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# Experiences of suffering and therapeutic nomadism of Mayan people with seizures in the Highlands of Chiapas, Mexico

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**Abstract:** *Background:* The indigenous population in Mexico lives in rural areas has great difficulties accessing medical care, and its epidemiological profile differs from the general population, showing greater vulnerability to various illnesses. However, little is known about the impact of the epilepsy within this population. *Objective:* This study investigated how epilepsy affects indigenous Mexicans by reconstructing the therapeutic itineraries of Tzotzil and Tzeltal people from the Chiapas Highlands who experience seizures. *Methods:* Through an anthropological approach, combining participant observation and 132 open interviews we document sixteen cases on convulsive crises among Tzotzil and Tzeltal people of the Chiapas Highlands, who were interviewed between 2000 and 2012. Using the three analytical concepts of *the experience of suffering*, *interpretative frames of the sickness* and *therapeutic nomadism*, we analysed the following dimensions: (a) frequency of seizures; (b) health consequences of seizures; (c) disease onset and causes; (d) care trajectories; (e) the impact on the sick and on their family's life, and (e) mediation of stigma and social discrimination in their experiences and in seeking care. *Results:* We observed an interweaving of structural and cultural processes that were threatening to the health of indigenous Mexicans. On one hand, there were structural dimensions such as poverty and ethnic discrimination. On the other, we found some problematic cultural dimensions, such as views related to gender, sickness, misfortune, and stigma associated with epilepsy. The interaction of both processes affected health seeking behaviour and health for these individuals, sometimes producing successful responses to cultural and structural oppression, but in most cases lead to uncontrolled convulsions and resulting suffering for them and their caregivers. *Conclusion:* The ethnographic perspective allowed to elucidate the complexity of broader sociocultural processes, which mediate the therapeutic itineraries of the participants. This underlines the profound neglect and suffering of these people and their caregivers, and the urgent need to carry out public policies that improve the timely diagnosis and care of epilepsy from a culturally and structurally relevant perspective.

**Keywords:** Epilepsy, Stigma, Indigenous peoples, Mental Illness, Therapeutic Nomadism, Therapeutic Itineraries, Experiences of Suffering.

### Introduction

From a biomedical perspective, most seizures are related to epilepsy (note 1), a chronic and non-communicable neurological disorder. It is estimated that globally, 80% of people with epilepsy live in low-and middle-income countries, and three-quarters of people living in low-income countries do not receive the necessary treatment (WHO, 2019). In these countries, which includes Mexico, two of the main documented causes of acquired epilepsy are neurocysticercosis and perinatal hypoxia-ischemia (Romero et al. 2004). These conditions are common in the poorest and most marginalized communities (Noriega-Morales & Shkurovich-Bialik, 2020), and this includes the indigenous contexts in Chiapas, where access to adequate hygiene and sanitation measures and timely care in obstetric emergencies are not readily available.

The prevalence of epilepsy is not well documented in Mexico, though several studies have been done to investigate this. The most recent research shows uneven prevalence of epilepsy across rural communities, ranging from 25.4 per 1000 in Hidalgo, to 3.9 cases per 1000 in Puebla (Noriega-Morales & Shkurovich-Bialik, 2020). However, the impact of the disease within the indigenous population is not known because there are no epidemiological data disaggregated by ethnicity. In México, the only existing studies to date in this population are those carried out by Eroza (2005, 2006) and Eroza & Álvarez (2008). These scholars argued that seizures are just one expression of illness and misfortune among many whose causes are linked to phenomena ranging from divine retribution to witchcraft, which pervade the various social responses from communities towards the afflicted individuals.

There have been a small number of qualitative investigations of epilepsy conducted in urban contexts of the country, such as one carried out by Espinola-Narudille et al. (2014) on social stigma and the experience of epilepsy in Mexico City, analyzing how internalized, interpersonal, and institutional stigma prevents people with epilepsy from participating in school and employment and reduces their opportunities to establish peer and couple relationships. There have been few investigations related to the therapeutic itineraries of people with seizures and/or epilepsy, and so-called medical pluralism (use of conventional medicine, local/Indigenous medicine, alternative medicine, etc.). One of the few studies that examined some of these mentioned aspects was conducted in an urban area of Sonora (Figueroa-Duarte, 2010), and found that there was a significantly limited capacity of the health systems to serve this population. Figueroa-Duarte (2010) attributed this issue to the precarious conditions under which these families live and, among others, physicians' existing work overload. In other Latin American contexts, there has been a small number of research related to seizures and seeking care, for example Areco et al. (2015) describes an Argentinian patient's own perception of the disorder and the

meanings he ascribes to it within a particular therapeutic itinerary. However, these investigations have not considered ethnicity as a socio-cultural process that affects the experience of suffering, the search for care and the consequences of the disease.

Epilepsy is a repetitive, unpredictable experience that is commonly accompanied by fear and loss of control, which can make it especially distressing (Krauskopf & De La Barra, 2013). The recurrence of seizures with its physical and psychological consequences make it a devastating disease both for those who suffer from it and for their family and social environment (Devinsky et al. 2018, cited in Noriega-Morales & Shkurovich, 2020). Research shows that psychopathologies such as depression, anxiety, and psychotic disorders are common comorbidities in people with epilepsy (Krauskopf & De La Barra, 2013). A review of studies conducted between 1980 and 2011 showed that the average rate of psychiatric disorders in people with uncomplicated epilepsy was around 30%, and for complicated epilepsy it was 50% (Reilly, Kent & Neville, 2013). Other studies point to epilepsy's impacts on mental health, such as lower self-esteem, reduced coping ability, and increased self-isolation (Smeets et al. 2007).

Several epidemiological and qualitative investigations have pointed to the importance of psychosocial, economic, and cultural factors linked to the incidence of psychopathologies among people with epilepsy. For example, social processes in the patient's environment are hugely consequential for their health because it can help or hinder timely diagnosis, care and control of the disease (Guo et al. 2012). In the Mexican context, social discrimination related to epilepsy has been shown to limit educational opportunities and access to employment (Espinola-Narudille et al. 2014). This coincides with other studies outside Mexico that describe the repercussions of social stigma at the internalized, interpersonal, and institutional levels (Guo et al. 2012). In the Mexican and Global South context, the high cost of access to diagnosis and treatment of epilepsy has been associated with lower patient compliance (Noriega-Morales & Shkurovich, 2020).

The indigenous people of Mexico have greater difficulties accessing medical care, and consequently they are more negatively affected by diseases that are among the top causes of death in the general population (Muñoz & Sesia, in press). The general population experiences several difficulties related to the adequate care and control of seizures (Espinola-Narudille et al. 2014), but little is known regarding ethnic minorities. In other health care situations, not related to epilepsy, racist attitudes towards indigenous peoples in health institutions has been reported. These racist attitudes are stemming from discriminatory attitudes or communications barriers due to a lack of linguistic and cultural translators and interpreters (Muñoz & Sesia, in press). This is interlinked to conditions of social and economic marginalization (note 2). As far as we know, as of 2020 there have been no initiatives in Mexico to provide professional translation of

biomedical and psychosocial information about epilepsy in any Indigenous languages (Agencia EFE, 2020).

The aim of this article is to reconstruct the therapeutic itineraries (Sindzingre, 1983) of Tzotzil and Tzeltal people who experience seizures. This involves anthropological reconstruction of the processes, starting with the emergence of the suffering to the care-seeking behaviour (Janzen, 1982), and examine to various resources that may belong to differentiated care alternatives. We relied on three key concepts for carrying out this method of analysis.

The first concept is *the experience of suffering* (Kleinman, 1985). This concept is understood as the one that articulates the subjective and intersubjective dimensions of illness in a broader sense, and therefore, involves processes at the family and eventually community level influencing social responses to the sick people, which is linked to the experience and treatment of seizures and mental illness caused by the disease.

The second concept is *the interpretative frame of the sickness and misfortune* (Eroza, 2016). This refers to the interaction between ideas relating to divine retribution, witchcraft and other spiritual concepts, and their link to the everyday lived experience and/or perceived character of social life. It confers room for health seeking behaviours related to modes of health care such as biomedicine, multivitamins, and religious congregations, considering the recognition of the suffering constructed by the social group to which the subject belongs.

The third concept is *therapeutic nomadism* (Muñoz, 2020). This concept is understood as the epistemic transition process inherent to health seeking behaviour, which consists of the articulation of the actor's life strategies, understood as a set of cultural practices destined to bio / socio-symbolic reproduction, interacting with the existing social stratification conditions. Therapeutic nomadism, as a critical modality of epistemic nomadism (enunciated by Deleuze and Guattari, 1998, in Muñoz, 2020) is a becoming (devenir) that, as a process and not as a set of positions or fixed points, condenses the social tensions and the specificities of the praxis and human thinking around the health seeking behaviour, which can become the expression of their success or failure to adequately care for a specific health problem (Muñoz, 2020). This proposal further broadens the analytical view associated with the approach of medical pluralism, allowing care-seeking processes to be conceived as a kaleidoscope of interacting medical practices and systems, rather than a mosaic in watertight and disconnected compartments.

Based on the documented testimonies, the knowledge we have of the life contexts of the people who provided them, and our many years of experience in field work on this and other healthcare-related processes, we reconstruct the therapeutic itineraries emphasising the economic and emotional consequences of the disease for both the patients and their caregivers in the contexts of the structural violence (Farmer, 2004) in which

they live. As described by Quesada, Hart & Bourgois (2011), this type of violence is expressed mainly through denial of basic needs such as access to medical care, which gives rise to forms of structural vulnerability. Unlike the proposal of these authors, we consider the affected persons to be agents that can also participate in the beliefs and attitudes that contribute to this vulnerability. Specifically, we analyse the following dimensions: (a) the frequency of seizures; (b) health consequences of seizures; (c) disease onset and causes; (d) care trajectories; (e) the impact on the sick and on their family's life, and (f) mediation of stigma and social discrimination in their experiences and in seeking care.

### **Methods**

We conducted an analysis of empirical data compiled through medical anthropology field work carried out in the period between 2000 and 2012. The included studies combined participant observation and open interviews. The temporality of the analysed material also made it possible to study the prevalence of social processes involved in the research problem, and the degree to which they were repeated throughout the study period. The processes of structural vulnerability pervade the therapeutic itineraries of the research participants, and so there were no significant changes in the impact of public policies on the indigenous peoples or the health system in the Chiapas Highlands during the period studied in relation to the study subject.

The testimonies presented here are part of a total of 132 interviews carried out in the framework of two studies. The first was undertaken between 2000 and 2001 and studied mental and behavioural disorders, while the second ran from 2008 to 2012 and focused on experiences related to various ailments of indigenous people in the Chiapas Highlands. The interviewees did not report having received a formal medical diagnosis of epilepsy, except for two cases in children. In certain instances, we inferred the diagnosis from the prescribed medications and mostly from the signs and symptoms.

The reconstruction of the therapeutic itineraries used the reported experiences the participants, and of the family members who were often their caregivers. The target population was the Tzotzil and Tzeltal Mayan peoples of the Chiapas Highlands of Mexico. The qualitative data was collected through open interviews, either with patients or their relatives, or sometimes both simultaneously. Nine are from the first study done in 2000 and 2001, while six come from the second study and were completed in the years 2008, 2009 and 2012. The municipalities of residence of the participants were: Zinacantan and San Juan Chamula, both Tzotzil; Oxchuc and Tenejapa, both Tzeltal; and San Cristóbal de Las Casas which has a population belonging to both ethnic groups.

Sixteen cases involving seizure experiences are documented, from twelve of the affected individuals and/or one or more of their close relatives. In the cases of interviewing only family or caregivers, this was due to the

inability of the seizure patients to report their experience themselves because of severe impairment or young age.

## Results

### Characterization of seizures from the experiences of the participants

Some of the interviewees referred to the seizures as *tup 'ik'* (Tzotzil) or *tup 'tup' ik'* (Tzeltal) (note 3). Some also used the term epilepsy, seizures, convulsions, or fits, though less frequently. Several participants were aware of the term epilepsy but did not refer to it explicitly. In general, they had heard it in a private or public clinic or hospital, or in their community setting. Regarding previous seizure experiences, they reported feelings of general fear, fear of falling, feeling dazed, heart weakness, dizziness, sensation of electric shock, cloudy vision, blocked heart (or Ko'ntontik, a reference to an area which encompass the chest and the abdomen, and also has implications involving consciousness and soul), chills, headache, loss of speech, and loss of memory and/or consciousness. They also report seeing a fading, purple hue while experiencing it. In terms of symptoms experienced after the seizure, they reported feeling fatigue or drowsiness, feeling cold, heaviness in the head, the sensation of having been hit, vomiting, thirst, loss of appetite, and shame.

A variation in how the experiences were characterized by some patients or their caregiver described the seizures as lapses into oblivion (note 4). These were also reported to include fainting and/or mild tremors, suggesting they were less severe episodes. Some participants mentioned both types of seizure occurring in same individual. Most noted that the sick person was salivating. The duration and number of seizures in a day, and their frequency over weeks and months, varied.

These untreated seizure experiences had had various consequences for patient health. Because ground-level stoves are still used in the region, some reported falling on them, causing severe burns and even loss of limbs, which the interviewers could confirm from the evidence on their body. The physical impact suffered when falling on solid surfaces or objects could have caused brain injuries and further deteriorated their health, which is also exacerbated by the lack of medical treatment. The latter seemed to be evident from observed disorderly behaviour in these participants.

### Onset of the disease

The onset of seizures was most often in childhood or adolescence, beginning during adulthood for only four participants. Some interviewees mentioned experiencing signs and symptoms before the onset of seizures, in some cases with a hallucinatory component. But after the first seizure, they later became recurrent. There are also examples in which other enduring conditions were considered to coincide with the seizures.

**Juan Domingo (Father of Braulio):** We noticed it when he was a year and a half, the usual age that a child walks, talks, is aware—but

for Braulio [this was] only at times. He was asleep as if having a bad dream, shaking softly. Then it got worse. He lasted two minutes convulsing, he started to have around fifteen fits a day.

At two years old he began to sit and grab his toys, but he would throw them. He wouldn't crawl properly, he would creep. He would grab something to get up, but fall down. He would walk holding onto something. He used to eat everything, but now just milk, because he does not chew. When falling he hits his head very hard [because] he doesn't know how to hold himself—when he falls down he does not put his hands out.

**Patricia:** I used to go out for water. [One day when] I was twelve years old, it was very hot. I sat and then I fainted for almost one hour. After that, it didn't happen for a year. I got married and then it started to happen every three months. I only rested for one or two months [between seizures]. The first time my husband saw me seizing he was scared, he asked me if it happened often.

**Sandra:** I started seeing anything and I imagined I was seeing black dogs here in the house, that is why I would go out some days, when they took me away from home I could stop looking at them (note 5).

#### **Attribution of Cause**

The causes attributed to seizures by participants were various and numerous. Some speculated about physical and emotional damage suffered at some point in life, or related to genetic heritage, or mysterious contagion mechanisms related to physical contact. There were also some ideas linked to indigenous beliefs of the region, such as speculations about witchcraft based on existing interpersonal conflicts. This last type of reading can acquire meanings linked to social dramas.

**Patricia:** My brother hit my head with a hammer [when] I was ten years old. It swelled, I felt pain for three weeks. But then it passed, although I started to feel dizzy, mainly when it was very hot. My brother was making a chair, but since I didn't hold it well, he smashed his hand and hit me.

**Alma (Mother of Natalia):** I helped a pregnant woman, who fell due to seizures, to get up. I think I got [the disease] there [and passed it to Natalia when I was pregnant]. There are quite a few with that sickness, they say that that girl has just started too. I don't know if the sickness comes from our Lord. I think that lady passed it on to the girl.

**Eugenia (Mother of Guadalupe):** My neighbours said that perhaps she passed out when she was born or she had a blow to the brain. She was born without delay, I don't know why she came like this, my other children are normal. The doctors said it was epilepsy. There are a lot of people I hear who have epilepsy, that's why I thought it could be, but she has never had a medical study. My husband has a cousin who suffers from epilepsy, her grandfather also suffered from it.

**Martín (Husband of Patricia):** Her dad had conflicts with her uncle over land. That could have motivated him to send the illness. The healers said that it was aimed at the men, but since they have strong spirits, [Patricia] caught the witchcraft. They added that she was born with that weakness, because she had been sick for twelve years. Where we took her to they said, “if you had taken her to healers first and not to doctors, the medicines would have helped. If someone is causing her harm [with witchcraft] they don't work.”

The etiological attributions observed, whether linked or not to some of the causes mentioned above, can be considered part of the culture bound syndromes, such as "fright" or "envy." Similarly, participants often made supernatural attributions, as with certain traditional therapists such as healers who make use of various interpretative frameworks related to this universe of meaning.

**Alonso (Father of Miguel):** He became ill when he stayed at school with his brothers to help the teachers, and an *ijk'al* (note 6) scared him. When he played basketball with his brother, he held the ball very tightly without letting it go. Though he had not fainted yet, he stayed motionless. But when he finished sixth grade, he worsened.

**María (Wife of Francisco):** He was not in serious condition. He had stomach and headaches, but he was always cured with prayers. A healer said that he had a gift, and others said that he did not get healed because other healers did not properly heal him the first time, and he lost the gift. Another said that his spirit, his body and his name are sold [to an evil spirit] or trapped. Other healers said that he has a combination of fright and that his soul was sold or trapped in a haunted place.

There tended to be more than one attributed cause. These would vary over time, or co-participate in a dynamic, changing, or even complementary way. This seems to be an expression of the dynamism, often conflictive and uncertain, of social life of the people interviewed.

**Andrea (Sister of Sandra):** In Esquipulas (note 7) [the doctors] said it was her bile. The same was said by the healers, who also said that it was envy—[some people] envy her because she quarrelled with a boy Sandra lived with.

**Sandra:** Beforehand, I asked him if he would buy my medicines and he said yes. Then I found that he didn't work. He only used to drink alcohol and sleep. I told the authorities, they locked him up in jail, but I told them I didn't want to continue with him and they accepted (note 8). His parents got upset, they told him that it happened because of getting together with [ethnically] different people (note 9).

The testimonies reveal a wide-ranging array of care seeking trajectories. These included mostly the use of medical drugs (whether acquired in pharmacies or through medical prescription), traditional treatments provided by indigenous and mestizo healers, up to relatively circumstantial contacts with hospitals, where they may end up out of acute need for specialized care. When these contacts occur, they often lead to the need to undergo medical procedures, which cost is not covered by health institutions, and hence it is difficult to advance, in terms of care, in these settings.

**Patricia:** The doctor gave me syrup. I took it for a short time, as my mother thought I had improved. For a year I had no seizures, but when I got to Martin's house they resumed.

**Martín:** They said it was a created sickness (note 10). We went to a spiritualist, but I don't know if he only wanted money, he said that he could pray to eliminate evil. ... They advised me to go to those who know how to heal, that there were those who gave medicine. I tried everything they told me to do, but she was still sick, and I said, "what if we go to the clinic?" ... They injected her with Epamin in a pharmacy and her fits became less frequent. Then we came to the clinic for treatment and she started having seizures only once a year.

**Pedro (Father of Bulmaro):** A spiritualist said, "your son has a gift," but those people only rob you. He said, "your son will be this and this," and he charged \$500 for each cure. The last time he wanted \$3000, he only swept his body (note 11), and we never saw improvement. In the Social Security (note 12) they took blood from him and they found out what it was. They gave him medicines to control the fits, but they made him feel worse. Every eight days, up to three times a day he had seizures, but thank God we brought him to Dr. Uribe (note 13) and he prescribed him Rebotril. He really helped him.

**Juan Domingo:** At the Regional Hospital they said it was his brain and they couldn't treat him, that we had to go to Tuxtla, where they asked for an electroencephalogram. It cost \$700, we borrowed \$1,300. Then a tomography, we paid \$1800. We asked the INI (note 14) for help, and they recommended us to go to Esquipulas where they helped us with \$200 to cover the cost of the tomography...

It was not possible to determine a predominant sequence from the analysed cases. The emergence of convulsions occurs in very different circumstances and conditions, and tracing from the start is a seemingly haphazard path to follow. However, it is necessary to consider factors such as poverty, ethnic discrimination (in the form of scolding and abuse), and greater or lesser access to health services (depending on the existing medical infrastructure in the communities, distances, and communication channels). These are variables that the interviewees consistently expressed despite their diversity of situations. They are compounded by the added conditions of vulnerability permeated by values and unequal gender relations, as well

as sociocultural views around health and sickness that are linked to stigma and discrimination.

**Manuela (Mother Augustin and Margarita):** Since I had no money and there was no clinic, I didn't seek treatment for [Augustin] as a child. Since he did not walk, they told me that he had double hair (note 15). His father looked for a *poxil* (note 16) in Cancuc (note 17). He brought herbs to bathe his head. That calmed his diarrhoea, then he started to get strong and to play, crawling with his little sister. He walked until he was three years old.... I gave him a hummingbird, they said he had to eat it smoked, also his nest. It improved him, I only gave him the cooked brain.... I thought Margarita had double hair too. A healer gave her a plant, I don't know if that cured her...

When Augustin was older he stopped eating. A nurse injected him, but he didn't get better. I hugged him and massaged him, but it didn't relieve him. The nurse recommended taking him to San Cristóbal. Since I'm a widow and I have no money, I didn't know how. My daughter who lives there took us to a private doctor. The nurse said that his liver was inflamed with many germs, which is why he suffered from so much diarrhoea. The doctor said the same and that he needed surgery. But we thought that he would die, because he did not have the strength, and it would be a waste of money for my daughter. He was only injected with serum, vitamins, and medicine to kill the microbes.

**Alma:** We looked for expensive medicines, but they didn't heal her. They told me to buy herbs, but nothing happened. She had seizures on February 15th, and on March 15th she will have seizures—every month she has seizures, sometimes not, but she falls and hits herself. There are months that the seizure doesn't arrive and she faints, her hands turn purple. There are times every week, recently it was daily. The doctor sent me to Ocosingo (note 18) with a letter, I went with his father.

In Ocosingo the doctor was to give her medicine and checked her little head to see what she had, but we forgot to ask for the result. We didn't know what she had and he told us to go again, but my husband no longer wanted to accompany me. In Ocosingo they took her blood with a syringe and I brought it to the clinic, but they found nothing ... The doctor only scolded us because we did not return the letter, he didn't want to write another to take her back. I asked him if there is medicine for fits or some vitamins for weakness, as she does not want to eat ... he said no and that I do not know how to take care of my children. In Ocosingo the doctor ordered that my daughter be bathed in cold water, because she had fever, but she got very sick. I went to a private doctor (note 19) for injections and she was cured.

By reflecting on the intrinsic logic of these trajectories, we will be in a position to understand that while they are partially a product of the pragmatism of those affected, they ultimately result from factors far beyond their individual decisions in the search for healthcare. This therapeutic nomadism (Muñoz, 2020) compels people who find relief somewhere in this process to wonder which one of the arrays of options was the cause of such improvement. Despite often achieving a temporary health recovery, the course that seems to prevail in the care seeking process of these individuals is far from encouraging. In this respect, it seems that regardless of the sequence followed in seeking care, both sick people and their relatives tend to arrive at the same hopeless conclusion.

**Cecilia (Sister-in-law of Rosa):** If someone saw her convulsing in the street, she/he would talk about a place where there was someone who knew how to cure her. In Pokolum (note 20) the *poxlawanej* (note 21) gave her herbs, injections, and pills.

**Petra (Mother of Rosa):** On Sunday she had convulsions and started taking the medicines. [She had them] on Monday and yesterday too, although without fainting, but it was tough. She did not want the plants; her treatment was to last a year and she was forbidden from eating many foods. The healer said that these plants were very potent. She takes them but does not improve. Someone told me before about San Juan Cancuc, where they gave us different plants, but they didn't work. And then we went to Pocolum, but when her fits started I didn't take her promptly, although they told me to do so, [because] I couldn't. In Cancuc the *poxil* gave us plants and lit candles... We don't know where or what medicines made her feel better, because we went to many places.

In line with these tendencies, the interviewees had threatening views concerning medical care in the public health system. These often entail a fear of being killed, as they report to have heard or witnessed the death of other indigenous peoples in these settings. This affects their decision-making regarding seeking care.

**Cristina (Mother of Domingo and Manuel):** The nurse said, “we know medicines for that, it will take three days”. But they took too long to discharge him, and since I didn't have a sweater, I got an air (note 22). The doctor only lied. “Why it is taking so long? You haven't cured my son, I'm leaving,” I told them. They accommodated him, bathed him, they were hanging something on the mattress. They put a needle in him and the serum came in, it ran out and another red serum came. They put a needle in his arm again, my son almost died.

The doctor said, “if he is not cured, let's take him to Tuxtla.” I heard that and ran out. I told a person that my son was in the hospital and that I was afraid because they were taking him to Tuxtla to kill him. He asked why and if I did not have a husband, I told him that he had died. He asked me not to cry and put a coin on the phone and I called

the nurse. When he arrived, I told him, “you lied to me, you said only three days and a week has gone by, his hands and feet are crushed on the edge of the bed by the rag with which he was tied.” “I’ll talk to the doctor,” he said. I knew that a man who was taken to Tuxtla had died there. The nurse told the doctors, “the boy doesn’t have a father, he is poor and the woman doesn’t have a husband, why take him there if they have no money?”

### **The spiritual and biomedical pathways of healing**

We have seen the diversity of alternatives that participants resorted to resolve seizures, including those related to religious and spiritual beliefs. These include practices based in ideas about a vast and complex spiritual reality where the spirits of human beings interact with each other, as well and as with other beings believed to exist in that realm. It is believed that in this reality, hidden animosities are revealed, and moral, intimate, and shared dilemmas are worked through and hopefully settled. Insofar as it is believed that the causes of suffering (in this case, seizures) reside in this sphere of spiritual interaction, it is also believed that there are healing pathways that can be alternatives or complementary to somatic forms of care. The complexity of these beliefs increases in contexts where religious conversion maintains a great presence and dynamism. Protestant cults have a conflicting but also somewhat complementary relation with traditional beliefs and therefore give room to ideas relating to this spiritual realm. Another significant aspect in the kaleidoscopic relationship between different “health systems,” relates to the fact that some doctors use local, non-biomedical nosological categories.

In relation to these spiritual beliefs, faith is considered one of the significant factors for being healed. This refers both to the sincere belief in the healing procedure, and to the moral integrity with which one must interact in the spiritual world, particularly regarding the sacred beings with whom one dialogues. In this respect, although such experiences do not give clear indications of having been medically effective in solving or controlling the health problem, it is possible to at least consider the emotional benefits it can provide.

**Alonso:** I thought maybe he got the sickness elsewhere. The healer said it could be his spirit, and a spiritualist told us that he found the sickness on his way. The doctor also said that he was frightened because of his nerves. The healers prayed for him with candles and incense.... Pastors [of Christian churches] also came. They used herbs, but with that he got worse. They also said that we should entrust ourselves to God. Sometimes we do not remember him, and if we do we don’t do it with our full heart, and that is why the prayers don’t work and Miguel is still sick.

**Pedro:** The preachers pray for him. They come home and thank God he got better by putting his faith in God. He has been without

seizures for a year. God spoke to him in a dream telling him to take the medicine and Bulmaro has done it.

**Bulmaro:** Jesus Christ came, he told me three times “take your pill and you will be healed.” At seven in the morning I got up and took it, but I doubted, will he be able to heal me? The preachers teach that the Bible says, “son do not doubt me,” and my father said to the pastor, “my son doubts our Lord a lot,” and the pastor prayed. I felt like a child. It was a change, I took the pills, and I no longer had such strong fits.

As we anticipated, becoming a healer is deemed an alternative path for being healed. Not only does it demand belief in that path as one’s destiny, but also entails proving one’s moral integrity to convince the sacred entities that the gift will be used only for benevolent purposes, as well as passing certain tests and tricks to overcome fear. Dreams are the predominant field of interaction in which people face these tests. Ideally, the outcome of this kind of trance would be as **Don Tono**, a Tzotzil man who at some point in his life suffered from seizures and afterward became a traditional healer, refers to it:

[A spiritualist healer] said, “You will be healed, but you ought to accept.” “Ah!” I said, “how am I going to heal if I don't know how?” “Your spirit will show you, if you don't accept, the older you are, the more often your fits occur and you will end up crazy.” “Well,” I said. The healer put candle and that was all, it was just one cure. I was worried because what were people going to say if I didn't heal them? “We will set a candle so that you receive the table (note 23), so that and you will be able to cure the sick,” he said. He prepared candles, herbs, small candles and a tallow candle.

In dreams they showed me what remedies to give, how to pray, the spirits told me everything, God sent all, how to put a candle, how to feel a pulse (note 24), the saints taught me. In dreams they test us, I saw a river, there are evil spirits that wanted to catch me. When they caught me, I would fly to the other side of the river. I was not afraid, they tried to grab me, they were envious because I would learn to heal. They were spirits of acquaintances with whom I got along well, but there I discovered his envy. I was healed because I believed and accepted what the healer said.

However, apparently Don Tono's experience is far from the rule. Instead, this can be an existential drama that starts with the hope of reaching good health, but gradually turns into discouragement.

**Guadalupe:** I have dreamed of roads that they say I should walk. Sometimes they put two or three roads, I don't decide which one to follow. I have also dreamed of distant hills. I climb [the hills], but before reaching the top I stop. The healers say I ought to keep trying. A man told me that I should arrive, but that's when I woke up.

[They tell me] that if I do what they tell me I will be cured. I have also passed bridges. They make me cross rivers, also from one door to another, and I have passed. I only remember some things. I must remember everything to heal myself, they have asked me and what I have remembered I have told them. They have told me, “you are going to get up and you are going to be healed.” I make the effort to win and to heal myself, but I'm still the same...

**Eugenia:** They said she had a gift, but even though they have cured her many times, I think she won't be healed anymore... Then they say “give me \$5000, \$10000. Where are we going to get those amounts? They are going to give a table. They want \$5000, besides the celebration...

Apart from the successful experience accounted by Don Tono, participants did report limited positive effects of prescribed medications to control or reduce the occurrence of seizures. But beyond these methods, other forms of care they resorted to failed to achieve the expected results.

Most of the testimonies gave an account of arduous, ongoing therapeutic journeys that attest to the economic and emotional burden these families face. This highlights the effects that poverty and discrimination these ethnic groups have historically suffered related to long term health problems. But this does not all come from oppression related to the history of colonialism; some of this strife is attributable to dealings with local traditional spiritualists and healers whose diagnostics and procedures were deemed inefficient.

**Pedro:** I have accumulated debts with the *poxiletik* (note 25) and spiritualists. I went to Mexico City, and I told my wife to look after the child. When she called me, I asked her how she was doing, she said Miguel was better and she asked me to work without worries. But my son was not well, the convulsions happened often. She told me later that she didn't want to worry me.

**Cecilia:** In Pokolum, they gave us injections, but we didn't go back, [because] we don't have money, we are also alone, [so] we don't know who to ask to bring us, and also because people would start gossiping (note 26) ... Her husband just went north to look for money for his medicine. He has spent about \$80,000. he worked at the IFE (note 27) and also drove a taxi, but he spent everything on medicine. There is hardly any work here.

**Juan Domingo:** It will be worse in the Tuxtla hospital. My mother dressed as a Zinacantecan, they will say, “we attend first to the lady of Tuxtla.” We already went through this in San Cristóbal, and private doctors said, “here is your prescription and buy that,” then I said, “I have no money,” and they answered, “then we will not treat your son.” That's how it happened to me, the good thing is that I knew a lady in San Cristóbal and I borrowed money from her.

### **The impact on their lives and those of their family**

In addition to the gradual deterioration of the patient and the impossibility of full recovery, the process of care-seeking seems to inexorably become a constant source of stress for family members. Given the risks that recurrent seizures involve, it is a concern that permeates the daily course of family life, especially for female caregivers.

**Alonzo:** We are always worried. He can't stay alone. If he goes out we don't let him to do so on his own, [because] he could fall into a ravine. If the seizures start we must wait for them to pass.

**Eugenia:** As I was making tamales, I went to deliver some of them outside and she fell on the fire, throwing the water which was boiling. I told her, "come with me" but she didn't obey. She remained in the kitchen and when I heard she had fallen, all the water spilled, and her arm and her leg were burned. There are times that I am washing and we are alone, she falls and hits her head ... We prevent her from being alone. I hardly go out, neither does she, in case of a great need, if she is going out I must accompany her.

The deterioration of the person suffering from seizures can lead to even more complicated circumstances for their family members when the sick person begins to manifest behavioural disorders such as running away, which exposes them to further dangers. Maintaining integrity and resolve while taking care of them can therefore pose a challenge.

**Maria:** ...Then he says, "my trousers are wrong, look at them." When we tell him that there is not anything wrong with them, he says, "you don't want to tell me, if you don't tell the truth, I'll tell the authorities or I'll see who advocates for me." And we say to him, "why do you say that? Your trousers are fine," and he says, "it would do me good to hit you because you don't want to tell me the truth, you make fun of me." Then he ran off. Ever since he is no longer weak, he has gained strength, but lost his memory.

**Cristina:** "Come here Domingo, come back," I said, grabbing his hand and he bit me. The other day he also wanted to escape, but I caught him not far from here. He grabbed my hair, he was going to bite me again, but I ran to hide. Well, I'll see if he escapes today because I'm already very tired and I have seen that he comes back alone.

### **Learning to live with limitations and stigma**

For the individuals suffering from seizures, they experience a personal process of a gradual and inevitable acceptance of their limitations, daily risks and dependence on their closest relatives. They must also learn how to cope with isolation, and to live with stigma. But while the family can be a bastion of support in various ways, it can also be a source of stigma for the affected person, whether obvious or ambiguous. Stigma and social

discrimination due to health status mediate their daily social relationships, which may include a family alliance with representatives of health institutions and with traditional therapists.

**Andrea:** Sandra takes care of the store, I don't because I work...

**Sandra:** My parents say that I don't appreciate all they spend to heal me, but they only tell me that and not my sisters. I have fits regardless if I am angry or not, my bile (note 28) is because my family never takes me when they go out, I am always left alone tending the store.

**Andrea:** We are afraid that she will have fits on the street.

**Sandra:** If that were the case, they would never leave me alone, I often have seizures and there is no one to help me, what happens is that they are ashamed.... There are very scolding doctors. They said, "if you want to be healed, don't be bilious (note 29)." "Could it be that I am bilious?" The healers also say that I'm sick because of me being bilious. Well, yes, they tell me any little thing and I get angry, I quarrel with my sisters, I see them sitting and I working, they only send me to look for things, and when I don't want to obey my mother scolds me, not them.

In addition to stigma and social discrimination, certain physical consequences of seizures deepen the social isolation and despair of those affected. One of them, which we find with greater recurrence, are limb amputations due to burns.

### **The uncertainties about the future**

With the above examples excepted, when it is close family members assuming responsibility for sick people, these dilemmas are shared. These circumstances become more dramatic in a context of poverty, marginalization and neglect, which is especially relevant in the case of women because of the gender-based oppression they face.

**Manuela:** My husband died a year ago—but he lived with his other wife, he only came now and then. He was a teacher, but he rarely gave me money. Although I received support from his work, when he died I lost it. My other children don't help. Margarita and I clean cornfields and cut coffee to buy corn, beans, and sugar. When I had chickens and eggs, I used to sell them, but all the chickens died from sickness. Sometimes, Augustin also cleans cornfields, so I try to get him bread. They say that my children will suffer even more. I don't know how they will buy their clothes and food when I die. They have other sisters who would help them, but it won't be the same.

In addition to poverty, marginalization, sociocultural views on health and sickness, and gender-based discrimination, the contradictory and conflictive dynamism of social life contributes to the stigmatization of sick people and their care givers. This makes it possible to link the sickness to family and even community dramas, which pervade the understandings and

responses to the sick and their families, setting the pathways for stigmatization.

**Alma:** My mother-in-law says that [I passed the disease to my daughter]. That's why my husband also says so, she advises him badly, that's why he doesn't care about Natalia's illness. "Let her die," he says. Since she was born he has despised her. We had two girls, he wants a boy. When I was pregnant he hit me a lot because my mother-in-law told him that I go back my mother's home (note 30). He didn't want me to leave, but sometimes he would come drunk at night and hit me. Maybe I got the sickness then....

My husband has an old uncle. If you say something to him, he sends illness. He is my mother-in-law's brother, she might have told him things about me and made Natalia sick, that's why I take her to have her pulse read. I have gone out with my father to look for healers, they say it is that old man's evil. I always look for someone to cure her, because my parents had more girls than boys. My father got angry because he had a lot of land and many girls were born (note 31). He rejected them and four died. Now he worries about Natalia, he saw that it is no use to despise daughters. That is what he tells my husband now, that's why he takes me to heal Natalia. The *poxil* had already talked to God and told my husband "you sought her illness because you don't love your daughter."

The degree of stigmatization to which people burdened by illness and misfortune can be subjected to within their community is evident in the following testimony provided by a member of the same community as Cristina's and her children:

Their mother and her father were healers, but also witches. That's why her children got sick. A man died because her deceased husband did witchcraft to him. God did not like that and he made their children sick. Once, one of her children fell and got burned, the people said, "let him suffer because of her mother." They also wanted to be witches, but as they had so many fits they were not able to, they are sick.

She talked once about how her husband buried candles in a cave so that she and her children would die. But she limps because one day she went to the same cave, that is where her knee pain began, she was kneeling down praying with bad meanings. It is a lie that it began in the hospital where she was seeing about her son. We got together in the community to take her to Chamula. A woman was dying because she did witchcraft to her, they found out because at night they saw a light in the cave and brought the police to see who it was. They called her through loudspeakers and asked her what she was doing. She replied that her children were dying and she wanted to save them, but none believed her because the other woman was sick.

### Discussion

The impact of convulsive crises, and the therapeutic itineraries that patients and their care givers carry out to restore good health, is a reality that has not been previously explored in the country in relation to indigenous peoples. Further, there are no qualitative or quantitative studies describing the sociocultural and economic aspects involved in this process.

Medical anthropology offers rich possibilities of analysis based on the representations and practices of significant social actors, in which the articulations between subject and structure are evidenced in the processes of seeking health care (Janzen, 1982) and in its scientific reconstruction. Therapeutic itineraries are reconstructed based on the illness experiences (Eroza, 2016) of patients and their caregivers that refer to subjective and structural aspects related to their mental and/or emotional health, and on the analysis of therapeutic nomadism (Muñoz, 2020).

One of the most remarkable aspects of the data obtained regarding the interpretive frameworks of the sickness' etiology and nosology is that interviewees did not tend to remain anchored to one explanation and frequently moved between different explanations, whether complementary or contradictory with each other. Both in the naming of the condition and in the attribution of causality, a series of community and institutional actors intervene, such as family, traditional therapists or health personnel from private and public clinics. The search for care is mediated by individual and collective processes in which local knowledge intervenes, as well as by the cultural and structural dynamics of greater or lesser affiliation to health institutions as a result of structural violence (Farmer, 2004) and institutional racism (Sibony, 1993). Some investigations into other health problems such as maternal death within the indigenous population of Chiapas have illustrated similar processes (Freyermuth, 2003).

Analysing the data from the axis of therapeutic nomadism, the search for attention occurs from the intersection of existing social stratification and life strategies. Life strategies are understood as enablers of cultural responses that may imply forms of access to care in response to new barriers in access to diagnosis or treatment (Muñoz, 2020). These do not occur in a linear way, or from a conception in distinct categories of medical systems (traditional, biomedical, etc.), but rather in a kaleidoscopic way from provisional and itinerant adhesions that are motivated by pragmatism and conditioned by cultural and structural processes. These nomadic itineraries in the construction of subjectivity and in the search for care demonstrate both the subordinate positions of the subjects in the social hierarchy based on ethnicity and/or gender, as well as cultural creativity in dealing with the illness.

This framework of analysis is opposed to the reductionist views of certain uses of so-called medical pluralism (Hsu, 2008), which tend to reify the explanations of inequities in access to medical care from the lack of adherence to the biomedical system based on culturalist or individualist

views. They tend to blame the victim for having beliefs and behaviours regarding health that are incompatible with biomedical science.

This transition and complementarity between interpretive frameworks can be seen in the example of the participant who said that thanks to the preachers, God appeared to him in a dream and asked him to take the medication. It also operates in some doctors, such as the one who during the consultation mentioned "fright" as a possible cause of the condition. As discussed by Helman (1978), doctors not only appropriate local secular interpretive frameworks, but also reinforce them.

In addition to high costs and ethnic discrimination, another factor excluding some from the use of public health services is the threatening social representations they have about these services, fueled by rumours about murder or other violence that many subaltern populations have in analogous contexts, as pointed out by Jacorzynski (2000).

During the course of the disease, various inequities are generated not only by structural processes, but also by those cultural practices and beliefs that their caregivers, members of the community, and sometimes the sick people themselves participate in, which are frequently articulated with stigma and social discrimination acting at various levels (Guo, 2012). For example, women face specific inequities that are justified with cultural expressions such as witchcraft or the greater value conferred on male children. Similarly, certain social expressions of these cultural views of illness and misfortune pose a latent threat, since they can harm the sick person and their family by involving stigmatizing social imputations, from which violent actions against those affected can arise.

The lack of effective control of convulsions in these individuals also has consequences that can deepen social isolation and distress for them and their caregivers, including behavioural disorders or body amputations. In this sense, we can observe how structural vulnerability (Quesada, Hart & Bourgois, 2011) is not only exercised by historical structural processes of ethnic oppression and marginalization—understood as processes without social actors—but is also co-produced by various actors in the participants' cultural environment, including those who care for them. Some studies on highly stigmatized health problems such as HIV have shown that care and violence are not always opposed in these cases, but can be interdependent (Muñoz, 2018).

In this way, the ethnographic perspective allowed us to elucidate the complexity of the broader sociocultural processes that mediate participants' therapeutic itineraries in this study. The results describe a situation of profound neglect and suffering of these people and their caregivers, and an urgent need to enact public policies based in social justice that can improve timely diagnosis and care of epilepsy from a culturally and structurally relevant perspective.

**Conflict of Interest**

There is no conflict of interest.

**Availability of data and materials**

Data will be made available upon reasonable request.

**Funding source**

None.

**Ethics statement**

All of the people interviewed were informed about the project, their right to confidentiality and to withdraw from the study. The guidelines established in the Helsinki Declaration were followed in the field-work and later use of the information. Informed consent, as well as authorization to record the interview were requested from the informants. We ensured the interviewees anonymity by refraining from recording personal data, and we only use invented names in each extract of interviews appearing in this article. At the time of investigation, the institution where we work did not have an ethics committee, as is common for anthropology research in Mexico.

**Authors' contributions**

Enrique Eroza carried out the field work, the codification and systematization of the data, as well as its analysis and the writing of the article. Rubén Muñoz participated in the analysis of the data and in the writing of the article.

*Note 1:* There are also other types of psychological causes and nosologies unrelated to epilepsy, such as non-epileptic psychogenic seizures derived from somatic symptom disorders or dissociative disorders (Abubakr, Kabingler & Caldito, 2003).

*Note 2:* In 2016, 71.9% of indigenous people (8.3 million people) lived in poverty and 28% (3.2 million people) lived in “extreme” poverty, compared to 35.1% of non-Indigenous people living in poverty and 5.5% in extreme poverty. (CONEVAL, 2018).

*Note 3:* *Tup'* literally translates to “turn off,” while *ik'* means “air” or “breath.”

*Note 4:* This was mostly reported by those close to the one who suffered the seizures, but it was also reported by patients as they usually had been told about the even afterwards.

*Notes 5:* The girl mentioned these hallucinations as something which preceded the onset of her seizures.

*Note 6:* *Ij'kal, Negrito* (“little black man”) or *maroon*: a supernatural being who appears to people, scaring them and making them sick.

*Note 7:* Esquipulas is a private clinic placed in San Cristóbal, mainly focussed on providing attention to poor indigenous people.

*Note 8:* In the indigenous communities of the region, it is common that domestic issues be brought to the local authorities with the aim that they settle the issue.

*Note 9:* Whereas Sandra was a Tzotzil girl, her former partner was a Tzeltal boy.

*Note 10:* This implies the disease was caused through witchcraft.

*Note 11:* The act of sweeping the body of a person in order to remove the evil which making her/him sick. The materials to do so can be plants, chickens or eggs.

*Note 12:* The *Mexican Institute of Social Security*, a governmental organization that assists public *health*.

*Note 13:* A private doctor.

Note 14: The National Indigenous Institute, which no longer exists.

Note 15: An illness locally defined and treated, it is assumed that is caused by a local kind of worm.

Note 16: A traditional healer in Tzeltal language.

Note 17: A Tzeltal municipality in the Chiapas Highlands.

Note 18: A city two hours from San Cristobal.

Note 19: She actually meant a person in her community who charge of injecting people.

Note 20: A community within the municipality of Tenejapa.

Note 21: A healer in Tzeltal language.

Note 22: "An air" refers to a perceived ailment thought to be caused by the cold in the hospital.

Note 23: The table refers to the altar where the saints are placed to pray in from of them when the healers carry out their healing procedures.

Note 24: Diagnostic procedure based on feeling the pulse of the patient with the hands.

Note 25: Plural of healer in Tzeltal.

Note 26: She meant that as they are women, they would be criticised for going out alone without being accompanied by men of their own family.

Note 27: Federal Electoral Institute

Note 28: Bile is believed to be associated with anger or irritability.

Note 29: An adjective derived from bile, meaning "bad tempered."

Note 30: Alma and her husband lived in his mother home.

Note 31: In her community, only men inherit lands.

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