

The Brain and the Heart, *Nada Mas*

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Sometimes epilepsy is defined as the brain and the heart, *nada mas* (nothing more). Sometimes it is defined as one or more uncontrolled, oftentimes unexplainable seizures. Whatever way a person with epilepsy has epilepsy explained to them matters. How people react when they tell a friend or family member matters. It impacts and influences the way they think of themselves. Usually seizures are not the worst part of epilepsy. In places where it is feared or stigmatized, the way people react to it is. Excellent intro – it really draws the reader in.

I learned this from my own personal experiences, as I was diagnosed with epilepsy when I was seventeen. I learned a lot about my own American, Utah community and culture by the way I was treated and can now look back on my reactions to those experiences and can see how they influenced and sometimes changed me and my perception of self. Need a better transition here.... From your experience to the world, to Peru.... Around the world sixty-five million people have epilepsy and I was excited to study cultural similarities and differences in the treatment of people with epilepsy in Peru.¹

I choose to study the perception of epilepsy in Huanchaco and Julcan, to see if there was a stigma of persons with epilepsy. I define a stigma as a negative social label that oftentimes, whether acknowledged or not, denies persons in a stigmatized group to the same access and privileges as other 'normal' members. Is this your definition, or is this from the academic literature? If the latter, provide a citation... As Erving Goffman explains there are different levels of being stigmatized.² I would label myself as having an internalized stigma as, without positive social support when I was diagnosed I began to fear that people would negatively label and shun me because I quickly learned how negative the label of epilepsy could be seen.

¹ "About Epilepsy: The Basics."

² Goffman

The epilepsy scholarship in Peru tends to focus on a type of seizure manifest as a symptom of neurocysticercosis. Neurocysticercosis (NCC) is a later manifestation of cysticercosis which is transmitted to humans through the eating of undercooked pork and which is often asymptomatic until much later in the carrier's life. Due to its prevalence in Peru (something like this)... I included questions in my semi structured interviews about cysticercosis. This is an easily preventable type of epilepsy which I was eager to study as access to proper doctors can lead to very effective treatment and the passing on of knowledge to future generations could lead to zero prevalence in all of Peru and the world. Great intro!

The informants I interviewed (should explain interviews in a methods section – try to work this into next section) were from Huanchaco and Julcan. or were interviewed as they were in one of the towns so lived nearby. From Trujillo, the city I will be referencing since it the largest and easier to find on a map Huanchaco is Northwest and Julcan about the same distance East of Trujillo. Looking on a map I would add a map here and reference it – that would be very helpful, Trujillo is about 250 miles up the coast from Lima, the capital of Peru. Huanchaco is a denser populated, touristy town directly on the coast whereas Julcan is a small mountain town, which in Peru, typically means less wealthy. Julcan is smaller and more isolated whereas Huanchaco, is larger with many commuters from Trujillo and always inhabited with international tourists because of its famous surfing. Trujillo is home to the hospital where epileptologists or neurologists and other doctors reside who practice western medicine. This would also be the same place a person with NCC should go to be given medication or surgery to treat their cysts.

A large portion of epilepsy's causes are unknown and are treated by bidaily or routine antiseizure medication prescribed through globalizing western medicine. To keep in mind about how many people have epilepsy, in the United States one out of twenty-six people will have

epilepsy at some point in their life.³ There are many types of epilepsy and the majority do not have generalized seizures, the type that affect both sides of your brain so lead to full loss of body control, it was interesting to look as word choice when putting together questions in Spanish. One of the words used to describe epilepsy is convulsiones. The word being translated means convulsions which I would label a generalized seizure, so it is only speaking to a part, usually the lower percentage of people with epilepsy. Excellent! Move all of this up!

While conducting interviews I made sure, at the beginning, to reference all words in Spanish used to describe epilepsy: epilepsia (epilepsy), convulsiones and ataques (attacks). This way an informant could use whichever they were familiar with and I could gather statistical data on how word choice influenced an individual's view of people with epilepsy. For those that didn't know any of these words, I continued my semi structured interview with the word *discapacidad* (disability) to still collect data on the perception of persons with disabilities in this culture.

Methods

As referenced above I advice against saying 'as referenced above', and moving things around so that you introduce all of your methods for the first time in your actual Methods section... , I conducted research using mainly semi structured interviews. Conducted in Spanish, I asked seven questions starting with one on how they defined epilepsia, ataques, or convulsiones after introducing myself as a student anthropologist studying health and medicine. After getting brief demographic information, the questions, all written in Spanish, started with, 'How do you define epilepsy?'. The second, 'What words do you think of when you hear the word epilepsy?'

³ "About Epilepsy: The Basics."

Next, 'What do you think causes epilepsy?' Following this answer, I would ask, 'How do you think it should be treated?' then, 'by who?' The sixth question was 'Do you know someone who has epilepsy?', with the last being 'Do you know what cercosis is?' All of these questions; if something interesting or informative came up, I would ask a follow up question for elaboration on points which could be key to my research.

Informants were those I met on the street or got to know while I was staying in Huanchaco and Julcan. For example, sometimes while we were in an activity; such as the viewing of the world cup, I saw a woman who was not very engaged in the game and asked if I could interview her on the spot. I would then proceed to ask for consent before I turned on the recorder on my phone so that I could later transcribe, translate and code these interviews. As this is so time consuming and difficult and as I am not fully fluent in Spanish I will proceed to walk you through a few of the interviews I carried out in the two cities and, before the conclusion, compare and contrast these small portions of data from Huanchaco and Julcan. Also take note that the informant I interviewed in Huanchaco lives in Trujillo, which means that it might not be representative of the majority culture, however, this must be taken into account for all informants no matter their place of residence because of personal differences and backgrounds. Add to this section how many interview you did, ect... you could say that this paper only looks at data from x, and y...(this will provide a nice transition to your data and analysis section,...) but be sure to state how many were done total... also... you will want to mention that you recorded, and how you coded and transcribed, what software you used, etc..

Data and Analysis

Informant 1, Huanchaco

Male, 58, lives in Trujillo, college education (I'd potentially add profession here)

1 How do you define epilepsy? It is a psychological problem that can come from the mother's belly from a lack of nutrients or minerals. It's an emotional problem that is a reaction a person has when they have psychological or emotional problems.

Note: This was enlightening and good to know before I interviewed others, this being the first of them, as I had not thought of epilepsy as an emotional problem before. The family I had also never heard referenced before. This is interesting however, as with most seizure types the only things that are known to trigger seizures are, for some people, flashing lights, and stress. Stress is a physical response to emotions.

2 What words do you think of when you hear the word epilepsy? Impotence. I want to help but don't know how and don't want them to swallow their tongue.

Note: I began to be glad I had not told this informant that I had epilepsy as, when with the first question, he talked about it being a psychlogical problem, I felt I could lose rapport because I would be labelled impotent and unable to do what I was doing. Also, that people could swallow their tongues when a person has a generalized, or tonic-clonic seizure is a myth (citation?). I fear that it promotes a bigger fear of epilepsy. Take note that the word convulsiones was the one that this informant was familiar with in talking about epilepsy so as the questions continued this word was the one used interchangeably with epilepsia, as he knew both.

-follow up question- What do you think a seizure (convulsione) would look like or is? *Fuerte* (strong), the few times I've seen one, a person is normal and then they fall. They might hit themselves hard and shake and bite their mouth.

3 What do you think is the cause? *Una problema, choques emotionales* (a problem or emotional shock). Maybe people have emotional shock they haven't got over; they might have something inside them that they haven't been able to express and it's a way of reacting.

-follow up question- So something emotional to express? Can you give me an example? Yes. Emotional. Some people close to me that have epilepsy say when they have a lot of stress they tend to have more of the seizures but when they get their life organized and do the things they like to do then the seizures don't happen as often as before.

4/5 How do you think epilepsy should be treated? Or who do you go see if someone has epilepsy? Seizures are old, it's not a new problem, but it is more common now and with young people, maybe because of their lifestyle. I think it's an emotional problem. Maybe they should have a closer relationship with people that could help them talk more about their problems, maybe their parents or partners.

-follow up question- So do you think this lifestyle is making this more prevalent? That maybe families or relationships need to be closer or emotional relationships are a thing that changes it? Yes, it is difficult because people are more conserved and society more closed. It's not something with society but something very personal, that has to be gone through with the person (who has convulsiones/epilepsy).

-follow up- How do you think it should be treated if it's personal? Do you think that you should see a doctor? I think that the family plays a very important role and yes a nutrition team could help because it is nutrition related but it should be more than just a doctor; a psychologist or psychiatric team.

Note: This is interesting to think of as emotionally, where I live people are getting less attached to people it seems and more attached to phones and things like Netflix for emotional, friend-like stimulus. Some in western medicine also do sometimes turn to nutritional means instead or to supplement medication usage; usually a ketogenic or modified Atkins diet. I also liked that he was looking at holistic health too. Counselling I think should be prescribed when a person gets diagnosed with epilepsy, as the experience and medical treatment can easily become traumatic.

7 Do you know what NCC is? Cercosis, yes, it's contracted when you eat the bacteria in undercooked pork and the eggs reproduce and enter through your spine and go up through your body into your brain. The seizures a person has from cercosis are different than persons with epilepsy because when a person with epilepsy has a seizure they act normally when the seizure passes. People with this disease (NCC) become like kids regressively. They speak like kids and loose balance and look like they're falling. They (doctors) can tell the difference with a tomography or CT scan plus the hospital should have their history of previous illnesses and nutrition problems.

I later asked if he thought there was a stigma with people with epilepsy and he said no. I thought this was interesting as, again, I felt stigmatized while I was conducting this interview and didn't want to reveal that I have epilepsy. This was a very good interview to start with for my research as I better knew what terms were used regarding epilepsy and what to expect on my informant's possible knowledge of NCC.

He also referred me to an article about some of the cultural history I asked for on disabilities, especially epilepsy. The article is on the Quechua culture's treatment of epilepsy or

sonko-nanay, an *enfermedad del corazón* or sickness of the heart.⁴ It is interesting to see how he did not refer to this directly as I was interviewing him but the medicinal views that address epilepsy seemed very similar to those discussed in the article. It spoke of different types of epilepsy and treatment by *curanderos* (again, all Spanish in italics) *corranderos* (traditional healers) with plants. I got to witness a *corrandero* healing in Julcan, add more detail. and it was fascinating to see how much the diagnoses lined up with the patient's emotional and physical well-being. The healing consisted of using a respected animal which was sacrificed to represent the patient and going through parts of the animal's body to see what needed to be treated physically and emotionally in the patient's body. When I later asked this informant we both agreed that a *corrandero* or traditional doctor's treatment and western medicine should equally valued and integrated for the patient's wellbeing.

Informants 2 and 3, Julcan

Informant 2: Male, pharmacy worker

Informant 3: Male, 60 booth health shop owner- taught by his family

Questions	Informant 2	Informant 3
1 What is epilepsy	Neurologico, convulsiones	A problem of the heart
2 Words you think of	Ataques, convulsiones, no Bueno	Triste, muy triste
3 Cause	Knows cysticercosis	muchas
4 Treatment	Hospital	plantas
5 Cereosis	Yes, knows what it is	Maybe a sickness, not sure

⁴ Cruz-Campos

Figure 1: *In the above you can quickly compare and contrast answers between the two informants (see text for English translations). I really like this table! Though, I am left wondering why Informant 1 isn't included? I would add him.... And then potentially put the table after you explain all of the interviews..*

In Julcan I spoke with a man working in a Pharmacy off the main plaza first (Informant 2). It was white washed with lots of bottled medicine, looking more like an American Pharmacy to my eyes. Beginning to ask the questions he knew what epilepsy was and began to describe it as mal neurolgico (bad neurological) condition or convulsiones (convulsions). Words he? I used to describe it were ataques (attacks), convlusiones (convulsions), and no bueno (a bad thing). When I asked what he thought the cause was he responded saying cysticercosis in a list of many causes. This was a surprise, as I ask this at the end and many of my informants didn't know what cysticercosis or NCC was. When I prodded he explained it was in chancho (pig meat) and was difficult to treat. He said you would need to get a tomography. When asked if he knew a person with epilepsy he responded and said that a person with epilepsy would need to go to see someone in the hospital in Trujillo to get treated. He stated they would need to get a CT scan and see a neurologist.

I thought this was very interesting as, having had a CT scan done along with many other tests, I know a CT scan can only be used to see the physical brain. Similar to an MRI, you usually cannot tell if a person has epilepsy based on a CT scan or other tomographic data unless there is a physical change in the brain, like when someone has spots from NCC. Usually the best way to see the difference in electrical activity in the brain during a seizure is to have a prolonged video EEG where one stays in the hospital for an extended period of time, off of medication, so that one can be sure of the type of seizure manifest and the place in the brain in which it is happening.

Other things we talked about to take note of are that he said that people should go to Trujillo to get treatment and, when I asked about stigma, he replied that there was no stigma in Trujillo. I thought this was interesting as by the way that he talked about people with epilepsy I felt there was an implied stigma. Though, one must take note, that as I have an internalized stigma from epilepsy my opinion is biased.

After speaking with the I2, I walked down the block and went to a stand labelled for healing, where I spoke with Informant 3. The stand, set up during this local festival, had books and plants for sale along with free advice from the man and woman selling the products. I had asked earlier if I could come interview the owner about his treatment of epilepsy. Returning, I knew that he knew what epilepsy was, so started with another question in front of my semi structured question set. I asked what he did or had to treat epilepsy? He started by saying that epilepsy is the “diferencia en su corason y cerebro” or, in English, difference between your heart and your brain. He described it as an illness from the heart that connects to the brain through the nervous system. This was fascinating as it seemed to correlate with what I1 had communicated. I like how you write about the interview and how you asked questions here.... I also like how you had it question by question for I1... BUT, I would stay consistent throughout.. choose one way to represent the data, and make each one look the same..

The booth was outside and we sat as he was speaking with me, using his hands a lot throughout the interview to add physical descriptions to what he was explaining or showing me the plants he used to help treat people with epilepsy. The sun was hot and bright around the tent booth almost setting it apart from the bustling crowd of festival goers. As you can see in figure 1 his answers were similar to I1's in that the heart and emotional problems were key to being solved in the treatment of epilepsy, along with nutritional supplements he was selling. Nice! He

focused on the importance of family and how the heart and nervous system needed to align. He thought depression was a major thing that needed to be addressed and said it was a very sad problem. I was impressed to hear that he had learned this information through a family line of knowledge and passing down of the healing arts. He was very easy to talk to and seemed very happy to teach me about his work again though, in this situation I was glad I had not told him I had epilepsy as he talked about the suffering of people with epilepsy, in the which I felt objectified. I kept thinking how a person with epilepsy's view of epilepsy would be very different depending on who they talked to and it seems like it would very much determine, depending on the interaction, if they developed a stigma with epilepsy.

Conclusion

Data from these three interviews leads me to conclude that there are two unique views of treatment for epilepsy in modern-day Peru: a cultural treatment involving the 'heart' and a western treatment involving the 'brain'. While Western medicine focuses on things that can be chemically and physically measured and is therefore often treated with medication and or surgery, the cultural treatment sees epilepsy as a problem of the heart that needs to be addressed very personally and emotionally with one's family. Ideally (in whose opinion? Yours? If so, say that ☺) one would have the two treatments come together under the wish of the patient and both be valued at the same level to properly treat the individual under the direction of the individual. In the current day the individual with epilepsy would need to be the one that would have to learn to advocate for themselves and integrate both treatments to achieve holistic treatment and health for themselves.

This is where the topic of stigma, especially internalized stigma, needs to be addressed. Depending on treatment and the reactions of family and friends when an individual is diagnosed

with epilepsy in their community they may feel a need to hide epilepsy or seek only one treatment method valued by those around them. Things such as distance to treatment at the hospital in Trujillo and traditional healers or spelling coranderas (healer), the cost of such travel and treatments also play into choice of treatment. Value of treatment as seen by the patient needs to play a role in healthcare.

To continue this research I will x, y, and z. I will be continuing this research to educate those who read it on the stigma of epilepsy, the importance of treatment diversity and the beginning of the elimination of NCC.

This research is a valuable stepping stone to end the global stigma of epilepsy and the integration and equality of cultural and medicinal treatment of epilepsy with the globalizing of Western medicine, as it x, y, and z (be specific here!) The brain and the heart nada mas. Globalizing western medicine only takes the brain into consideration when treating epilepsy but equally important is the heart.

Anna,

Great job here! I love this conclusion!!!! Can you expand a bit more here.... I would add a bit more into this paper where you really dive into the data from the informants that talked about the heart and family... and how you think that could really help lessen the stigma.. I think that is the bread and butter of your research, and that needs to be clear! Also, I'd like to see you introduce that right away in the introduction! Also, I think you need to re-work the structure of the beginning (particularly the methods section, where it is and what all should go into it). Also, go back through and keep in mind that 1st person in no way means informal... I also want you to think about this question of how much YOU and your feelings while interviewing should be

interwoven in your results. They can be, to a larger extent, but then you need to make that clear that that is a purpose of the research. As it reads now the reader reads all about informants in Peru and then all of a sudden there is a sentence in there that ties back to you and your thoughts as someone with epilepsy.. Just introduce this more clearly.....

I am excited to see the second, final draft, and then we can publish it on the website!

Paper Grade: 94%

Final Grade in Course: A

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