The strange and seemingly unnatural symptoms continue to give epilepsy the dubious honor of being a highly discriminated disease. Unlike other stigmatized chronic diseases, because of the unpredictable, sudden, and disruptive nature of the seizures, the outward manifestations of epilepsy cannot be concealed (Jacoby, 2002). Along with the physical challenges, PWE also have to go through the psychosocial impact of living with the disease.

In spite of being one of the most common neurological diseases worldwide, epilepsy remains undiagnosed and undertreated in many countries. It is estimated that of the 50 million PWE world-wide, 80% live in developing countries where resources are limited, and belief systems and practices are outdated regarding the treatment of this disease. Studies have projected that the majority of the PWE have a good prognosis for control of symptoms with appropriate anti-epileptic drugs (AEDs) (Meyer, Dua, Ma, Saxena, & Birbeck, 2010; Wang et al., 2008). However, most PWE in the developing world live without proper treatment, a phenomenon called “treatment gap” (TG) (World Health Organization, 2012). Treatment gap, expressed in percentage, is the number of people with a disease who need treatment but do not get it (Kale, 2002).

In 1997, the International League against epilepsy (ILAE), the World Health Organization (WHO), and the International Bureau for Epilepsy (IBE) jointly initiated the

“Global Campaign against Epilepsy: Out of the Shadows” to improve the acceptability, treatment, services, and prevention of epilepsy worldwide (de Boer, 2010; World Health Organization, 2015). Since then there has been active discussion about eradicating the epilepsy treatment gap.

Living with a chronic stigmatized disease such as epilepsy can negatively affect the quality of life of those afflicted and when left untreated, the situation can worsen posing a critical public health issue (Meyer et al., 2012). In India, a reported treatment gap of 22% among the urban population and 90% in the rural population exists (Meyer et al., 2010; Santhosh et al., 2014). Studies have also reported two major categories of treatment gap: (a) people who do not seek any treatment for seizure control and (b) people who initially seek treatment through anti-epilepsy drugs (AEDs) and later opt out (Das et al., 2007; Radhakrishnan, 2009). However, there are no known studies describing the experience of living with epilepsy and its treatment gap.

The prevalence (5 per 1000 people) and pattern of epilepsy in Kerala, South India, is comparable to that of developed countries (Radhakrishnan et al., 2000c). Yet, an average epilepsy treatment gap of 38% is reported in Kerala (Radhakrishnan, 2010). In spite of its low economic growth, Kerala, the South Western coastal state, is heralded as the most developed state in India and historically, the health status of women in this state has been considered superior compared to other parts of South Asia (George, 2011; Thresia & Mohindra, 2011). However, the struggles of women living with epilepsy are comparable to those of any other state in India and these women undergo many unexplained challenges compared to men. Arranged marriage is practiced in Kerala and women in Kerala consider marriage as their primary goal in life. Leading a happy and contented family life is of utmost importance for them (George, 2011).

One of the major problems women with epilepsy face is the inability to find a husband (Santosh et al., 2007). Compared to men, fewer women, especially those in lower socioeconomic groups, receive treatment from tertiary care centers for their epilepsy (Thomas et al., 2006).

The purpose of this study was to describe the lives of women with epilepsy living in the outskirts of Kozhikode (a district in Kerala) who have seizures/fits and who either receive treatment from traditional Indian healers without any allopathic medications (anti-epilepsy drugs) or do not regularly take allopathic medications as prescribed.

Methods

Design

Using interviews and participant observation, this study describes the experience of women living with epilepsy and its treatment gap in Kozhikode, Kerala, South-India. This focused ethnography was useful in understanding the beliefs and practices in relation to this disease and, by extension to health in general, in this community (Savage, 2000).

Setting

With an area of 30.61 Sq. Kms and a population of approximately 4 million people, Kozhikode (Figure 1) is the third largest district in Kerala (Census of India, 2013). The district is home to Hindus, Muslims, Christians, and Jains. People from other states in India like Gujarat, Bengal and Bihar have also settled here. The language spoken is Malayalam.

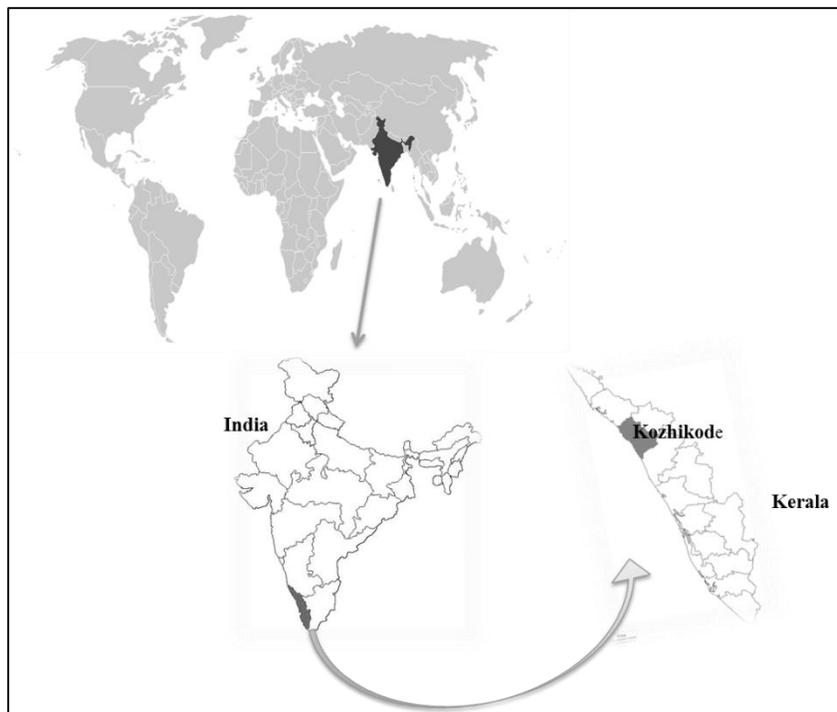


Figure 1: Kozhikode district in reference to Kerala and India.

Data Collection and Analysis

The study was approved by the institutional review boards of a major Mid-Atlantic academic medical center (IRB- HSR# 16858) and the Indian human ethical committee (#001/CUEC/CR/2013-14-CU) before any data collection began. Recruitment took place between August and October 2014. Participants were recruited through purposive and snowball sampling from the traditional healer's area of practice and through word of mouth among the women. Prior to the initial visit to a potential participant, the investigator contacted the woman by telephone, briefly explained the study, and obtained an appointment to meet her in person. The majority of the women stayed at home and did minimal activities outside of the home. Participants lived in different areas of the district. The investigator visited each participant at home over a period of two weeks and all interviews were conducted at the participants' homes.

Data consisted of field notes, interviews, and relevant demographic data. Contexts and cultural meaning of what was observed were included in the field notes that were written immediately after each visit to the participant. The first author (JvG) is from the area and shares some of the cultural background of her participants. All interviews conducted in native dialect, Malayalam were audio recorded, transcribed verbatim, translated to English by the first author, and transferred into NVivo 10 software (NVivo, QSR International, version 10). Steps of analysis were guided thematic analysis by Cohen, Kahn and Steeves (2000). The transcripts were read multiple times for data immersion for line by line analysis and data reduction to developing categories and themes based on the meaning and experience of living with epilepsy (Cohen et al., 2000). Categories and themes were reviewed by the other authors of this article. Rigor and trustworthiness were ensured by respondent validation during follow-up interviews with participants and de-briefing (Cohen et al., 2000; Lincoln, Y & Guba, E, 1985).

Results

A total of 6 women diagnosed with epilepsy and living in treatment gap from the outskirts of Kozhikode district were enrolled. The participants' ages ranged from 20 to 63 years (mean 39.5; SD 17.87). One woman was unmarried, one widowed, and one divorced. Their years of education ranged from 0 to 17 years (mean 8.3; SD 6.34). One participant was employed as an office staff member in a local business firm and one participant worked as daily wage laborer. The others were not employed at the time of the study. The religion of the majority of the participants was Hindu, one was a Muslim. The length of time participants had been living with seizures ranged from 4 to 42 years (mean 21.5 years; SD 15.00).

Participants and their families believed that epilepsy was caused by certain supernatural causes, including possession by evil spirits. All the participants sought treatment from religious

healers from Hindu or Muslim backgrounds. Religious healing was sought as an adjunct to allopathic treatment and traditional medicine. However, one participant had sought only religious healing in the past and was not taking any kind of treatment at the time of this study. Of note, in the Indian culture there is no stigma in seeking treatment for epilepsy from these healers as they provide treatment and ritualistic remedies for various kinds of problems, diseases, disorders, and family or individual issues.

Six interrelated themes emerged from the data. This paper elaborates on three of those themes, describing the financial and societal consequences, and aspirations of these women with epilepsy. The other themes regarding beliefs about causes and treatment for their disease, and the processes and coping strategies adopted by them are explained elsewhere (Reference: Epilepsy & Behavior; Journal of Transcultural Nursing).

“Money is tight”

Chronic diseases lead to enormous financial burdens for both the individuals with the diagnosis as well as their families. All the participants in this study came from a lower economic background and the majority of them lived under minimal living standards. All participants except one (who did not seek any treatment) depended on their family for financial support. Of the six participants, four were taking medicines prescribed by traditional healers (traditional medicine) and a reduced dose of their prescribed allopathic anti-epileptic drugs (AEDs). Participants did not have health insurance and paid out-of-pocket for their health care expenses. They explained the cost difference between the two types of medications. Depending on the type of AED they were taking, these medicines were 10 to 15 times more costly than traditional medicines. More frequently than not, buying these AEDs was a financial burden for the women

and their families. Showing the pharmacy receipt to the interviewer, one of the participant's family members explained:

“...see this, for three days' supply of these medicines [AEDs] it costs rupees 95*. But for the other medicine [traditional medicine from the healer], we pay rupees 40 for one month's supply. And there [at the healer's], if we don't have the money now, we can even pay it next month....” (**1USD*≈~ 60 *Indian rupees*).

The reduced cost of traditional medicines and concession from the healer was considered a tremendous help for this family.

Participant 3 lived with her parents and brothers. Her brothers were daily wage laborers and the primary supporters of the family. The construction of her house had been left unfinished for the past 22 years and the family lives with bare minimum living conditions. The bricked house was not plastered; windows were without grills and kept closed with plastic sheets. The only furniture in the house was a cot and two plastic chairs. The kitchen, which was outside the house was a raised platform of mud, covered all four sides with plastic sheets. Snakes and rodents were frequent visitors inside and around the house.

Living with epilepsy for the past 13 years, participant #3 has had to make difficult choices in her life. Following her first seizure (probably status epilepticus) she had to be hospitalized for 23 days in the intensive care unit. Unable to afford the treatment, the family had to rely on people in the community to raise funds to pay the hospital bills. The participant has been on daily medication for her seizures since her hospitalization. She discontinued her education at 12th grade as her family could not afford it. According to the participant, a full day is required for her to visit the doctor's office because of the travel time from her home to the

hospital. That distance is approximately 30kms, and involves unreliable bus transportation. The time the trip takes is further complicated by waiting time at the hospital. Because of time and the expenses related to travel, the participant has skipped doctor's visits multiple times. In addition, the medications for her seizures are purchased by her family and she has skipped doses of her AEDs so that she could stretch out her medication supply for a longer duration. She explained:

I have to take medicine [for seizures] in the morning and night. I am not taking it [the morning dose] and I keep it for the following night. I take medicine only in the nights. No one here [at home] is aware of what I am doing. My hope is that this will reduce their [family's] burden of buying medicines for me. And then, everything is in God's hands....

Participant 5, a widow who is illiterate, works as a daily wage laborer. She was the only bread winner within the family until her children grew up. She has had multiple falls and injuries because of her seizures but refuses to seek any treatment because of the cost. Her children were always her priority and she believed that spending money and time for her health needs was "unimportant and irrelevant."

Participant 1, a middle-aged woman with an elementary school education, depended on her family and the 'giving mentality' of the community to help with her day to day needs. Her family does not want her to go out anywhere alone for fear of unpredictable seizures.

... I am unable to go for any work...neither do I have any other skill to do something from home [to earn money]. If it is season [to harvest nuts], sometimes they [owners] bring areca nuts and I get paid for shelling [these]...

“Adjust accordingly and live”

Some of the major problems women with epilepsy face are beyond their seizures. The emotional struggles caused by lack of understanding and misconceptions in the society and their own family members can be devastating. Arranged marriage, where elders in the family find suitable partners for their children, is customary in this community. All the young participants and their family members concealed the history of participant's epilepsy during the marriage negotiations for fear of breakup of the marriage proposal.

Participant #1 started having seizures when she was 13 years old. Her parents were illiterate and attributed the reason for her seizures as the possession of certain evil spirits. They worried that no one would come forward to marry their daughter because of this disease and by concealing her disease, they got her married at the age of 15 to a much older man who was already married. Upon witnessing her seizures after marriage, the participant's husband was upset with her family, blaming them for cheating him. He took her to a physician for treatment but later divorced her. During the time of this study, participant #1 did not have any permanent income and depended primarily on her family and people in the community to support her. Because of her disease, she had trouble with marriage negotiations for her daughters as many refused to marry them because of their mother's medical history.

Participant #4, who has a graduate education, was married three years ago and had also concealed the history of her disease from her fiancé. Her husband found out about her disease when he inquired in the pharmacy about the purpose of the medication she was taking and later witnessed one of her seizures. He felt cheated and blamed her family for concealing her epilepsy from him. The participant stated:

[Husband's] anger is shown on me.... He can only show it on me, not my family... when he is upset, he says, 'you have this disease, your family cheated me and so now, whatever I do, you have to adjust accordingly and live.' ...meaning, even if he is wrong, or makes any mistake, I have to adjust because I have this disease. That is how he talks. He is a very sensitive person... sometimes I see him sitting and crying, saying he was cheated and blames his own fate.... I often ask him what he is gaining by getting angry with me! I did not bring this disease on me... He was not like this earlier... now, even for small things he gets angry with me... He has also started drinking [alcohol] more and comes home very late.... He knows I will not tell about his behavior to anyone in his family because if I have to say that I have to tell them about my seizures, too... My family knows about this and they are really feeling bad. My father tells me not to trouble him [husband] and gives me money to buy medicines.

All participants echoed that the disease was a burden to the people around them and that they (the participants) had to adjust and quietly face the consequences.

“Live my life”

The participants were asked about their dreams about their lives in spite of their seizures. Participant #1 explained: “I wish I could work... I wish I could attend weddings and other functions... if I didn't have this (seizures), I could have done everything... I could have lived my life....”

At the time of the study, participant #2 had been married for a year. She had had an abortion a few months prior to the enrolling in the study. She said: “If I dream of an ideal life, it is a life with a child. I want to have children....”

Participant #3 is preparing for her long-awaited wedding. She and her family have not told her fiancé about her seizures. They have lost count of the number of marriage proposals she had received and that were broken when the prospective spouse and his family discovered that she had a history of epilepsy. Participant #3 explained:

I dream of a life with my husband in his house, enjoying to the maximum... without troubling them [his family] in any way, doing all the help I can... You know, sometimes when a daughter-in-law goes to her husband's house, we hear a lot about the daily fights and quarrels... But without any of that, I want to lead a very good family life and that is what I dream of...

Participant 4 explained:

... [A life] without [listening to] any hurtful words [from husband] and without allopathic [AEDs] medicines. I don't like the side effects of those medicines... and I wish my husband will understand me and my sickness... that would be the best....

These participants were quick and spontaneous in narrating their dreams and aspirations. Finding happiness and living their lives in spite of the chronic disease was a hope for all of the women in this study.

Discussion

The study was conducted using qualitative methodology and therefore the authors had no a priori assumptions or hypothesis about how these women live with epilepsy and the reasons for the treatment gap that exists. Our attempt was to listen to their stories and understand how they live day to day with this chronic disease and how they make meaning of their experiences. Many of the problems they face are similar to what other PWE, especially women, experience

elsewhere (Baskind & Birbeck, 2005; Birbeck, Chomba, Atadzhanov, Mbewe, & Haworth, 2007; Elliott, Charyton, McAuley, & Shneker, 2011; Santosh et al., 2007). A few of the potential reasons suggested by ILAE commission report (2001) for the treatment gap are (a) level of health care development, (b) cultural beliefs, (c) economy and (d) lack of priority (Meinardi et al., 2001). These are relevant to the participants in this study.

This study, which is first of its kind in describing the lives of women living with epilepsy and its treatment gap in India, adds to our understanding of the experience of living with epilepsy by providing a window through which to view their day to day lives and to learn of their hopes and aspirations. The effect of the treatment gap is reflected not only in the adverse health outcomes but in undesirable cultural and behavioral consequences.

Living with epilepsy affects the individual in many ways. Apart from the stigma and other related social consequences, the financial burden related to the costs of treatment for the disease forces them to make critical decisions about the type of treatment they choose. Participants in this study verbalized the difficulties of dealing with expenses related to allopathic treatment. The participants were from a low socio-economic background and they paid out-of-pocket for health care needs. Studies from India have shown that although there is cost-effective treatment available for epilepsy, unfortunately, the majority of the patients are treated with multiple and often expensive AEDs (Radhakrishnan, 2009).

A survey done among primary care physicians in Kerala suggested that the commonest choice of drugs for both generalized and focal seizures were Valproate and Carbamazepine, both of which are relatively expensive (Iyer, Rekha, Kumar, Sarma, & Radhakrishnan, 2011b). The major step towards ensuring cost-effective treatment has to be based on health care policies and a conscious attempt from the health care providers to prescribe lower cost drugs. In an attempt to

eradicate poverty among women especially in the rural areas of the state, the Government of Kerala had initiated a commendable project to empower women (Kadiyala, 2004b). Revisiting health care policies and initiating an accessible and affordable treatment model for these women with epilepsy could empower them and improve their quality of life.

Everyone, including people with epilepsy, should be able to live a normal and productive life without fear and low self-esteem. Epilepsy is a complex disease and living a normal life can be a struggle. Studies have shown that with appropriate treatment, seizures can be reduced and people can live a normal life (Birbeck et al., 2002; Meyer et al., 2010). Based on findings of this study, for women in this community in Kerala, the psychosocial consequences of living with epilepsy can cause more distress than the seizures itself. Although the disease was concealed from the prospective spouses with the intention of promoting a happy marriage, the women later were unhappy and had difficulties in their marriage.

Promoting in individuals and community a clear understanding of the cause for epilepsy and the appropriate ways to effectively treat the disease could reduce the stigma associated with epilepsy. It could also encourage these women to continue with the treatment and thereby reduce their incidence of seizures. Epilepsy should not define the lives of people. There are considerable misconceptions about epilepsy and the major unhappiness in the participants' lives after marriage was when their spouses became aware of their diagnosis. The reason why the women and family choose to conceal the history of epilepsy is because of the stigma that exists regarding this chronic disease in the community. The important measures to overcome the social consequences of living with epilepsy are by providing the women with appropriate treatment to reduce seizures and by empowering those affected with epilepsy. These women and their families believed that the cause of the disease was supernatural. A major step would be to educate these women and

enable them to help themselves. Knowledge about the disease, treatment, and expected outcomes of the treatment are important to both eradicating the treatment gap and empowering women living with epilepsy. It is important that these women, along with their families and other care givers, conceptualize epilepsy as a neurological disease and that the disease is seen separate from the individual themselves (Aujoulat, Marcolongo, Bonadiman, & Deccache, 2008; Van Manen, 1998).

Implications for Practice:

This study has implications for health policy, clinical practice, and education. The two types of health care systems in Kerala, the public and private, do not provide adequately for the needs of the poor. There is a lack of adequate health care facilities in the public health system and the poor cannot afford care from the private health system (Rajagopal, 2010). Reducing the treatment gap and improving epilepsy care in this community thus involves both health policy and clinical practice efforts. Developing policies that can be viable politically and economically sustainable can bring long-term benefits in eradicating the treatment gap.

Based on these findings, there is an education gap in the Kerala community and among patients and their caregivers about epilepsy and its treatment. Culture plays an important role in how people perceive and experience a disease. Many of the social and family issues these participants face are because of the disease stigma that exists in this community. Ignorance and superstition about the etiology and treatment for epilepsy is the root-cause of the epilepsy treatment gap and the related consequences for these women. It is important to leverage the knowledge of traditional healers who are the common cultural health workers in the community, family caregivers, and responsible others who may be involved in treatment decisions about the cause and effective treatments for epilepsy. Women, especially in the rural Indian communities,

are generally submissive to men and people in authority. Keeping social and cultural factors in the forefront, nurses, along with other community health care workers, can play an important role in educating the women. Epilepsy is a chronic neurological disease that requires long-term treatment. The nurses and community health workers should also empower the women to talk about their experience of living with epilepsy and its treatment-related issues with health care providers, so that appropriate action could be taken to improve their quality of life. To attain these goals, members of the health care team should empower nurses and other community health workers to accept their role as patient advocates to work toward making the voices of these vulnerable populations heard.

In February 2015, the WHO and ILAE unanimously approved a new resolution to support epilepsy care, the health, social, public knowledge implications and research to make the fight against epilepsy a global effort. The authors of this study recommend consideration of intervention research in the Indian community similar to that in the Global Campaign against Epilepsy demonstration project conducted in China (Ding et al., 2008; Wang et al., 2008). Such a project should include an epidemiological study to understand the burden of the problem in Kerala; ethnography to understand better the attitude of key stakeholders (including health care providers) in the community toward epilepsy and its treatment; qualitative and quantitative studies to compare attitudes and quality of life of PWE and its treatment gap versus PWE with appropriate treatment. The outcomes of these studies could facilitate the development of a better epilepsy care model that could eradicate the epilepsy treatment gap and improve quality of life of PWE in Kerala. It could also serve as an example for other parts of India and the developing world.

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CHAPTER SEVEN

SUMMARY AND IMPLICATIONS

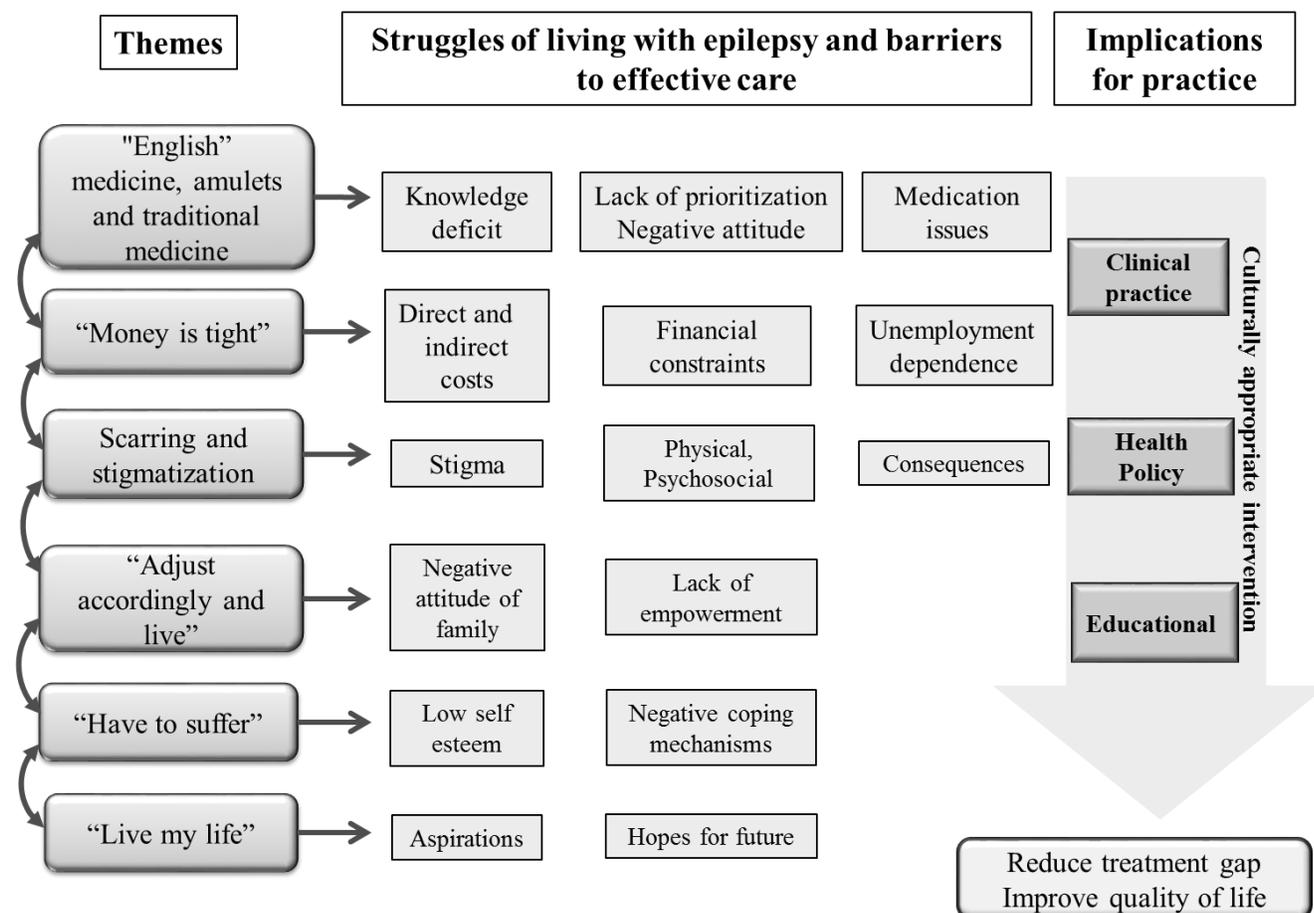
Summary

While epilepsy and its treatment gap are significant issues in India, few researches have descriptively addressed the topic. This study was consistent with qualitative methodology and gives a nuanced description of the cultural factors impacting six women living with epilepsy (WWE) and its treatment gap in Kozhikode, Kerala, South India.

In India, gender-based differences are seen in all domains of the epilepsy profile. Women suffer more than men. Although consistently modelled as the most developed state in India, gender disparities persist in the treatment of epilepsy in the state of Kerala. The purpose of this study was to describe the lives of WWE living in the outskirts of Kozhikode who either receive treatment from traditional Indian healers, were not on any anti-epilepsy drugs (AEDs) or were not regularly taking the AEDs as prescribed. Using ethnography methods, this study describes some of the day to day struggles and challenges of the six women along with the perceived barriers to appropriate care. The study provides insight into these women's knowledge, attitude, practice, and beliefs regarding the disease.

The six interrelated themes that emerged from the data were, (a) "English" medicine, amulets and traditional medicine; (b) money is tight; (c) scarring and stigmatization; (d) adjust accordingly and live; (e) have to suffer; and (f) live my life. Figure 1 below describes the integrated model based on themes.

Figure 1: Women living with epilepsy treatment gap: An integrated model based on themes



The struggles of living with epilepsy and the perceived barriers to effective epilepsy care is detailed in the three manuscripts developed around these themes. The implications for practice are based on the social and cultural background in this community and may be useful to reduce epilepsy treatment gap and thereby improve quality of life of those afflicted.

Manuscripts

Manuscript one is titled "I just want a cure for this": Ethnography among women with epilepsy in Kerala, South India, will be submitted to the journal, *Epilepsy and Behavior*. The

theme used in this manuscript is, 'English' medicine, amulets and traditional medicine and describes how these women perceive the disease, their understanding and beliefs about the cause, and their views about treatment. The manuscript also details the various barriers to effective treatment, which include financial constraints, the stigma of epilepsy, difficulties related to medication side-effects, medicine availability, and difficulties of being dependent on others. In general, the knowledge deficit, religious beliefs, negative attitude towards the disease, accessibility, and availability issues of anti-epilepsy drugs (AEDs) are highlighted in this manuscript

“A struggle to balance: Women with epilepsy in Kerala, South India,” the second manuscript, to be submitted to the *Transcultural Nursing Journal*, describes the participant's physical and psychosocial struggles of living with epilepsy and their coping mechanism. The themes that are discussed are (a) 'scarring and stigmatization;' and (b) 'have to suffer.' To the women interviewed, living with epilepsy did not mean simply living with the physical manifestations of the disease as the struggle went beyond the seizures. Because of the stigma that exists in this Indian community, the WWE reported that they had to deal with the psychosocial struggles that cause deep, hidden emotional scars. The women adapted two major coping strategies (a) accepted their disease and its stigmatization and/or (b) concealing the disease and seeking different types of treatment till they found a cure for epilepsy. The consequences of living with epilepsy created in them low self-esteem and negative coping mechanisms.

“Living in the Shadows: Women with epilepsy and its treatment gap in Kerala, South India” is the third manuscript and it will be submitted to the *Journal of Nursing Scholarship*. The three themes discussed in this manuscript are (a) 'money is tight,' (b) 'adjust and live accordingly,' and (c) 'live my life.' This manuscript focuses on the financial, societal and family

struggles related to epilepsy, and the participants' aspirations. The manuscript details the aspirations and dreams of the participants in spite of the struggles and challenges they face. All the participants were from low socio-economic backgrounds. Most of the participants were unemployed and were dependent on their family members for their treatment needs. The direct and indirect costs related to the treatment caused financial constraints for the family and thereby severe psychological burdens among participants.

Recommendations

This study has implications for education, clinical practice and health policy interventions in Kozhikode. Because of the social implications that epilepsy has in this community in Kerala, culturally appropriate interventions to reduce epilepsy treatment gap should be community-based. There are a few possible interventions that might be employed to improve the quality of life for women living with epilepsy in Kerala. Figure 2 describes the recommendations based on this study.

Education about epilepsy

Educational intervention is of utmost importance and probably the first and foremost to be considered. Educating these women and their families about the scientific cause of epilepsy and its treatment could be key to empowering them. Improving their awareness and understanding about the disease and its management might help improve their self-esteem and their ability to make appropriate decisions about treatment. Informing and educating the community in a culturally appropriate way to emphasize that epilepsy is due to neuronal outbursts rather than to any evil-spirits could help de-stigmatize the disease.

While ensuring quality of life among WWE in Kerala will require team effort by the health care professionals, involving nurses and other grass root community health workers in educational interventions and awareness programs has the potential to facilitate better outcomes. Accredited social health activists (ASHA), project undertaken by the Government of India, are trained female, voluntary health workers who are selected from the specific rural community and accountable to it (Jayakrishnan et al., 2011; National Health Mission, 2014). Involving these community health workers who understand the living experiences in these communities to act as a bridge between the health care system and the women with epilepsy; create awareness and education about epilepsy and its treatment among these women, their families and the community can create a positive impact in epilepsy care in this community. Since 2009, ASHA workers have been used successfully in promoting family planning programs, ante-natal/ post-natal care, home based new-born care, immunization, and mental health awareness and follow-up (John, 2014; National Health Mission, 2014; Varghese et al., 2014).

Nurses, both in the public health field and hospital setting could also play an important role in creating awareness and promoting individualized education based on these women's culture and beliefs. Nurses have a unique role in the health care system in India in that they are involved in all aspects of care of WWE. Furthermore, nurses can take responsibility in empowering these women to take care of themselves. As patient advocates, nurses can ensure that these women's voices are heard.

Clinical practice and Health Policy

Fostering active participation of WWE in Kozhikode, in the treatment process rather than being passive followers of the treatment plan prescribed by the physician could also lead to

improved compliance with AEDs. Encouraging and empowering WWE to talk about the struggles of living with epilepsy and difficulties related to treatment side effects can enable health care providers to suggest appropriate, reasonable and affordable treatment. Nurses and ASHA workers could encourage active participation of WWE in their health care decisions.

The financial burden that epilepsy imposes on WWE and their families cannot be ignored. The cost related to treatment is one of the major reasons for epilepsy treatment gap among these women as they have to pay for all expenses out-of-pocket. A study completed in Kerala revealed that although there are cost-effective drugs available, PWE were often treated with the more expensive AEDs (Radhakrishnan, 2009). In a survey done among primary care physicians in Kerala, it was found that the most common AEDs prescribed were Valproate and Carbamazepine, which are comparatively cost more than some other similar effective drugs like Phenobarbital (Iyer et al., 2011a). Physicians making a conscious effort to understand the economic status and financial burden for WWE in Kozhikode could prescribe the lower cost drugs.

Though this study has not examined the current health care policies existing for WWE in this specific district of India, re-examining or creating economically sustainable and politically viable policies for this vulnerable population could also be considered.

Implications for further research

Finally, as researchers have suggested in the literature, future studies should be conducted to gain a better understanding of the burden the disease and community attitudes towards epilepsy and its treatment in India and in other regions of the world where epilepsy is prevalent. Research should also be conducted about possible interventions to develop long-term gender-

based solutions to address the treatment gap in epilepsy in India and to improve the quality of life of WWE. Intervention research similar to the Global Campaign against Epilepsy demonstration project conducted in China could be considered (Ding et al., 2008; Wang et al., 2008) in the Indian community. Such a project should include an epidemiological study to understand the burden of the problem in Kerala; ethnography to understand better the attitude of key stakeholders (including health care providers) in the community toward epilepsy and its treatment; qualitative and quantitative studies to compare attitudes and quality of life of people with epilepsy (PWE) and its treatment gap versus PWE with appropriate treatment. These studies could facilitate the development of a better epilepsy care model that can help to eradicate the treatment gap and improve the quality of life of PWE in Kerala. That model could also serve as an example for other parts of India and the developing world.

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Appendices

Appendix A: Regional ethical committee approval



CALICUT UNIVERSITY HUMAN ETHICAL COMMITTEE

University of Calicut, Malappuram - 673 635, Kerala, India

Chairman :

Sri. P. N. Vijayakumar,
Former District & Sessions Judge,
Thrissur, Kerala, India;
Former Kerala State Information
Commissioner;
Chairperson, Kerala State
Commission for Scheduled Castes
and Scheduled Tribes.

Member Secretary :

Head of the Department,
Department of Zoology,
University of Calicut,
Malappuram, Kerala, India

Members :

Dean,
Faculty of Science,
University of Calicut,
Malappuram, Kerala, India

Director,

Directorate of Research,
University of Calicut,
Malappuram, Kerala, India

Dr. S. P. Shaji Prabha,
Junior Scientific Officer,
Chemical Examiner's Laboratory,
Thiruvananthapuram, Kerala, India

Dr. P. B. Gujara,
District Police Surgeon,
District Hospital, Palakkad,
Kerala, India

Dr. V. V. Unnikrishnan,
Additional Professor of Physiology,
Government Medical College,
Thrissur, Kerala, India

Dr. Ajith Kumar,
Additional Professor of Dermatology,
Government Medical College,
Thrissur, Kerala, India

Sri. Jayesh K. Joseph,
Criminologist,
Kerala Police Academy,
Thrissur, Kerala, India

Smt. Jayasree,
Asst. Professor,
Department of Philosophy,
University of Calicut,
Malappuram, Kerala, India

Sri. P. Aboobacker,
Pookat House, Pallikkal,
Malappuram, Kerala, India

001/CUEC/CR/2013-14-CU

Date: 11/07/2014

CERTIFICATE OF ETHICS CLEARANCE TO INVOLVE HUMAN PARTICIPANTS IN RESEARCH

CUEC Application No: 001/CUEC/2013-14-

Protocol/ Project title/ Ph.D topic:

"Lives of women with seizures in Malabar, South India"

Principal Investigator/ Research Scholar:

Ms.Jane Von Gaudecker, RN, MSN

Name & Address of Institution:

University of Virginia, School of Nursing, Charlottesville, USA

New review Revised review Expedited review

Date of review (D/M/Y): 11/07/2014

Date of previous review, if revised application: 07/02/2014

Decision of the CUEC:

Recommended Recommended with suggestions
 Revision Rejected

Suggestions/ Reasons/ Remarks (If any):

- The Investigator should adhere to all legal formalities.
- Submit a report of the study to the CUEC after completion of this study.

Recommended for a period of : **Six months from the date of issue of Ethical clearance**

Reporting frequency : **After completion of the study**

Number of Samples : 15

Please note *

- Inform CUEC immediately in case of any Adverse events and Serious adverse events.
- Inform CUEC in case of any change of study procedure, site and investigator.
- This permission is only for period mentioned above. Annual report to be submitted to CUEC.
- Members of CUEC have right to monitor the trial with prior intimation.

Signature of the Chairperson

Date: 11/07/2014

Signature of Member Secretary

Date: 11/7/2014

Address for Communication :

Head of the Department, Department of Zoology, University of Calicut, Calicut University P.O., Malappuram - 673 635, Kerala, India | Telephone No: 0494 2407420 | e-mail: zoohod@uoc.ac.in

Appendix B

IRB approved informed consent in Malayalam

IRB-HSR# 16858: ദക്ഷിണേന്ത്യയിലെ മലബാറിൽ അപസ്മാരത്താൽ ജീവിക്കുന്ന സ്ത്രീകളുടെ ജീവിതത്തെ പറ്റിയുള്ള പഠനം പങ്കെടുക്കുന്ന വ്യക്തിയുടെ പേര്:

ദക്ഷിണ ഇന്ത്യയിലെ മലബാറിൽ അപസ്മാരത്താൽ ജീവിക്കുന്ന സ്ത്രീകളുടെ ജീവിതം എന്ന റിസർച്ചിൽ പങ്കെടുക്കാനുള്ള സമ്മതപത്രം:

ഈ റിസർച്ച് എന്തിനെ പറ്റിയാണ്?

അമേരിക്കയിലെ യൂനിവേർസിറ്റി ഓഫ് വേർജീനിയയിൽ നിന്ന് നടത്തുന്ന റിസർച്ച് പഠനമാണ് ഇത്. അപസ്മാരം അഥവാ ഫിറ്റ്സ് ഉള്ളവർക്ക് അലോപ്പതിയിൽ ഫലപ്രദമായ ചികിത്സാവിധികളും ഔഷധങ്ങളും മലബാറിൽ ലഭ്യമാണെങ്കിലും ചിലപ്പോൾ ചിലർ അവ ഉപയോഗിക്കാറില്ല അല്ലെങ്കിൽ, ഇടവിട്ട് ഉപയോഗിക്കുന്നു. അങ്ങനെ ഉള്ളവരുടെ ജീവിതത്തെ കുറിച്ച് കൂടുതൽ പഠിക്കാൻ വേണ്ടിയാണ് ഈ റിസർച്ച്.

താങ്കൾക്ക് കഴിഞ്ഞ രണ്ടു വർഷമോ അതിലധികമോ ആയി ഫിറ്റ്സ് ഉണ്ട് എന്ന് മനസ്സിലാക്കുന്നു. താങ്കൾ സ്ഥിരമായോ ഒട്ടും തന്നെയോ അല്ലെപതി മരുന്ന് ഇതിനായി ഉപയോഗിക്കുന്നില്ല. ആയതിനാൽ ഈ റിസർച്ചിൽ പങ്കെടുക്കുവാൻ താങ്കളോട് അഭ്യർത്ഥിക്കുന്നു. ഈ റിസർച്ച് മുഖാന്തിരം കിട്ടുന്ന അറിവ് ഈ രോഗത്തെ ചികിത്സിക്കുന്നവർക്ക് ഈ രോഗം മൂലം ബുദ്ധിമുട്ട് അനുഭവിക്കുന്ന സ്ത്രീകൾക്ക് വേണ്ടി പദ്ധതികൾ രൂപംനൽകാനും, നിലവിലുള്ള പദ്ധതികൾ കൂടുതൽ മെച്ചപ്പെടുത്തുവാനും ഉപകരിക്കും. ഈ റിസർച്ചിന്റെ ഉത്തവാദിത്വം ഡോ. ആൻ ഗിൽ ടയിലർ അവർകൾക്കാണ്. ജയിൻ ഗൗടെക്കേർ എന്ന വ്യക്തി ഈ റിസർച്ച നിങ്ങളുടെ പ്രദേശത്തു നടത്തും.

ഈ റിസർച്ച് നിങ്ങളുടെ പ്രദേശത്തു നടത്തുന്നതും, പങ്കെടുക്കുന്ന ഓരോ വ്യക്തിയുടെ കൂടെ 2 ആഴ്ച ചിലവിട്ടിട്ടായിരിക്കും.

ഈ റിസർച്ചിൽ എന്ത് സംഭവിക്കും?

ഈ റിസർച്ചിൽ പങ്കു ചേരാൻ നിങ്ങൾ അനുമതി തരികയാണെങ്കിൽ,

1. അപസ്മാരം മൂലം ജീവിക്കുന്ന തങ്ങളുടെ ജീവിതത്തെ കുറിച്ച് നന്നായി മനസ്സിലാക്കുവാൻ ജയിൻ എന്ന വ്യക്തി ഇവിടെ ചുറ്റുവട്ടത്തു അടുത്ത രണ്ടാഴ്ച താമസിക്കുകയും, തങ്ങളുടെ ദൈനന്ദിക ജീവിതത്തി നിരീക്ഷിക്കുകയും ചെയ്യുന്നതാണ്. ഈ നിരീക്ഷണത്തിന്റെ ഉദ്ദേശം, അപസ്മാരം മൂലം ജീവിക്കുന്ന തങ്ങളുടെ ദിവസേന ഉള്ള അനുഭവങ്ങളെ കുറിച്ച് കൂടുതൽ മനസ്സിലാക്കാനാണ്. ചില നിരീക്ഷണങ്ങൾ തങ്ങളുമായി മുൻകൂട്ടി പ്ലാൻ ചെയ്തതായിരിക്കും. ഉദാഹരണത്തിന്,

IRB - HSR
APPROVAL DATE 08.07.2014
EXPIRATION DATE 08.06.2015

IRB-HSR# 16858: ദക്ഷിണേന്ത്യയിലെ മലബാറിൽ അപസ്മാരത്താൽ ജീവിക്കുന്ന സ്ത്രീകളുടെ ജീവിതത്തെ പറ്റിയുള്ള പഠനം

തങ്ങളുടെ കൂടെ വൈദ്യരേ കാണാൻ പോവുക, ആരാധനാലയത്തിൽ പോവുക എന്നിവയാണ്. മറ്റു ചിലപ്പോളു നിസർച്ച് നടത്തുന്ന വ്യക്തി താങ്കൾ ജീവിക്കുന്ന പരിസരത്തു പോതിവേ ഉള്ള നിരീക്ഷണങ്ങൾ ചെയ്യുന്നത് കാണാം. താങ്കളുടെ വൈദ്യർ അനുവാദം തരികയാണെങ്കിൽ നിസർച്ച് നടത്തുന്ന വ്യക്തി താങ്കളുടെ കൂടെ വന്നു അവിടെ നിരീക്ഷണം ചെയ്യുന്നതായിക്കും.

2. നിസർച്ചിന്റേ തുടക്കത്തിൽ ജയിൻ താങ്കളുമായി അഭിമുഖം നടത്തുന്നതാണ് ഇത് ഏകദേശം ഒരു മണിക്കൂർ നേരം എടുക്കാം. താങ്കളുടെ ആരോഗ്യത്തെ പറ്റിയും, നിത്യ ജീവിതത്തെ പറ്റിയും പൊതുവെ ചോദിക്കുന്നതായിരിക്കും.
3. ഇതിനു ശേഷം സാഹചര്യത്തിനനുസരിച്ച് പരമാവധി 3 അഭിമുഖങ്ങൾ ഉണ്ടാകാവുന്നതാണ്. ഇവയും താങ്കളുടെ നിത്യജീവിതത്തെ കുറിച്ച് കൂടുതൽ അറിയനായിരിക്കും.

താങ്കളുടെ അനുവാദത്തോടെ ഈ അഭിമുഖങ്ങൾ ട്രേപ്പ് റെക്കോർഡ് ചെയ്യുന്നതാണ്. താങ്കളുടെ പേര് ഒരിക്കലും വെളിവാക്കാത്ത രീതിയിൽ റെക്കോർഡ് ചെയ്യുന്നതാണ്. ഈ അഭിമുഖങ്ങൾ പിന്നീടു ഇംഗ്ലീഷ് ലേക്ക് തർജ്ജിമ ചെയ്യുകയും അതിനു ശേഷം ട്രേപ്പ് മുഴുവനായും മായിച്ചു കളയുന്നതും ആയിരിക്കും.

ഈ നിസർച്ച് കാരണം വേദനിപ്പിക്കുന്ന എന്തെങ്കിൽ സംഭവിക്കുമോ?

ചിലപ്പോൾ ഒരു നിസർച്ച് പഠനത്തിൽ പങ്കെടുക്കുന്നവർക്ക് വേദന അനുഭവ അനുഭവപ്പെടുകയോ അവരെ വിഷമിപ്പിക്കുന്നതോ ആയതു സംഭവിക്കാം. താങ്കൾക്കു അഭിമുഖത്തിന്റേ സമയത്ത് ചില കുറിച്ച് സംസാരിക്കാൻ ബുദ്ധിമുട്ടുണ്ടാവാം. ഉദാഹരണത്തിനു, അഭിമുഖം ചില വേദനിപ്പിക്കുന്ന ഓർമകളെ കൊണ്ട് വരാം. താങ്കളു്ക്ക് സംസാരിക്കാൻ താത്പര്യമില്ലാത്ത ഒരു കാര്യത്തെ പറ്റിയും താങ്കളോട് ചോദിക്കുന്നതല്ല. മാത്രമല്ല, അഭിമുഖത്തിനിടയിൽ താങ്കൾക്ക് അല്പം സമയം വേണമെങ്കിലോ, അഭിമുഖം പിന്നീട് ഒരു സമയത്തേക്ക് മാറ്റി വെക്കുകയോ ചെയ്യണമെങ്കിൽ അങ്ങനെ ചെയ്യാം

ഈ നിസർച്ച് എന്തെ സഹായിക്കുമോ?

ഈ നിസർച്ചിൽ പങ്കെടുക്കുന്നത് കൊണ്ട് താങ്കൾക്ക് ഇപ്പോൾ വ്യക്തിപരമായ ഉപയോഗങ്ങൾ ഒന്നുമില്ല. ഒരുപക്ഷെ, മനസ്സിൽ അടച്ചു പൂട്ടി വച്ച കാര്യങ്ങൾ ആരോടുകിലും പറയുന്നതിന്റേ ആശ്വാസം ലഭിക്കാം. പക്ഷെ ഈ നിസർച്ചിന്റേ ഉപയോഗം ഈ രോഗത്താൽ ജീവിക്കുന്ന മറ്റനേകം വ്യക്തികൾക്ക് ഉപകരിക്കാം. പിൽക്കാലത്ത് താങ്കൾക്കും ഉപയോഗം ചെയ്യാം. ഈ നിസർച്ച് മുഖാന്തരം ഈ

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എന്റേ സ്വകാര്യത എങ്ങനെ പരിരക്ഷിക്കും?

താങ്കളിൽ നിന്ന് ലഭിക്കുന്ന എല്ലാ വിവരങ്ങളും ഇന്ത്യൻ സ്വകാര്യത നിയമങ്ങളും അമേരിക്കൻ സ്വകാര്യത നിയമങ്ങളുമനുസരിച്ചു സ്വകാര്യമായി വെക്കുന്നതായിരിക്കും. ഈ നിസർച്ച് നടത്തുന്ന പ്രൊഫസർ ആൻ ജെയർ എന്നവർക്കും ജെയിൻ എന്നവർക്കും, യൂണിവേർസിറ്റി ഓഫ് വെർജീനിയയിൽ ഈ നിസർച്ചയുമായി ബന്ധമുള്ളവർക്കും താങ്കളിൽ നിന്നു ലഭിക്കുന്ന ആരോഗ്യ വിവരങ്ങൾ പങ്കു വെക്കാൻ താങ്കൾ ടിപോക് കൂടെ സമതം തരുന്നതായി കരുതുന്നു.

തങ്ങളുടെ വിവരങ്ങൾ ലഭ്യമാകാവുന്ന മറ്റു ചിലർ താഴെ പറയുന്നവരാണ്:

1. ഈ നിസർച്ചിന്റെ സുരക്ഷ ഉറപ്പു വരുത്തുന്ന അംഗീകരിക്കപ്പെട്ട പ്രതിനിധി
2. ഇന്ത്യയിലെയും അമേരിക്കയിലെയും നിസർച്ച് സുരക്ഷിതത്വം ഉറപ്പാക്കുന്ന പ്രതിനിധികൾ; ഉദാ: United States Department of Health and Human Services (DHHS)
3. യൂണിവേർസിറ്റി ഓഫ് വെർജീനിയയിലെ ധർമ്മനിധി കാര്യങ്ങളെ വഹിക്കുന്ന Institutional Review Board (IRB), ശ്രീ ചിത്ര തിരുനാൾ ആശുപത്രിയിലെ നീധിന്യായ കാര്യങ്ങൾ ഉറപ്പു വരുത്തുന്ന കോഴിക്കോട് സർവകലാശാലയുടെ Institutional Ethics Committee.

ഈ കരാറിൽ ഒപ്പ് വെക്കുന്നത് കൊണ്ട് താങ്കൾ നിസർച്ച് മുഖാന്തിരം ശേഖരിച്ച വിവരങ്ങൾ മേൽ പറഞ്ഞ വ്യക്തികളുമായി പങ്കു വെക്കാൻ അനുവാദം തരുന്നു. ഇതിനു കാലാവധി ഇല്ല. താങ്കളുടെ അനുവാദം പിന്തള്ളി നിസർച്ചിൽ നിന്ന് പിന്മാറാൻ താത്പര്യപ്പെടുകയാണെങ്കിൽ, ദയവു ചെയ്തു ജെയിൻ ഗൗടേക്കർ എന്ന വ്യക്തിയുമായി 9947712573 എന്ന നമ്പറിൽ ബന്ധപ്പെടുക. താങ്കളുടെ തീരുമാനം എഴുതി, അനുവാദത്തിൽ നിന്നും നിസർച്ചിൽ നിന്ന് പിന്മാറാനും അവർ താങ്കളെ സഹായിക്കും.. അതുവരെ ലഭിച്ച എല്ലാ എല്ലാ വിവരവും നിസർച്ചിനു ഉപയോഗിക്കപ്പെടും എന്ന് ദയവു ചെയ്തു ഓർക്കുക

ഈ നിസർച്ചിൽ താങ്കൾ പങ്കെടുക്കുന്നത് തികച്ചും സ്വേച്ഛാനുസാരമായിരിക്കും. എന്തിനാലും, ഈ കരാറിൽ ഒപ്പ് വയ്ക്കാതെ ഈ പഠനത്തിന്റെ ഭാഗമാകുവാൻ സാധ്യമല്ല

ഈ നിസർച്ചിൽ പങ്കെടുത്താൽ എനിക്ക് പ്രതിഫലം കിട്ടുമോ?

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താങ്കൾ പങ്കെടുക്കുന്നതിനു പ്രതിഫലമായി, ഈ റിസർച്ച് അവസാനിക്കുമ്പോൾ (അഭിമുഖവും നിരീക്ഷണവും കഴിയുമ്പോൾ), അഥവാ രണ്ടു ആഴ്ചക്ക് ശേഷം, രൂ:750/- താങ്കൾക്ക് പ്രതീക്ഷിക്കാം. റിസർച്ചിനിടയിൽ താങ്കൾ പിന്മാറാൻ താല്പര്യപ്പെടുകയാണെങ്കിൽ ചിലവിട്ട സമയത്തിനനുസരിച്ച് പ്രതിഫലം പ്രതീക്ഷിക്കാം.

ഞാൻ പങ്കെടുക്കേണ്ടതുണ്ടോ?

താങ്കൾക്ക് താല്പര്യമില്ലെങ്കിൽ ഈ റിസർച്ചിൽ പങ്കെടുക്കേണ്ടതില്ല. അത് തികച്ചും താങ്കളുടെ തീരുമാനമാണ്. റിസർച്ച് നടക്കുന്നതിനിടയിൽ താങ്കൾ പിന്മാറാൻ താല്പര്യപ്പെടുകയാണെങ്കിൽ അങ്ങനെ ചെയ്യാവുന്നതാണ്. പക്ഷെ അത് വരെ താങ്കളിൽ നിന്ന് കിട്ടിയ അറിവ് ഈ റിസർച്ചിനായി ഉപയോഗിക്കുന്നതായിരിക്കും. റിസർച്ചിൽ പങ്കു ചേരുന്നത് നിറുത്തിയത് കാരണം താങ്കൾക്കു ഒരു വിധത്തിലും വിഷമങ്ങൾ ആരിൽ നിന്നും അനുഭവിക്കേണ്ടതായി വരില്ല.

ഞാൻ പങ്കുചേരുന്നില്ല എങ്കിൽ വേറെ എന്ത് ചെയ്യാൻ പറ്റും?

ഈ റിസർച്ചിനെ സഹായിക്കാൻ വേറെ മാർഗങ്ങൾ ഒന്നുമില്ല.

ഈ റിസർച്ചിൽ എന്തെ അവകാശങ്ങളെ കുറിച്ച് കൂടുതൽ അറിയണമെങ്കിൽ ഞാൻ ആരെ സമീപിക്കണം?

താങ്കൾക്ക് ഈ കുരാർ ഒപ്പ് വയ്ക്കുന്നതിനു മുൻപ് സംശയങ്ങൾ ചോദിക്കാം. കൂടുതൽ ചോദ്യങ്ങൾ ഉണ്ടെങ്കിൽ താഴെ കാണുന്ന വിലാസത്തിൽ എഴുതാവുന്നതാണ്.

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Director of Research,
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ഈ റിസർച്ചിനെ കുറിച്ച് എനിക്ക് ചോദ്യങ്ങളുണ്ടെങ്കിൽ ഞാൻ ആരെ സമീപിക്കണം?

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IRB-HSR# 16858: ദക്ഷിണേന്ത്യയിലെ മലബാറിൽ അപസ്മാരത്താൽ ജീവിക്കുന്ന സ്ത്രീകളുടെ ജീവിതത്തെ പറ്റിയുള്ള പഠനം

അല്ലെങ്കിൽ

Jane von Gaudecker, 9947712573

കൈയൊപ്പുകൾ:

ഈ നിസർസച്ചിനെ കുറിച്ചു താങ്കൾക്ക് എന്തെങ്കിലും ചോദ്യങ്ങൾ ഉണ്ടെങ്കിൽ ദയവായി ചോദിക്കുക. കൈയൊപ്പ് തരുന്നതിനു മുൻപ് നിസർസച്ചിനെ പറ്റി നന്നായി മനസ്സിലാക്കി എന്ന് ഉറപ്പു വരുത്തുവാൻ അപേക്ഷിക്കുന്നു.

നിസർസച്ചിൽ പങ്കെടുക്കാൻ സമ്മതം കാണിച്ചു കൊണ്ടുള്ള കൈയൊപ്പ് അല്ലെങ്കിൽ വിരലടയാളം:

ഒപ്പ് / വിരലടയാളം	പേര്	തിയതി
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ഇത് 18 വയസോ അതിനു മുകളിലോ പ്രായമുള്ളവർ പൂരിപ്പിക്കേണ്ടതാണ്.

പങ്കെടുക്കുന്നവരിൽ നിന്ന് കൈയൊപ്പു വാങ്ങുന്ന വ്യക്തി പൂരിപ്പിക്കേണ്ടത്:

താഴെയുള്ള കൈയൊപ്പു കൊണ്ട് ഈ നിസർസച്ചിനെ കുറിച്ച് പങ്കെടുക്കാൻ താല്പര്യമുള്ള വ്യക്തിക്ക് മുഴുവനായി വിശദീകരിച്ചു കൊടുത്തെന്നും ഈ കരാർ വായിക്കാൻ അല്ലെങ്കിൽ വായിച്ചു കൊടുക്കാൻ സമയമെടുത്തെന്നും, പങ്കെടുക്കാൻ താല്പര്യമുള്ള വ്യക്തിയുടെ എല്ലാ ചോദ്യത്തിനും മറുപടി കൊടുത്തെന്നും സമ്മതിക്കുന്നു

കരാർ ഒപ്പിട്ടു വാങ്ങിക്കുന്ന വ്യക്തി	പേര്	തിയതി
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Appendix C

Demographic form

If the participant is literate, the form will be given to her to be filled out; if not, the interviewer will help the participant to fill this form. The form will be translated to the local language.

Instructions: Please check (✓) your response or write your answer. If you do not wish to answer a question, please leave it blank.

1. How old are you? _____
2. What is your marital status?
 1. Single (never married) _____
 2. Separated or divorced _____
 3. Married _____
 4. Widow _____
3. What is your education level? (if you are illiterate please say that, or mention grade)
4. Are you employed? (1) Yes _____ (2) No _____
If yes, what is your occupation? _____
5. What is the annual income in your household?
 1. Rs. 10,000 or less _____
 2. Rs. 10,001 to 25,000 _____
 3. Rs. 25,001 to 35,000 _____
 4. Rs. 35,001 to 45,000 _____
 5. Rs. 45,001 to 55,000 _____
 6. Above Rs. 55,000 _____
6. How many people live in your household (including you)? _____

7. Do you have children? (1) Yes _____ (2) No _____

If yes, how many? _____

8. Are pregnant now (ask this only if married)? (1) Yes _____ (2) No _____

9. What is your religious belief? (1) Hindu _____ (2) Muslim _____

(3) Christian _____ (4) Other (specify) _____

Appendix D

Interview Guide

Date and Time of Interview:

Place:

My name is Jane. Like you, I am from this area. I am currently doing my doctoral studies from University of Virginia in the United States of America.

Please feel free to share any information that you feel comfortable sharing. If you need a break in between our conversation, feel free to let me know. I will be taking notes occasionally while you are talking and this interview will be recorded. Please do not use names during the interview, but if you happen to do so, I will erase the name from the recording.

Thank you for agreeing to participate in this research study.

1. How long have you been living with fits/apasmaram?
2. What is a typical fit like for you? What happens before, during, after the fits?
3. How often does this happen?
4. What do you do after you have one?
5. How do you take care of yourself during your fits?
6. Who helps you and how?
7. Were you ever diagnosed by an allopathic doctor as having epilepsy?
If yes, Has anything changed since the diagnosis?
If no, who have you consulted?
8. What kind of treatment has helped you the most and how?
9. Who do you talk to about your disease?

10. Describe any changes in your personal, family or social life since you started having ‘fits’?
11. What are your biggest worries about living with ‘fits’?
12. What do you believe is the cause of your ‘fits’?
13. How do you think is the best way to take care/deal with your ‘fits’?
14. I want you to imagine this. You have fits; that has not changed. I am not talking about avoiding the disability but if you were to dream of an ideal life even by living with fits, what would it be like? What would you change?
15. Is there anything else you would like to tell me about your life since you started having ‘fits’?