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## **Carrion's disease: neglected diseases of neglected people**

### **Reflection component of summer research**

With enthusiasm, before I was even awarded the Laidlaw scholarship, I started getting in contact with the entities that would make my research possible. Carrion's disease, a neglected tropical disease (NTD), is very much understudied. Therefore, I thought of getting in contact with universities and specialists in the matter ahead of time so the fieldwork part would go smoothly. My research involved interviewing people who live in endemic areas for the disease, and I knew getting in contact with them would be a hard task. I had the expectation medical universities would be a great bridge to reach the potential participants. However, this disease is so neglected that not every university knows about it or does not hold any records of the people they have worked with.

After getting accepted into the program, I continued talking to the specialists in this disease. At the same time, I was applying to obtain REB approval. This process was a bit rocky; there was a lot of changing plans due to political upheaval in the locations I wanted to conduct my interviews in. Because of this, I submitted my application later than expected, so I had to change my start date from June 19<sup>th</sup> to July 1<sup>st</sup>. Despite this, and all the stress that came with it, I received my approval letter just before my start date.

I was not able to start travelling right away as expected due to the uncertainty regarding the ethic's approval. Therefore, during the first week of research, I decided to work on the literature review component of my project while booking my flights to my first location, Cajamarca. *I was posting on fb groups, calling hospitals to get participants.* I also happened to have a cousin who lives there and was willing to help me reach out to people in the city.

On July 8<sup>th</sup>, I flew to Cajamarca, the third city with the most cases of Carrion's disease. Upon arriving, I got altitude sickness, which put me to bed for a couple of days. As soon as I felt better, I started my fieldwork. I was excited to get to talk to citizens about their experiences with Carrion's disease and with the health system in Peru. Before arriving, I had 5 confirmed interviewees, which was exciting. However, this number did not meet my goal of having 10 participants per location. Thus, I decided I would find participants on the go. Having received the Laidlaw scholarship, the approval from the board of ethics, being a student at the University of Toronto, and on top of that all, being Peruvian, made me confident on the belief that obtaining participants like that would be easy. Unfortunately, I soon understood I was wrong. When approaching potential participants, I was received with skepticism and fear; people were not sure my research project was legitimate, and even thought I was an undercover agent sent by the government to take their information and act against their behalf. Trying to convince people to be interviewed involved negotiating for over 30 minutes and proving I was in fact a student conducting research that could be beneficial to them. Even when they understood the study was real, they would not trust *me*. They explained this fear came from past experiences, where they were also told they would participate in certain projects that ended being an excuse to use their personal information. I had the false idea that because I was Peruvian like them and grossly had their same traditions, I would be welcomed and trusted immediately. However, I was still an outsider, a *limeña*, who would not understand life outside thereof. Today, due to the political

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climate and increase in criminality, people are less and less trusting of others, which makes complete sense.

Not being able to obtain any other participants in the city, I decided to drive further from the centre to La Llica. This village was a 4-hour drive away from where I stayed. After getting there, I was able to talk to 2 people who accepted being part of my project. Their interviews were concrete and simple; I asked questions and they answered with not too much detail. Both of these people lived a rural life, where they produce what they consume, and work seems more like their lifestyle rather than a chore. Even if I was welcomed here, I still felt the lack of trust and space between us.

On July 12<sup>th</sup>, I returned to the capital to get ready to travel to my second location, Áncash. However, my plans were soon interrupted by nationwide protests. My father had offered to come with me so I would not travel alone. After telling him my experience in Cajamarca struggling to talk to participants, he decided he would talk to some friends so we could have a person from the place show us around, who would serve as a bridge between the participants and me. In his quest of doing so, he was advised not to travel using the highway (which was the only way I could get there) due to truck drivers strikes. We decided to postpone the second location until the situation improved. This would mean we had to also postpone traveling to the third location, Loja, Ecuador. In the meantime, I continued reading papers on this disease and watching lectures made by specialists. This also gave me time to continue pushing to get in contact with the right people to obtain participants. I was put in contact with the epidemiologist of the Ancash region, but he was not as helpful as I expected. He redirected me to the health department of the city, but despite multiple tries of calling and emailing them, I did not receive an answer. I tried calling other hospitals, but they did not pick up either. After discussing this with my supervisor, she advised it was better for me to work with what I have and use my time strategically. Instead of spending time driving for hours— and risking not having any interviewees— I decided to get in contact with the leading scientists on the disease, and they agreed to be interviewed by me.

Once the interviews were ready, came up with a story to tell. I let my worries behind and worked with what I had. This was a huge lesson learned for me. I was the type of person to keep going when things did not exactly work out. I keep a positive attitude in front of every challenge. However, this time it was different. This time I did my best to get in contact with the right people, I kept pushing but I was going nowhere. This experience taught me that sometimes it is not about overcoming obstacles— because sometimes there is nothing to overcome—, but about redirecting your initial plan, about becoming fluid. Even though I planned ahead, when a situation does not depend solely on you, you have to learn how to adapt and work with the tools and material you possess at the moment. Dr. Ulloa, one of the experts in Carrion's disease, told me during our interview that what I got done was great. For projects like mine, you need a longer time for field work.

And I think this is what Laidlaw does: you are allowed to come up with a crazy big project because they *want you to fail*. They want you to embark on ambitious, even audacious projects to eventually understand that failure is a possibility. They aim to illuminate the challenges inherent in conducting research, to underscore the essence of meticulous planning, and to highlight that receiving a grant is not a magic key to secure willing participants.

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This experience completely changed my outlook on who I am and my career goals. It provided an invaluable opportunity for self-awareness, serving as a stark reminder that even though I was born and raised in the same country as my interviewees, I am an outsider. Such experiences are necessary to truly comprehend the complexities involved.