

5-12-2019

Women's Experiences with Epilepsy Treatment in Southern India: A Focused Ethnography

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Recommended APA Citation

von Gaudecker, J. R., Taylor, A. G., Buelow, J. M., Benjamin, S., & Draucker, C. B. (2019). Women's Experiences with Epilepsy Treatment in Southern India: A Focused Ethnography. *The Qualitative Report*, 24(5), 1034-1051. Retrieved from <https://nsuworks.nova.edu/tqr/vol24/iss5/7>

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Abstract

Women with epilepsy in rural southern India often do not receive anti-epilepsy drugs (AEDs) or take these drugs regularly, but little is known about how they experience the epilepsy treatment they do receive. The purpose of this study was to provide an in-depth description of the treatment experiences of women in this region who had been diagnosed with epilepsy but who do not consistently take AEDs. Focused ethnography was conducted using participant observation and in-depth interviews with six women with epilepsy, eight of their family members, and two traditional healers. The women's treatment experiences are best described as living at the intersection of Western allopathic ("English") medicine and traditional healing practices—approaches that could be complementary or conflicting. The women revealed a variety of perceived barriers to the use of "English" medicine. Health care professionals should appreciate the dynamic interplay of the two treatment approaches and consider all cultural, social, and economic factors that influence the women's treatment experiences.

Keywords

Epilepsy Treatment Gap, Barriers to Treatment, Treatment Decision, Indigenous Health Care, Ethnography, South India

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Acknowledgements
University of Virginia Global Health Scholar award and the Skinner Scholarship funded this study. This publication was supported by the 5T32 NR007066 award from the National Institute of Nursing Research. Its contents are the responsibility of the authors only and do not necessarily represent the official views of the NINR or the NIH.

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In India, an estimated 6-10 million people have active epilepsy (Megidido et al., 2016). Although 70% of people with epilepsy (PWE) can be treated effectively with first-line, cost-effective anti-epilepsy drugs (AEDs) (Megidido et al., 2016), nearly 90% of PWE living in rural India do not receive these drugs or take the drugs regularly (Santhosh, Sinha, & Satishchandra, 2014). This reflects an epilepsy treatment gap (ETG), which is the percentage of PWE in a given population who do not receive evidence-based treatment for their epilepsy (Meyer, Dua, Ma, Saxena, & Birbeck, 2010).

Epilepsy is associated with a number of adverse consequences, including high rates of morbidity and mortality, especially if not treated effectively (Greenlund, Croft, & Kobau, 2017). People with uncontrolled seizures, for example, experience accidents and injury that lead to high health care utilization and expenditures (Krumholz & Sanchez, 2014). PWE are also at risk of Sudden Unexpected Death in Epilepsy (SUDEP), a syndrome marked by sudden and unexpected death in the absence of trauma, drowning, or other known causes (Hesdorffer

et al., 2011). Epilepsy is also associated with negative psychosocial effects such as perceived stigma and poor quality of life (Margolis, Nakhutina, Schaffer, Grant, & Gonzalez, 2018).

Literature Review

Women in developing countries are particularly vulnerable to the negative effects of epilepsy. The state of Kerala on the southwest coast of India has a population of more than 30 million people and has the highest literacy rate in the country (Census of India, 2013). Although Kerala has some of the best medical facilities in the country to treat epilepsy, the services are under-utilized and ETG is reported to be between 35% and 41% in the state's urban population (Radhakrishnan, 2010; Thomas et al., 2001). Women from this state in particular report high illness burden and face more disease related stigma and discrimination (Thomas & Nair, 2011), lower quality of life (Ashwin et al., 2013; Gopinath, Sarma, & Thomas, 2011) and less access to medical care (Thomas, Deetha, Nair, & Sarma, 2006) than their male counterparts. A study done in Kerala demonstrated that 55% of women with epilepsy concealed their disease prior to marriage and a majority experienced marital disharmony, separation, or divorce (Santosh, Kumar, Sarma, & Radhakrishnan, 2007). Another study of women with epilepsy in Kerala revealed the women were at increased risk of divorce and, had more problems with marriage, mood, and employment than men (Gopinath et al., 2011).

Due to the severity of the negative effects of epilepsy if not well-controlled, researchers have addressed the causes of the ETG in India. (Gourie-Devi, Gururaj, Satishchandra, & Subbakrishna, 2004; Mani et al., 1998; Nizamie, Akthar, Banerjee, & Goyal, 2009; Radhakrishnan et al., 2000). Social stigma of the disease is found to hinder PWE accessing AEDs (Thomas & Nair, 2011), as well as lack of awareness, poverty, and distance from health care facilities (Nizamie et al., 2009).

Studies have also revealed that PWE in India often hold beliefs about the cause of the disease that are incompatible with allopathic treatment approaches. Studies conducted among various population groups in different parts of India reveal that people attribute the causes of epilepsy to heredity (Krishnaiah, Alwar, & Ranganathan, 2016; Pandian, Santosh, Kumar, Sarma, & Radhakrishnan, 2006); insanity (Goel, Dhanai, Agarwal, Mehlotra, & Saxena, 2011; Goel, Singh, Lal, & Singh, 2013; Krishnaiah et al., 2016; Radhakrishnan et al., 2000; Thacker, Verma, Ji, Thacker, & Mishra, 2008); evil spirits, supernatural power, or possession (Gourie-Devi, Singh, & Bala, 2010; Sureka & Sureka, 2007); brain disorders (Gourie-Devi et al., 2010; Sureka & Sureka, 2007); and contagion (Pandian et al., 2006; Radhakrishnan et al., 2000). Thus, absent a physiological explanation or understanding of the disease, "English" medicine is likely to be undervalued by PWE or their families.

To develop strategies to effectively address the ETG, an in-depth understanding of the treatment experiences of women living with epilepsy in India is needed. To our¹ knowledge, no studies have been conducted in which narratives have been elicited from women in India who have been diagnosed with epilepsy but who do not receive regular evidence-based treatment. The purpose of this focused ethnographic study was to provide an in-depth description of the treatment experiences of women in a rural area of Southern India who have been diagnosed with epilepsy but who do not consistently take AEDs to control their seizures. This information may provide the foundation to develop strategies to actively engage this population in evidence-based treatment and improve their health outcomes.

¹ References to authors will be with pronouns "we," "us," "ours." The references to first author will be with pronouns such as "I," "me," "my."

Contribution of Authors

I, the first author (JvG), am a native of the region where the study was conducted and fluent in the native language Malayalam and was a doctoral student in the United States at the time of the study. This paper reports the findings from my dissertation study. I have over 13 years of experience working among people with epilepsy and their families. The second author (AGT) is my pre-doctoral mentor who gave guidance in developing study design, conducting research, and analyzing the data. She has over 4 decades of experience guiding young researchers and has also conducted intervention studies among people with epilepsy. SB was the Director of Research at Calicut University, and the consultant for this study. JMB, an epilepsy researcher, has over 3 decades of experience working among this population, and CB is a qualitative expert with over 3 decades of experience guiding students and faculty. They both were my postdoctoral mentors and gave guidance in manuscript development.

Methods

The method used to address the study aim was focused ethnography (Cruz & Higginbottom, 2013). Focused ethnography is used to explore a distinct problem or social phenomenon in a particular sub-culture, community, or organization. The characteristics of a focused ethnography include samples with a limited number of participants, short-term but intensive field work, participant observation that can occur episodically, and structured interview topics. Thematic analysis is often used as the data analysis technique in focused ethnography (Cruz & Higginbottom, 2013; Higginbottom, Pillay, & Boadu, 2013; Knoblauch, 2005).

Focused ethnography was determined to be the appropriate method for this study as the research aimed to describe the experience of a specific sub-group of women (e.g., women diagnosed with epilepsy who did not consistently take AEDs) from a particular area in Southern India (e.g., district of Kozhikode) about a discrete phenomenon (e.g., their treatment experiences). The study procedures were consistent with focused ethnography and included the following phases: researcher immersion in the culture, networking with traditional healers and recruitment, participant observation, interviews with key and general informants, and data analysis. The protocol for the study was approved by both the University of Virginia Institutional Review Board (IRB- HSR# 16858) in the U.S.A. and the Human Ethical Committee at Calicut University in Kerala, India (#001/CUEC/CR/2013-14-CU).

My Immersion as a Researcher

Consistent with both conventional and focused ethnography practices (Cruz & Higginbottom, 2013), I first spent time immersing myself in the local community in which the study was to take place. As mentioned above, I am familiar with the culture and speak the language fluently. Approximately one year before conducting this study, I had traveled to the Kozhikode district where I spent 6 weeks living in and observing the community and engaging with and establishing rapport with traditional healers. I observed that medical care systems in the region included (a) western style (allopathic) medicine (referred to as “English” medicine), which is the state’s dominant medical system; (b) Ayurvedic medicine, which includes the prescription of herbal compounds; (c) homeopathic medicine, which includes a variety of health practices to stimulate the body to fight the disease (Bodeker, Ong, Grundy, Burford, & Shein, 2005); and (d) indigenous or religious healing methods, which includes use of regional medicinal plants, and use of prayers and rituals.

Networking and Recruitment

In 2014, I returned to the Kozhikode district to conduct the study. The first step I took was to network with the traditional healers in the region. All healers other than western allopathic physicians are referred to here as traditional healers. These healers agreed to identify potential women for the study. The study was to include both key informants (i.e., women with epilepsy who met inclusion criteria) and general informants (i.e., others who could provide indirect information about the women's experiences, such as traditional healers or family members)

Inclusion criteria for the key informants were as follows: (a) aged 18 and over, (b) had seizures over the prior 2 years, (c) received diagnosis of epilepsy by a qualified medical practitioner, and (d) was receiving treatment for epilepsy by a traditional healer and/or was not adhering to an anti-epilepsy drug protocol for at least the prior year. Exclusion criteria were as follows: (a) unable to participate in an interview because of conditions such as mental retardation or autism, (b) had a diagnosis of psychogenic non-epileptic seizures or pseudo seizures, and (c) was pregnant or nursing.

I screened 21 potential participants, identified through traditional healers and word of mouth, for study eligibility. Fourteen met the study criteria, but eight declined to participate for fear of disclosure of their disease to the people in the community. Six women thus served as key informants for the study. Family members (N = 8) and traditional healers (N = 2) involved in the care of the key informants served as general informants. The family member participants included five mothers, two husbands, and one aunt who lived with a key informant and her family. The overall research questions that guided this study were, how do women with epilepsy live their day-to-day lives, and what are the barriers and facilitators to biomedical treatment they encounter?

Data Collection and Management

Data collection for this study was guided by the principles discussed by Higginbottom et al. (2013), who provided guidance for performing focused ethnographies in healthcare research. They indicate that in focused ethnography interviews and observations are structured around specific issues and often include significant others to provide insight on the issues of interest. Interviews are used to validate observations and to collect information on phenomena that cannot be observed (e.g., participant thoughts and feelings). The researcher often serves in the role of participant-as-observer by collecting specific information in locations in which participants carry out activities that are of interest in the focus ethnography. We followed these procedures by observing participants in their homes and communities and keeping in-depth field notes and by conducting semi-structured interviews with the participants (key informants) and family members and traditional healers (general informants). As we sought an in-depth description of their experiences with epilepsy and its treatment, these topics were the focus of the interviews. However, as recommended by Higginbottom et al. (2013), the interviews began with informal questions about the participants' daily activities to put them at ease before asking questions about epilepsy.

I collected data from August through October 2014. Informed consent approved by both IRB and Human Ethical Committee at Calicut University, was obtained in the participant's local language prior to data collection from each participant. All participants except one who was illiterate, were able to read and sign the consent form. The consent was read to the participant who was illiterate, and her thumb impression was obtained to indicate consent.

To observe the participants in their daily activities, I lived in the Kozhikode district during data collection. I visited each woman daily for 2 weeks to observe her day-to-day

activities. A total of 62 days of observation were conducted and detailed field notes were kept describing key informants' interactions with family and community members, daily events in their lives, and happenings in their communities. The field notes also included the investigator's reflections on her observations. For example, I observed some family members using unpleasant tones and words which I interpreted as their attitude towards the disease.

Twenty-one interviews were conducted with key informants. Based on the information obtained, on average, three interviews were conducted with each key informant. The first and longest interview was designed to gather initial information based on the interview guide. The following interviews (typically two) were designed to reflect on my observations and for any clarifications from the prior interviews. This helped in triangulation, which is the convergence of information from different sources to develop a comprehensive understanding of the phenomena (Carter, Bryant-Lukosius, DiCenso, Blythe, & Neville, 2014).

The initial interviews lasted a maximum of 100 minutes and subsequent interviews lasted between 15 to 30 minutes.

Fifteen semi-structured questions guided the interviews, which focused on understanding the cultural aspects of living with epilepsy, beliefs and attitudes regarding the disease, treatment options, and the impact of seizures on the women's lives. These questions were designed based on the interviews I conducted with the traditional healers in the area during my preparatory visit, and literature review findings of quality of life of women with epilepsy in India. Examples of the interview questions follow: What do you believe is the cause of your seizures? What kind of treatment has helped you the most and how? What are your biggest worries about living with seizures? Who takes care of you during a seizure and how? Multiple interviews with participants ensured in-depth data collection and data saturation (Hennink, Kaiser, & Marconi, 2017).

Semi-structured interviews that addressed similar topics were also conducted with the general informants. Because loss of consciousness or awareness is common during seizures, family members were interviewed regarding participants' seizure events and care during seizures. Examples of these questions included, "What happens during participant's seizure?" "Who cares for the participant and how do you care for her during and after her seizure?" The general informants were also asked about their concerns about the participants living with epilepsy. The traditional healers were asked about the treatment and care recommended for and provided to participants. Each general informant was interviewed one time and the interviews lasted approximately 30-45 minutes.

All interviews were audio-recorded, and I transcribed them verbatim, translated them into English, and checked for accuracy. Transcribed interviews and field notes were imported into QSR NVivo 10 software package to facilitate analysis.

Data Analysis

Higginbottom et al. (2013) point out that data analysis in focused ethnography is iterative and self-reflective. They indicate that a "gathering of researchers" (p. 6) can provide the intrasubjectivity needed for rigorous analysis of data. They suggest that the analysis moves from descriptive coding to the discovery of patterns and themes. We therefore chose to analyze the data in team meetings and used data analysis procedures outlined by Cohen, Kahn, and Steeves (2000), which we believed were consistent with the principles of systematic data analysis as discussed by Higginbottom et al. (2013).

Four team members who are experts in epilepsy or qualitative methods analyzed the data. The team members had weekly meetings to discuss the data analysis. The data set included the interviews of the key and general informants as well as all field notes. We organized the data according to each participant; in other words, we kept data that related to

each women with epilepsy together with data supplied by her family and healer and related field notes.

We implemented data analysis according to the six steps outlined by Cohen et al. (2000).

- 1) **Data immersion.** This step involved reading through all the data several times to obtain a holistic understanding of the participants’ experiences. I read all transcripts and field notes multiple times initially and throughout the course of the study (Cohen et al., 2000).
- 2) **Data reduction or data transformation.** This step involved highlighting all data that were related to the study aims. I completed this step with the input from other team members. This was done by eliminating information that was off the topic (e.g., talks about impending rains or distractions caused by children running around), and simplifying the spoken language of the participants into coherent phrases without changing the unique character of the participants’ words. (Cohen et al., 2000)
- 3) **Line-by-line coding.** This step involved coding each relevant phrase with a label that captured its meaning or essence. I completed this step, and other team members verified the codes. Table 1 provides examples of how some of the data was coded during this step (Cohen et al., 2000).

Quote	Code
1. I had [English] medicine that had to be taken in the morning and night. 2. I skipped the morning dose and kept that for the night. 3. No one [at home] knew about it. I hope it was less [financial] trouble for them.	skipping medicine financial burden
1. I often bite my tongue during my seizure. 2. My mother takes a cloth and cleans everything.	physical consequences seizure care
1. No one can watch it [the seizure]... 2. They say I am like a slaughtered ox.	during the seizure
1. My mother says it [seizures] becomes weaker when I take [English] medicine. 2. I have also gone to Muslim faith healers and other indigenous healers. 3. I don’t know what gives me the relief.	effect of AEDs different treatments confusion

- 4) **Category formation.** Using NVivo, codes related to similar topics were grouped together in categories. For example, the codes missing medicine, cost of English medicine, skipping medicine, restrictions in buying English medicine, and side-effects due to English medicine were gathered into category labelled “struggles with English medicine.” Some of the experiences of the participants could fall under two categories. For example, a participant was skipping the morning dose of her medicine to reduce the financial burden on her family but did so due to the lack of knowledge that skipping medicines could trigger seizures. Therefore, codes related to this text would fall under the categories “financial barriers” as well as “ignorance about seizure management.” After identifying the similarities, I discussed them with the team to ensure no improper biases impacted the analysis (Cohen et al., 2000).

- 5) **Development of preliminary themes.** This step involved arranging categories into preliminary themes. These preliminary working themes facilitated discussions among team members. I presented a brief summary with the rationale for the themes. The team reviewed the codes and categories and suggested changes as appropriate. I then re-examined the data from the transcripts and observations in order to verify or modify the preliminary themes (Cohen et al., 2000).
- 6) **Determination of final themes.** I presented the themes to all the members of the research team with evidence from the transcripts and memos. Changes to the final themes were the result of an iterative process during these meetings with the research team. I then wrote a narrative description of each theme supported by verbatim quotes from the transcript. The team members reviewed and approved the narrative descriptions (Cohen et al., 2000).

We insured rigor through extended contact with participants, seeking clarifications of information provided by participants and triangulation of information through multiple data sources including interviews of key informants, general informants and field notes (Krefting, 1991; Morrow, 2005). In addition, team members held regular de-briefings and the first author regularly consulted participant for the purpose of participant validation during the interviews. The first author maintained an audit trail of all analytic decisions (Farrelly, 2013; Lincoln, 1995).

Description of Participants

The women were between the ages of 21 and 63 years. They had been diagnosed with epilepsy between 4 and 42 years (mean: 21.5 years) prior to enrollment in the study. Four participants reported having experienced convulsive seizures (tonic-clonic) with loss of consciousness, and two reported symptoms of dizziness, wandering, brief loss of consciousness with facial twitching, and/or staring. As per inclusion criteria, the participants were either not receiving AEDs or taking these drugs intermittently.

The sample is described in Table 2. The majority of the key informants were literate and did not have a job, which is not unusual for women from this rural setting.

Table 2: Demographic Information for Key Informants		Total N=6
Education	No formal education	1
	Elementary education	2
	High school	2
	Master's degree	1
Marital Status	Married	3
	Divorced	1
	Widow	1
	Single	1
Employment	Employed	1
	Daily wage laborer	1
	Unemployed	4
Religion	Muslim	1
	Hindu	5

Results

Several themes were created from the interview data. These themes represented findings about participant's psychosocial struggles and experience with epilepsy treatment. The themes related to the women's psychosocial struggles (von Gaudecker, 2015) and their aspirations (von Gaudecker, Taylor, Keeling, Buelow, & Benjamin, 2017) are reported elsewhere. The findings reported here focus on the participants' experiences with epilepsy treatment. Their descriptions about their treatment experiences yielded two major themes. We labeled the first theme "The Intersection of "English" Medicine and Traditional Healing Practices because all the women addressed the role these two healing approaches played in how they dealt with their illness. We labeled the second theme "Barriers to the Use of "English" Medicine because the women provided substantial explanations of why they did not take AEDs or why they did not take them consistently.

How the women and their family members experienced each of these treatment approaches and how the approaches intersected in the participants' lives are described below. Pseudonyms are used to protect the women's identities. The term, participants, is used to refer to all informants, but when data are specifically attributed to one of the groups of informants, the participants are referred to as women, family members, or traditional healers.

Theme 1: The Intersection of "English" Medicine and Traditional Healing Practices

All the participants discussed the role of "English" medicine and traditional healing practices in their attempts to manage their epilepsy and discussed how these two approaches intersected. Some women used them concurrently and some used each one at different times.

All women had received a diagnosis of epilepsy by a physician, although only one had diagnostic tests to confirm the diagnosis. At the time of the women's first seizure, family members typically rushed the women to the nearest hospital or clinic where they were prescribed AEDs. The most commonly prescribed AEDs were lamotrigine and sodium valproate. The women were asked to return for a follow-up visit, and if their seizures had continued, the diagnosis of epilepsy was confirmed, and the AEDs were continued. While some of the women acknowledged the value of the AEDs, all had stopped taking these drugs regularly as prescribed at the time of the study.

Since their diagnosis and initial treatment, most of the women had engaged in both "English" medicine and traditional healing practices to manage their epilepsy. Some had used the two approaches simultaneously and felt them to be complementary. Subaida, who had been living with seizures for the past 35 years, was receiving medications from both a physician and a traditional healer. She stated, "I will never completely stop these medicines. What has helped the most is this one [AED]. He [traditional healer] gave me pills and asked me not to stop my English medicine."

In other instances, however, the use of both "English" medicine and traditional healing at the same time was not helpful, primarily because the recommendations of physicians and traditional healers were inconsistent. For example, some healers had the women stop their AEDs completely and instead gave them herbal compounds. When recommendations were contradictory, most often the women favored the advice of the traditional healers. Nalini, whose traditional healer was tapering the AED dose she had been prescribed by a physician, noted,

I had this amulet even when I was on that [English medicine] and I think it [seizures] became worse when I removed it. Until I went to [a] healer, I was having [seizures] twice or three times a month and now it is once a month.

In some instances, the women sought out traditional healers when they found “English” medicine became ineffective. One traditional healer explained:

They [women with epilepsy] come only when English medicine stops working and then we slowly reduce those medicines and increase this [traditional medicine] as both together can cause interactions. . . . If they believe in doing any rituals or prayers, we encourage them to do so. That is the first step in stress relief. If not, that [stressor] will remain and the treatment we do will not be effective [as] stress can trigger seizures.

Even when using both approaches, some of the women were frustrated that their seizures continued. Geetha said,

I have been taking English medicine for a very long time now. . . and still it [seizures] happens. It became worse and so I am going to this healer now. Those medicines [AEDs] were reduced by my healer. I have not stopped that [AEDs] completely. I have tried many treatments. . . . There was a time when I had so many amulets tied on my body that I found it hard to even sleep. . . my family would bring them from different holy places and I tied it on my body. . . and when I have another seizure, I get angry and I just pull it off.

Theme 2: Barriers to the Use of “English” Medicine

The participants identified a number of barriers to English medicine. These barriers included the following: (a) cost and inaccessibility of the drugs, (b) side effects of the drugs, (c) stigma of the illness, (d) other life burdens, and (e) inconsistencies with their beliefs about epilepsy.

Cost and inaccessibility of the drugs.

One barrier to the use of AEDs was the cost of the drug. The women and/or their family members had to pay for these medications “out of pocket” and found them to be very expensive. Anitha’s mother noted that

for a 3-day supply of these medicines [AEDs], it costs rupees 95 [\$1.58]. But for the other [healer’s] medicine we pay rupees 40 [\$0.66] for one month’s supply. And there [at the healer’s], if we don’t have the money now, we can even pay it the following month.

Because Anitha’s family was paying for her medicines, she discontinued her formal education and skipped her morning doses of the AED to save them money. Her family was unaware she was not taking all the doses she had been prescribed.

Sarasu, the oldest woman in the study, stated,

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] . . . I cannot afford to buy [these] medicines [AEDs].

Some of the women had difficulty obtaining the drugs in their villages and had to purchase these drugs near the urban hospital during a visit to the doctor. In some cases, family members purchased the drugs during a trip to the city. Anitha said, "My brother buys it (her AED) for me from the city, [but] I cannot always disturb him." Subaida reported that the pharmacy in the nearby town did not always have the AEDs in stock and she often had to wait to get them until the pharmacy received a new supply. She said, "These medicines [AEDs] are costly. The pharmacy [close-by] does not stock them. I don't have the money to go to another place and purchase it. . . I will wait till they stock those [AEDs]"

Side effects of the drugs.

Another barrier to the use of AEDs was the side effects of the drugs. Several of the women who had taken sodium valproate and lamotrigine complained of drowsiness, weight gain, and fatigue. The women did not report these side effects to their physicians but rather managed these on their own or with the assistance of a traditional healer. Subaida, whose physician had increased her AED dose because of an increase in the frequency of her seizures, reduced the dose herself as she was experiencing drowsiness that made it hard to function and she did not wish to spend money on a hospital visit to address this side effect. When asked if she discussed with the physician about the medication side effects, she said: "even if I go again, they will say the same thing [to continue]. I have to travel to that place and pay for the doctor's consultation fee. It will be around Rupees. 200. Where is the money for that?" 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.

Social stigma of the illness.

Another barrier to "English" treatment was the social stigma associated with epilepsy in this region of India. Because the women and their families took precautions to hide the women's seizures from others, they feared that seeking treatment in a hospital or clinic could expose the woman's epilepsy. Anitha, who had been hospitalized for seizures, said, "If I get hospitalized, my father's sister will come along with me and we tell everyone that she was hospitalized, not me." While some women hide their treatment in this way, other women avoided treatment to avoid experiencing the stigma associated with the illness. Geetha said:

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. There are times when I have missed doctor's appointments because I wanted to avoid people from seeing me [there] or telling [anyone] where I was going.

Other life burdens.

Other barriers to the use of "English" medicine were the multiple life burdens experienced by the women that took priority over treating epilepsy. For example, Sarasu who became a widow at a very early age, was the sole wage earner for her family, and had no support from her extended family. She said,

I never had such thoughts [of getting treatment for seizures] at that time [when the seizures started]. My eldest son was always sick. How could I think of myself or my sickness. . . and I [would have] needed someone with me to go for

any treatment. If there is no one, where will I go? What will I do? I cannot always rely on my neighbors. Now, if I have to die with this, so be it. I am 63. Why should I worry about this now?

Nonetheless, Sarasu traveled to the nearest town at least once a month to get medicine for her chronic knee pain or asked her son to do so for her. She was a laborer on a plantation and carried stones at construction sites. She explained that “the seizures do not happen every day, but I am unable to do any work with this knee pain.” Although she would sometimes fall during her seizures at her workplace, she feared that her knee pain could end her employment.

Yet another example is Nalini who was diagnosed with epilepsy prior to her wedding had concealed the diagnosis from her husband. She had been on “English” medicine earlier and reported that one of the reasons she was not regular in her treatment was because her husband was unaware of her disease. She said:

There are times when I am unable to buy the medicines because my husband would be with me when I go to the city [where she buys the medicines]. Several times, I have asked my father to buy that [medicine] for me. I have missed several doses because I did not have the medicine with me.

Beliefs regarding the cause of epilepsy.

A major barrier to the use of “English” medicine was that it was not consistent with the beliefs held by many of the women and their families held about the cause of epilepsy. They believed epilepsy was caused by the fate or the will of God, a frightening experience, being “possessed, being the victim of evil,” or experiencing a “divine curse.” Anitha, who had seizures from childhood, said, “I used to have a playmate [whose] family [did] not like anything good happening to anyone. I am not sure if they did something [bad to me] . . . they can do black magic. . . . Maybe they put something in my food.” Anitha’s mother added,

This [seizures] is a possession. We have tried everything for her. She has two kinds [of evil spirits] in her [that] are joined. Now it is hard to separate those two and [make the spirits] leave her. That is why it is so hard to cure this.

Subaida said,

They [her family] say I got scared that day [of her first seizure]. They also say I am possessed. They have done various types of treatments for me. Everyone says it [seizures] is hard to cure. I just want a cure for this.

The traditional healers also attributed the cause of epilepsy to a variety of factors, including sudden fright, a problem within the brain, an evil spirit, or stress.

Due to their beliefs about the cause of epilepsy, the women and their family members consulted religious and indigenous healers about how to treat the women’s epilepsy. The healers would listen to the women’s account of their symptoms, acknowledge the diagnosis made by the allopathic physicians or other healers, and conduct astrological calculations based on each woman’s horoscope. The religious healers recommended visiting temples or other places of worship, making offerings to gods and goddesses, or saying prayers to promote the participants’ healing. The indigenous healers used Ayurvedic medicine and prescribed “secret herbs” and *ghee* (clarified butter), a “treatment recipe” that was passed on to them by their ancestors.

One common treatment recommended by the traditional healers was the wearing of an amulet around the neck, waist, or arm. An amulet is a metal capsule tied in the center of a long, thick, black string. Amulets are worn to protect participants from evil forces and harm. All the women had worn amulets at least once since their diagnosis. They wore these with reverence and were convinced that the amulets had a major influence on seizure control. Subaida revealed that verses of the Koran were written on a piece of paper and placed in the capsule. Geetha revealed that herbs were in her amulet. Nalini stated, “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.”

The women and their family members often used traditional healing practices to manage seizures. Several women had visible scars on their faces and arms that resulted from falls during seizures. Subaida, who had a scar on her earlobe, reported that she had fallen on a sharp object in the kitchen during a seizure, tore her earlobe, and was rushed to the hospital. One practice used during seizures was the placing of an iron key in the palm of the convulsing woman. This practice was based upon the belief that iron could shackle the evil spirit causing the seizures. Other practices included restraining the person until the seizure stopped, smearing *ghee* on the forehead, inserting a coconut husk into the seizing woman’s mouth, and giving her water to drink. Subaida’s mother said,

I used to keep pieces of coconut husk here [in the house]. During [her] seizure, we insert one piece into her mouth, so that she won’t bite her tongue.

Sarasu and Seetha, the two oldest women in the study, treated their seizures with herbs, *ghee*, and consecrated material that included holy ashes from a temple.

Because traditional healers used practices that were consistent with the women’s beliefs about epilepsy, the women had much trust in and respect for the traditional healers and found it comforting to talk to them. Anitha said, “He [traditional healer] is my God now.” Thus the women’s beliefs about the cause of epilepsy often caused them to reject “English” medicines.

Discussion

Focused ethnography was used in this study to produce an in-depth description of how women diagnosed with epilepsy in Kerala, India, who did not take AEDs regularly experienced treatment for their disease. The findings revealed that the women received both Western allopathic treatments and engaged in religious and indigenous healing practices. In some cases, the two approaches were complementary but in other cases the two approaches clashed, such as when the traditional healers advised women to discontinue their medicines.

The participants’ descriptions of their experiences with “English” medicine were dominated by discussions of the many barriers they encountered in affording and accessing the AEDs. Although the government of Kerala has taken steps to eradicate poverty among women in this region (John, 2017), the out-of-pocket costs of the AEDs and the expense of travel to access the medications remained a major obstacle for the women in this study. A study of epilepsy management in Kozhikode revealed that primary care physicians from 14 districts in Kerala usually prescribed two of the most expensive AEDs: sodium valproate and carbamazepine (Iyer, Rekha, Kumar, Sarma, & Radhakrishnan, 2011). Our findings support the conclusion of this study that the cost of English medicine was a major contributing factor to treatment gap suggesting that prescriptions of more low-cost medicines could improve epilepsy treatment in this region. Moreover, our finding that stigma was another major barrier to the use of “English” medicine resonates with studies conducted in Zambia (Baskind & Birbeck, 2005) and Ecuador (Luna et al., 2017), which also revealed epilepsy stigma interferes with treatment utilization.

The participants' beliefs about the cause of epilepsy often caused them to embrace traditional healing practices, sometimes in lieu of "English" medicines. The finding that they tended to offer spiritual- and culturally-based rather than physiological explanations for their epilepsy was consistent with studies conducted in other developing countries that revealed that local beliefs about the cause of epilepsy, coupled with limited evidence-based information about the causes and course of the disease, influence persons' choice of treatment approaches (Ismail, Wright, Rhodes, & Small, 2005; Mbuba, Ngugi, Newton, & Carter, 2008; Mushi et al., 2012).

The importance of traditional healers in the management of epilepsy was clearly evident in our findings, for example, the participants and their families trusted the healers and their treatment. As other authors have reported, these healers are well-respected, provide comfort and guidance, and tend to acknowledge the role of stress in the trigger of seizures (Novakova, Harris, Ponnusamy, & Reuber, 2013). Traditional Indian healers assume multiple roles as caregivers, health educators, counselors, moral and ethical guides, teachers, and community leaders (Payyappalli, 2010).

Our findings also support recommendations that health care providers should partner with local stakeholders to improve access to care for PWE. For example, a study conducted in tribal communities in Ranchi, India, where the epilepsy treatment gap was determined to be at 95%, found that when health care professionals partnered with traditional healers and other community health care volunteers, treatment utilization could be improved considerably (Nizamie et al., 2009). Community health workers often provide a link between the community, traditional healers, and health care professionals. Several successful collaborative health initiatives in Kerala have been used to promote a smoking cessation intervention trial (Jayakrishnan, Mathew, Uutela, Auvinen, & Sebastian, 2013), detect developmental delays and disabilities among children (Nair et al., 2014), and provide surveillance of non-communicable diseases (Menon, Joseph, Thachil, Attacheril, & Banerjee, 2014).

Our findings thus suggest that improving the treatment of epilepsy among women in rural Southern India requires an appreciation of the complex and dynamic interplay of "English" medicine and traditional healing practices in the lives of women. While health care providers can provide education for women and their family members about the cause and course of epilepsy, strategies for the safe and effective management of seizures, and the actions and potential side effects of medications, these efforts must occur with a full appreciation and respect for the culturally based beliefs and values of the community and the women's commitment to the healing practices espoused by traditional healers.

Limitations

Our findings should be understood in the context of several limitations. While all the women in our study were diagnosed with epilepsy by a physician, the diagnoses were made primarily by clinical history rather than diagnostic testing, thereby making it impossible to verify that all the women had epilepsy. Moreover, because our sample included only six key informants and several women referred to the study refused participation because of fear that their disease would be revealed to others in the community, the voices of many women in the community who met study criteria are not represented in the study. Yet with the use of extended observations and multiple interviews with the key and general informants, we were able to provide a robust description of the participants' experiences with treatment for epilepsy. Studies from a variety of regions in India would provide additional information about how the lived treatment experiences of women with epilepsy can contribute to the both positive and negative outcomes for this population.

Conclusion

This focused ethnography brings to light the stories of six women who live within the epilepsy treatment gap in rural South India. Their treatment experiences represent a combination of allopathic and traditional strategies used to manage their epilepsy. Their treatment choices are influenced by their cultural beliefs, their social situation, and their economic resources. The findings are pertinent to stakeholders who are interested in exploring barriers to evidence-based care and improving epilepsy care of women living with epilepsy in Kozhikode area. While health care professionals can provide epilepsy education and spearhead community initiatives to diminish epilepsy stigma, they should do so with a nuanced appreciation of the cultural and religious beliefs of the women and their families as well as the social challenges that influence their treatment decisions. The study also has potential to guide future researchers to develop studies related to epilepsy treatment gap and to develop culturally appropriate interventions to epilepsy care.

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University of Virginia Global Health Scholar award and the Skinner Scholarship funded this study. This publication was supported by the 5T32 NR007066 award from the National Institute of Nursing Research. Its contents are the responsibility of the authors only and do not necessarily represent the official views of the NINR or the NIH.

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Article Citation

von Gaudecker, J. R., Taylor, A. G., Buelow, J. M., Benjamin, S., & Draucker, C. B. (2019). Women's experiences with epilepsy treatment in Southern India: A focused ethnography. *The Qualitative Report*, 24(5), 1034-1051. Retrieved from <https://nsuworks.nova.edu/tqr/vol24/iss5/7>
