# Carrion's Disease: Neglected Diseases of Neglected People

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**Abstract:**

Neglected tropical diseases often relegate Carrion's disease to the lower echelons of medical priorities. This is unsurprising, given its prevalence among underserved rural communities in Peru, Ecuador, and Colombia (Sanchez Clemente et al. 2012). Carrion's disease, caused by the bacterium *Bartonella bacilliformis* and transmitted by the *Lutzomyia verrucarum* sandfly, continues to be overshadowed by more prominently studied ailments. While scientific literature predominantly focuses on the disease's clinical aspects, this research sheds light on the experiences of those afflicted by Carrion's disease and their interactions with healthcare systems. As this disease remains in the shadows, it becomes imperative to delve into the perspectives and concerns of experts.

The primary objective of this research is to investigate the oft-overlooked impact of Carrion's disease — a painful and potentially lethal condition — within the context of Latin America's historical legacy of discrimination and marginalization. This disease is divided into two: acute phase, which manifests as severe fevers, and the chronic phase, characterized by Oroya warts (painful red lesions that can cover the entire body) (Ruiz 2022). Now, in the midst of a climate crisis, it could be expected that the vector's range is expanding, resulting in unexpected outbreaks in new climatic regions. This research project seeks to gather firsthand data from Cajamarca, Peru, offering an exclusive perspective on this often-neglected illness.

In essence, this research endeavors to shine a light on Carrion's disease, explore its socio-medical implications, and contribute to a deeper understanding of the challenges faced by affected communities.

**Methods:**

As stated, the research was divided into two; the people and the experts.

A total of seven people from the city of Cajamarca, Peru — the third city with the most cases of Carrion's disease — were contacted and interviewed individually. The interviews followed a semi structured format. In other words, a question bank provided structure, but ultimately, the participants were the ones to guide the conversation. The interviews were conducted in Spanish, one of Peru's official languages. The interview questions were holistic and focused on two main pillars: healthcare and the environment. The former related to the access the participants have to proper services, and the latter will focus on the impact climate change has had on their lives, complications that have arisen, and changes in the disease patterns due to the climate crisis. The interviews ranged from seven to seventeen minutes of duration.

The interviews were later transcribed using the software Trint, and findings were drawn. Although personal information was shared during the interviews and during the collection of contact information, this research guaranteed anonymity to the data shared by the participants.

During the transcription phase, any names mentioned were given an alias (used in this report as well), and the researcher kept out personal data such as addresses related to home and work to protect the identity of the participants. To ensure the proper flow of collection of information, the participants were given a consent contract to sign.

The second half of the project involved interviewing three leading experts in Carrion's disease. These were Dr. Ruiz, Dr. Ulloa Urizar, and Dr. Minnick. Questions about their papers were asked, as well as their concerns about the disease. As the first part of the project, the conversations were

led by the scientists interviewed, so each interview was different. The interviews were held online on the Zoom platform.

**Findings:**

After the interviews to the people in Cajamarca were completed, the following results were found:

1. People that know about the disease: 2/7

Two out of the seven people interviewed had heard about the Carrion's disease. However, their knowledge on it was very limited, or could just recognize the name. One of the interviewees, Juana**,** said: "I remember there were some cases of that fever (referring to the acute phase of the disease), but I do not remember anything else. […] That was long ago". She also commented that she had seen people with warts on their skin (which appear in the chronic phase of the disease) but was not sure they were because of Carrion's disease. Raul, the other interviewee that recognized the disease said: "I recently heard about it on the TV". Other interviewees were unsure about the disease, and even when being described the symptoms, they were still dubious and abstained from giving an answer.

Considering this illness affected 932 people in the Cajamarca region from 2010 to 2020 (Fabián, n.d.),it was surprising to find that not many knew about it. This revealed the lack of government interest to educate the citizens in endemic regions about the presence of this disease.

After asking the experts about why this might happen, they provided different answers. Dr. Ulloa Urizar said: "In endemic areas, such as Ancash, Cusco, or Cajamarca, the first thing after a patient comes in with a fever and anemia, is to suspect of Carrion's disease. However, what takes time is cultivating the bacteria, […] because the diagnosis techniques require a lot of expertise. […] It

takes around a month to grow the bacteria and to check if the patient is positive for Carrion's disease." She explains this contributes to a lack of registration of the cases, which leads to lesser concern from the governmental agents. She adds that "It could also be due to the lack of health promotion in this area. Having those would be ideal. Sadly, the interventions for prevention and promotion of health are associated to risk. For example, in the case of dengue — we just saw a spike —, [the government] started the prevention and promotion campaigns. They inform you about the mosquito, they make up a song to tell you what to do and not to do, and they reinforce it."

In the case of Dr. Ruiz's interview, he thought the reason why cases go unreported is because "symptoms are ambiguous that could be confused with dengue, with hepatitis…". He tells a story about an outbreak in Cusco in the 90s, which was attributed to hepatitis. He said "40% to 50% of people started dying due to hepatitis until they [the government] sent someone to see what was happening truly. The real cause was revealed to be *Bartonella bacilliformis*." Another reason given was that different populations could have a different name for the disease, as Colombia, which calls it *fiebre de Guáitara*. Moreover, he explains the possibility of another disease shadowing Carrion's disease, such as COVID. During the pandemic, any deaths that were preceded by malaise were ruled as COVID. This means this disease acted as a blanket, putting all other potential causes of death — such as Carrion's disease — under the shadow. Dr. Minnick agrees. He says: "since it's not life threatening, it probably doesn't rise to the level that some life-threatening illness would. Even though it can cause scarring and it causes a reservoir of this bacterium to exist in more children and adults. So yeah, I think that having endemic region with potentially a large, non-life-threatening chronic illness, a carrier state, if you will, will contribute to its not being as important

as some diseases like COVID or influenza or, you know, fill in the blank. And so, it falls again to that neglected category."

2. People that approach the doctor: 7/7

All the participants interviewed claimed to always go to the doctor, with no exceptions. However, this was contradictory with what they expressed during their interviews, such as the negative experiences with the doctor, and the lack of resources (discussed later in the paper). During the interviews, they all affirmed going to the doctor even for a mild headache. However, this is dubitable as all the interviewees were either self-employed or had informal jobs, which means they do not count with a paid sick leave in the case they would need one. People would rather make money by showing up to work with some discomfort and earn money, than approach a facility which might not give them the best attention or any at all.

3. Bad experiences at the hospital: 4/7

Four out of the seven interviewees claimed to have had or heard about a bad experience at a health facility. For instance, Juana told the story about her sister being dismissed at the hospital after she complained about intense pain in her ear after she was struck by lightning. She said "my sister was struck by lightning while she was on the phone, and the cellphone keys went in her ear and the doctors didn't see it. […] When she couldn't listen anymore, she touched her ear and could feel the keys. […] We had to bring her back to the hospital and they finally took care of her".

Lorena, another interviewee, said doctors misdiagnosed her in her city after she approached the hospital due to a paralyzing headache. "Here, in Cajamarca, I had an issue with this part of my face, my head. It hurt a lot, it felt like my face was going to fall off. I had a year of feeling like this

and the doctors did not detect a thing. I felt like my face and my eyes were falling off. I felt very ill. Then, I decided to go to Lima, where I got detected an early stage of sinusitis. I also had migraine, which I was not detected here. I got exams done and all, but I still felt so much pain. In Lima they did the same thing and detected sinusitis and migraine. They put me on a treatment that required me to travel to Lima repetitively. Nothing was working so I got put in new treatments, […] which made me feel tired during the day. […] During COVID, it got worse because of bleach and all the chemicals used to disinfect and not get sick. But honestly, I liked it because I eventually was given the hierba mora plant (black nightshade) as treatment. […] I had to put a drop of the plants juice in my nostril, which made me cry for three to four hours. […] The next morning it was like I woke up from the dead, it leaves your face looking ugly, but you get to sleep, and the pain is gone." This herb was given to her not by a doctor's recommendation, but by a lady from her hometown. She said after taking this, she did not go to the doctor again. She also added that doctors in Cajamarca said her pain derived from stress. However, she was sure that was not the case. Lorena was also asked about the general experience in the hospital. She stated that there is not a timely response, "they want to see you dying in front of them before they take action."

4. People that approach a different service than the hospital: 5/7

As a consequence of the negative experiences, five out of seven interviewees reported resourcing to alternative health practices. Juana explained she had to go to a doctor's private consult because her public health insurance had expired without her knowing. To her, going to the hospital involves paying large amounts of money, while the doctor she visits costs her 20 soles, which is the equivalent of 5 USD. Although no information was asked about the doctor, his legitimacy is dubious due to the very low rates as a particular doctor.

However, the rest of our participants counted with the government health insurance SIS, participants revealed they do not receive attention at a public facility in a timely manner and with adequate scrutiny. Four described visiting a doctor's private practice, while one described opting for his religion's spiritual healer. Raul told: "one day I got a very strong fever and He put a white dove on the side of my chest. This is what He reveals when someone is not loyal, because no one could entirely be so other than Jesus. […] And right after, my fever was gone." Raul commented that when he approached this religious healer, he was given immediate attention — the complete opposite of what would have happened if he were to approach a public health service. He added that he did not get vaccinated against COVID because he believes in God's will: 'The scriptures say that if we truly honor God, no plague will be sent to us." One of his religion's main rules is to refuse vaccines.

Nadia, another interviewee, expressed her complaints on the inefficient attention given in hospitals in Cajamarca. "They take long. Especially when you try to schedule an appointment. They will tell you there are available timeslots two months from now. That is why we just prefer going to a doctor's private practice. […] Our insurance works sometimes, and sometimes it is unstable." She told the story about one time she had excruciating pain in her mouth and went to the hospital but got turned down. Thus, she had to rush to a particular doctor because she could not bear the pain. "Apparently, I had to wait because a doctor was finishing his shift and they were waiting on the next to arrive. I had to wait for this and that… […] But when I went to the doctor's practice, he took me in straight away." Nadia expressed that this doctor is meticulous, whereas in the hospitals, nurses can be mean and apathetic. "Some doctors know how to treat patients, but others are there only because they already made a commitment to their internship and do not care about properly interacting with patients. This is something that should definitely be improved. […] It is not even

the fact that they are running low on staff, because you will see nurses chatting on their phones while people are waiting to receive attention. Maybe there should be a better service and less nurses, because they talk with each other and leave all of us hanging." Nadia brought up an innovative point; leaving aside doctors' or medical interns' inexperience, she speaks on the relationship they should build with the patients, one based on respect and kindness.

5. Low resources from the institution: 3/7

Finally, during the interviews, the participants were asked to give a description of their health centre. The participants were mostly satisfied with the infrastructure of the facility and the number of doctors. However, some were not happy with the attention they were given. Like previously mentioned, Nadia brought up the topic of respect and kindness between patients and medical staff, something that should be considered a resource.

Dr. Ruiz comments that there are many medical school students completing their SERUMS, a mandatory program for recent medical school graduates to become public health officials, which brings medical attention to the most humble and marginalized populations in Peru ("Listado de Procesos del Servicio Rural y Urbano Marginal de Salud (SERUMS)" 2023). This could bring up issues that relate not only to experience with patients, but to experience with techniques, such as properly performing the GIEMSA stain to detect Carrion's disease. "I think what happens is that there is not much information about the disease, and a lot of doctors in Cajamarca are surely not from there. They are doctors that go to complete their SERUM, especially in rural areas in Cajamarca, and all they want is to go back to the city (Lima)". This definitely contributes to the under-registration of this disease's cases and the proper treatment thereof.

Moreover, various participants mentioned the lack of adequate treatments. A recurring comment was that when getting a prescription from doctors, the only drug given is paracetamol, an analgesic and antipyretic, used as a painkiller. Maria, who lives in a secluded town in Cajamarca, called La Llica, said that because paracetamol is not effective against their symptoms, "sometimes we just choose not to go to the health centre." She mentioned how because of this, she kept a headache for around three weeks. "But eventually it will go away…". There are no pharmacies in town, and this health centre is the only place that provides aid.

Maria also revealed that the health centre in her town is closed on Sundays. If someone has an emergency that day, they have to take the bus (if there even is one) and then *walk* to Bambamarca, which takes more than two hours — a route she had to take one Sunday, when her son had an emergency. She desires to have a health centre that is always open, and that is more accessible for everyone in the town and around.

Lorena had a similar situation with paracetamol. She commented that she worked at an international association's branch in Cajamarca which provided her with a private health insurance. She said having a better insurance made her feel happy and protected, until she realized it only covered paracetamol and ibuprofen. "If you had a headache, paracetamol. If you felt pain in your tendons from standing all day at work, ibuprofen and paracetamol. For everything. […] You have to accept it. […] I guess it was better than receiving nothing at all." The experiences and the stories about hospitals lacking resources to provide to patients are obvious to create a breach between the people and the services. Therefore, it is no surprise that people are not up to date on the illnesses present in the area —other than the ones saturated on TV and news media—. In the event that an individual were to contract Carrion's disease, it is likely that it would go unreported by the public hospital, given its limited interaction with the community.

Because most participants did not know about Carrion's disease, it was difficult to infer from them if cases had increased due to climate change. They were aware of the climate crisis, as it has affected their jobs, which mainly focus on farming and selling fruits. However, some mentioned the increase of mosquito populations after the raining periods. Because Peru is facing the El Niño natural phenomenon, which leads to an increase of temperature, humidity, and precipitation (Saha and Gupte 2023), Dr. Minnick indicated that "if El Niño were accompanied by increased rainfall and humidity, it would set up the stage for increased replication and incidence of vector borne transmission. At least that that would be the prediction. And you know, if it's all dry, it would actually reduce the incidence of transmission because they're very sensitive to humidity levels."

Additionally, the increase of temperatures can expand the travel area of mosquitoes, making them able to fly to new locations(Garcia-Quintanilla et al. 2019). During his interview, Dr. Minnick stated: "climate change undoubtedly is affecting the geographic ranges of these insect vectors, and there are probably three or four routes in the air. There are currently too many appearances, for instance, that can transmit and have been shown to be infected in the field with *Bartonella bacilliformis*. And as temperatures change, as climate change occurs, those geographic ranges could expand or contract for that matter, depending on how the change occurs. But right now, it's warming. We see this in the United States with tick borne illnesses. We're starting to see malaria in Florida and so forth. So, climate change really does affect vectors and vector transmission." This could be one of the reasons why cases of the disease arise in non-endemic areas. However, according to Dr. Ulloa Urizar, there are various vectors that have not been identified (Caceres et al. 1997). She was able to identify the bacteria *Bartonella bacillifromis* inside the *Lutzomyia*

*maronensis* sand fly, proposing this as a newly identified vector (Ulloa et al. 2018). According to Dr. Ruiz, "it is more probable to have a sand fly adapt to a new area and act as a vector for diseases." He mentions the example of *Aedes salvopictus* in Spain, which is now identified vector of different illnesses, such as yellow fever and dengue.

Dr. Ruiz mentions that *Bartonella bacilliformis* is a very susceptible bacteria, which he explains is a good thing. As long as it stays like this, we can control it, and even eradicate it. However, adaptation is also a reality in this species. The moment it becomes resistant to the conventional treatments, Carrion's disease will be huge problem.

I also asked him about the possibility of a bacteria that is similar to *Bartonella bacilliformis* that could cause Carrion's disease. For now, *Bartonella ancashensis* and *Bartonella peruensis* are known to be the only other species that can do so (Mullins et al. 2017). In his opinion it is more dangerous to have a vector adapt to a new area and spread the disease.

In one of his papers, Dr. Ruiz mentions incredible cases of the bacteria being able to live inside a human, without being activated until years later. This is to say, the bacteria can be present in the organism without causing any disease, and at some point, it could activate and start the infection of red blood cells and the endothelium. "An immigrant from Ecuador went to Spain. He had reported a fever only when he was a child. And then he went to the emergency room because he developed a wart; it was the Carrion's disease wart. He only developed the disease after spending years in Spain. […] There was another man, from Ecuador, who had not visited his country in three years. He went to the hospital for a routine checkup, and they found he was infected with *Bartonella bacilliformis*." Dr. Ruiz affirms that normally, when these types of cases happen, the

patients develop the wart, meaning they go straight into the chronic phase, without experiencing any fevers.

An innovative concept is asymptomatic carriers. Dr. Ruiz, along with Dr. Ulloa Urizar, explain that 40% to 50% of the population in endemic areas carry the bacteria in themselves, but do not express any symptoms. These were labelled *human reservoirs* of Carrion's disease (Ulloa et al. 2018). Dr. Ulloa Urizar mentions "they are like the containers of the illness, which have legs and walk around. These are where the bacteria is stored, because we do not know of any animal reservoir for the disease. […] It is these reservoirs that maintain certain focal locations, which present spikes every so often and at a certain point in the year." In the interview, Dr. Ruiz expanded the dangers of migration of these people. He described that having these silent reservoirs migrate to different parts of the country could potentially lead to the spread of the disease, so long there is the appropriate vector for it. He complains "this is not talked about at all. It is impossible for a migration from an endemic zone not to have 50% of carriers. It is statistically impossible. […] What is not found in Europe — and outside the Andes — is the adequate vectors. Now, if a local vector were to adapt in order to carry the bacteria, that would spread the disease.

In the early 2000s, Dr. Minnick was invited to Peru to research the Carrion's disease in the quest of the production of the vaccine against Carrion's disease. This vaccine, still inexistent, remains a dream of his. During the interview, I asked if the vaccine would target both stages of the disease (acute and chronic). He replied: "I think that the important thing would be to get a pan-specific vaccine that targeted the organism that you could apply prophylactically in children so, a) they never become infected, and b) chronic carriers. […] And by doing that, you basically would stop

acute and chronic types of illness […], so you're targeting the organism rather than a specific disease presentation or acute or chronic disease." According to him, this is an opportune time to eradicate the bacteria.

**Conclusion**

Carrion's disease should be a disease that the Peruvian government should try to eradicate while the conditions are still favourable. Although this study aimed to get the communities' perspective on the disease, they were not able to provide any anecdotes, let alone knowledge about it. Nevertheless, their responses provided valuable insights to the intricate issues surrounding healthcare access in Peru, especially in cities distant from the capital. Their testimonies served as an exposé of the realities people face, and resurfaced all the aspects in which the government must put in a great amount of work. Education on health was insufficient, if barely existent.

Health education should. Preventive programs should be increased in areas where health is not the most accessible. Even though most participants count with public health insurance, they rather resource to a third-party institution, such as private doctors or religion.

The experts that took part on this project long for this disease to be dealt with before it escalates into something the country is clearly unable to bear: before more vectors adapt and new, more resistant species of bacteria arise.

Information on Carrion's disease is extremely scarce. Very limited attention has been given to it because of who it affects: the marginalized. Because of the lack of importance given to these populations, scientists have even been turned down research funds and collaborations because "this illness does not affect the occidental world". Considering the climate changing, this is an answer

that should not be given, as it could become an issue that affects that enclosed world. If we wait until that happens to deal with it, it will be too late.

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