EPISODE 26. DIALOGUES: A CONVERSATION WITH DAISY HERNÁNDEZ

Daisy Hernández [00:00:01] The technician dug into the bag and pulled out a jar that had a single kissing bug. It was the species *Triatoma dimidiata*, and it was beautiful. The orange stripes at the edge of its abdomen gleamed in the morning light. The more I looked at the insect, the more it struck me as a practice in contrast. The bright stripes alternating with black, the six legs at perfect angles; two dark spots like teardrops above its belly.

Garry Aslanyan [00:00:38] Welcome to Dialogues. I'm Garry Aslanyan. This is a special series of the Global Health Matters podcast. In this series, I'll be blowing open some of the echo chambers that exist in global health. To help me in this quest, I have invited thoughtful and inquisitive individuals from different walks of life. Each of them has explored and written about global health issues from different disciplinary perspectives. I hope this dialogue series will give you, the listeners, an opportunity and space to step out of your daily routine and contemplate global health issues through a different lens. So let's get started.

[00:01:21] For our first Dialogues episode, I'm joined by Daisy Hernández. Daisy is a journalist and an associate professor of creative writing at Northwestern University in the United States. Daisy's investigation into Chagas disease started at an early age when she experienced first hand the impact of this disease on a close family member. In her attempt to make sense of this experience, she undertook a rigorous journey to understand the multifaceted nature of this disease. In her book, The Kissing Bug, she brings together her personal story and those of numerous other families. Time magazine named her book in the top ten nonfiction books of 2021.

[00:02:15] Hi, Daisy, welcome to the show. How are you today?

Daisy [00:02:30] I'm fantastic. I'm so excited to be with you.

Garry [00:02:32] Where do I find you today, Daisy?

Daisy [00:02:34] I am in Southwest Ohio in the United States, near Kentucky and Indiana.

Garry [00:02:40] Oh, great. So Daisy, in your book Kissing Bug, it explores the history of the neglected condition, Chagas disease. Why did you decide to do this and what inspired you to write about this particular disease, which affects mainly the poor and the marginalized?

Daisy [00:03:01] I wanted to write a little bit about what had happened to my auntie, my Theodora, who was diagnosed with Chagas disease when she was about 30 years old. And so I assumed that there was a book out there for a general reader. I knew there would be medical articles and science articles, but I just assumed that there would be an easy to understand book about this disease, and I couldn't find that. And what I found was that that book did not really exist. And it made me wonder about the stories of other families, specifically in the United States, because my auntie was diagnosed in the United States when I was very young. I grew up in the shadow of Chagas disease, and I say in the shadow because it's been so neglected that we thought it was a very rare disease. We had no idea about the millions of people who have this disease around the world, mostly from Latin America. And so initially, I actually didn't know that I would write a book. I just wanted to find those families and I thought I would write an article, which I did. I wrote an article for The Atlantic, interviewed a woman who had tried to get prenatal screening because she actually was somebody from South America who was aware of Chagas disease and wanted to see if she herself was infected and what that would mean for her child, and she ran up against the obstacles that you would expect in the United States, which is that her doctor did not know what Chagas disease was. So I learned her story and I started talking to the few doctors in the United States that have been really dedicated to their Chagas patients, and I thought, okay, I have at least a second article to write, and then a third and then a fourth, and I realized that I needed this to be a book. That I wanted to write about the history. I wanted to write about the political situation in the U.S. around public health. I wanted to write about the Latinx diaspora in the United States. So it became a book, and I really followed in the footsteps of the great Toni Morrison, the novelist, who said that she wrote her first book because it was a book that did not exist and she wanted to read it, and she just said, if there is a book that you need to read, it's your job to go and write that book. And so I basically decided that's what I needed to do, even though I did not have a background in science or medicine or public health, I knew nothing. So I tell people, don't be afraid to move forward, because people have been very generous with me with interviews and their time.

Garry [00:05:42] Did you feel that putting a human face to the disease helped make it real or more understandable for your readers?

Daisy [00:05:53] It's interesting you ask that because when I talk with people who are in the medical field or in public health, that's some of what I hear. But I wasn't coming at it from a medical perspective, I was coming at it from the other way where I desperately... I knew the human story, I was the human story, my auntie was the human story. So I had grown up with the story but we felt, I felt very isolated with it. So I wanted more stories to see what other people had experienced and what I found was stories very similar to my auntie's; feeling very isolated, feeling like you're the only person who has this disease in the entire world, struggling to find a doctor who knows about it, struggling to understand what medication could do or not do at the stage that you're at with this disease. For me, though, in a larger context, I have a journalism background, I also write memoir, so for me, I've always come to the work from the beginning of my life that the human story has to come first, that the narrative of people's lives have to come first, because ultimately everyone, every person is interested in stories of other people. There's a particular part of your brain that's interested in the statistics, that wants the data, but at the end of the day, what evokes emotion is the story of another person's life. It allows readers and total strangers to walk into a much larger conversation. So it's that doorway into a much larger conversation.

Garry [00:07:29] Interesting, thanks for that, because even in the name "kissing bug", there is clearly a human connection because the name comes from the habit that insects have of feeding from around the mouth of people. And in fact, it depends, I'm sure when you worked in Colombia, but in Brazil they call this bug barbeiro, meaning a barber. So an insect that comes to your beard or your moustache, around your mouth, and it's really fascinating how the communities already put real humanity into it. It's just not being as well known.

Daisy [00:08:12] Garry, I have to tell you a really fascinating story about the title. So in English, it's been nicknamed the Kissing Bug, but it actually was not for scientific reasons. It was actually for the most unscientific reasons, which was a fascinating part that I ended up discovering initially through some interviews with these wonderful researchers in Texas. So, in the late 1800s in the United States, we had this really strange situation that happened where people were showing up in emergency rooms with these huge swollen lips, and they were claiming that they had a bug bite that came in the night and that they were never able to catch the insect. And some people have said that it was like a case of mass hysteria where people, perhaps had a spider bite or it could have been anything else. But what happened was that it reached the point where the Department of Agriculture got involved and they ended up writing a piece for popular science at the time, and they basically said it might be one of six insects, it might be this, it might be that. But what happened was that one of the six insects is the Triatoma species, and I think that what happened is that was about 1899, and of course, the discovery of Chagas disease in Brazil with Dr Carlos Chagas happened about ten years or so later. And what I could find, I actually went into newspaper archives trying to track down the development of this phrase, and I think what the journalists did is that they went back in their own archives and saw, oh this was the nickname for that kind of insect. And they ended up applying it without fully... I don't know that they fully appreciated how the insect operates and so forth.

Garry [00:10:10] And of course, you already mentioned that Chagas itself is named after Carlos Chagas, the Brazilian physician who first described it. And really the parasite's name is *Trypanosoma cruzi*. Cruzi for Oswaldo Cruz, another pioneer of medical science in Brazil, but he used his name to name a parasite. Anyway, something about names in this story.

[00:10:31] So, I was tracking your book, Daisy, by the narrative, multiple narratives that you've included, all connected to the parasite and the disease. Why did you take this approach and how did these narratives support your advocacy efforts with diverse audiences?

Daisy [00:10:54] I was not expecting to have multiple narratives. I really thought that the primary narratives would be of the patients that I was interviewing, these many families across the United States. And it was actually my editor who asked me if I would be willing to write more about my relationship with my auntie. And I said yes because I wanted to work with this editor, and I was excited. I like to write memoirs, so I'm happy to write about my family's experience. I was worried because my auntie, her experience with the disease is really different than the experience of other people. And this was a really powerful lesson for me as a writer, is that I worried so much that because there were some anomalies in terms of the fact that she was able to be diagnosed in the 1980s in New York City was very, very unusual. The fact that she was able to receive medical treatment at that time in the U.S., without being a U.S. citizen, was very unusual, not something that would so easily happen today. So there's just a lot of things that were unusual, and what it taught me was that I was... As a writer, you are able to find the points of connections between a story that seems really different and the stories of many other people. And ultimately, the narrative of me and my auntie was about a mother-daughter relationship. It was about caretaking in both directions, how she took care of me, how I took care of her. And that actually was really a connective tissue with the stories of other patients, because even though I think we talk about this as a neglected disease, this is also a disease of a family, it becomes a chronic ailment, and so you have lots of family members doing caretaking. So I felt like actually that ended up being this unexpected moment of connection as I was writing the book. So I felt like starting there was the most intimate experience and the most universal in a lot of ways, but before I felt like I could fully transition to the stories of patients, I felt like I had to basically take the readers on the same journey that I went on, which was that I had to learn everything about the disease as well, as much as I could as a layperson, through interviews. So the second part of the book walks readers through my interviews with doctors, biologists, infectious disease specialists, entomologists, all these different people. And then the third part of the book, we see, well what are the stories of other families, mostly in the United States, a little bit in Colombia as well.

Garry [00:13:39] There is a very powerful scene in the book where you are visiting the hospital and your mother whispers the word Chagas for the first time. Little did you know at the time the impact this word would have on your family. Daisy, could you read this part to us?

Daisy [00:14:00] "The New York City Hospital is a black, cavernous mouth. I am six years old and I am not afraid. Bolting from the elevator, I run down the corridor ahead of my mother and baby sister, my sneakers squealing on the clean floors. The doors are half open. The doors are invitations. A *cuarto* or room here belongs to us. The room holds Theodora, my mother's sister. My auntie mother. A single window in the room stretches toward the ceiling and Theodora is there with her pointy chin and thin face. The Spanish words tiptoe from her mouth. *Mi vida*, she murmurs when she sees my mother. Theodora rises onto her elbows, the gown sways on her small frame. She smiles at me with approval. My mother has combed my black hair into two ponytails. My sister, almost a year old, giggles in her summer dress. Outside the Manhattan heat licks our faces, but in the hospital, in my auntie's room, the cold air bites our ears. The doctors have sewn a line of dark stars across Theodora's belly, las cicatrices, and they have told her a word my mother whispers when she thinks I am not listening: Chagas."

Garry [00:15:22] Thank you, Daisy, for this very vivid account. How did your aunt's illness impact you, your family and your community?

Daisy [00:15:30] In our case, my auntie was diagnosed in the U.S. early in the 1980s, and what we experienced was, this is of course before Google, which maybe was a difficult thing and a good thing, we couldn't get all the misinformation. So for us, there was an incredible.. we really had to rely on the doctors, we really had to rely on the knowledge that they had. It was, for my auntie, she had a very intense fear around stigma. She never wanted people to know that she had Chagas disease. And I think for her, that was tied absolutely to her status as an immigrant in the United States. It's also a parasitic disease which people have all sorts of very adverse reactions to the idea of someone having a parasite. So for her, she taught me as a young child that I was never supposed to tell anyone that she had Chagas. And actually, that was one of the parts of her story that was really heartbreaking for me, was realizing when she died from Chagas disease and we had a funeral, there were her co-workers. She ended up staying in the United States, becoming a Spanish language teacher, and she had co-workers who came to the funeral who didn't know what she had died of. And this is someone who spent months. There were months that she was hospitalized and she lost time from work because of Chagas disease. And her co-workers thought that it was cancer and she never wanted to talk about it. And so I think she carried a certain level of shame around that. I was really surprised, actually, when I started interviewing families and ended up interviewing around stigma, ended up interviewing someone in Texas who's not from the Latinx community, she's a white woman who was born and raised in Texas and ended up being infected there by a local kissing bug. And she also had the same fear around stigma, and around telling people, and it was reinforced by one of the medical providers that she consulted with who said, she was basically told, don't go around telling people even though she thought, wait, we should raise awareness about this because we have these insects and people should know what's going on in their community. So I think there's still a lot of fear and a lack of knowledge. It really depends on what community you're in in the United States, but I was really surprised to find that. And then I think the biggest impact for my family, as I just mentioned, my auntie was... there would be years that were wonderful, very few symptoms, and then there were years where she was hospitalized for weeks, even months. And so it's a chronic disease, right? So it becomes a disease in which the whole family is affected in terms of everything from emotional caretaking to physical caretaking to employment and loss of income, and my auntie lived with us for a number of years herself so the financial support and the emotional and physical caretaking. I saw that when I started interviewing other families. There were many stories I could have included in the book, but across the board there are sisters and brothers and children and grandchildren, it becomes a family experience in terms of taking care of someone with Chagas disease.

Garry [00:19:02] Your book highlights the issue of access to care even in high income countries such as the United States. You describe that Chagas disease is contained to a second America. Let's listen to this description.

Daisy [00:19:19] "Standing in a church basement watching the line of immigrants to be tested grow longer, I began to consider another narrative because it seemed to me that the kissing bug disease, Chagas disease, is contained to a second America, and that in a broad and sweeping way, this containment is often the goal of public health programmes. We do not consistently eradicate infectious diseases, we contain them to communities of colour, to the poor, to the homeless, to people in this second America. The phrase the great epi divide makes me think of old paper maps and signs about who is allowed to enter and who has to stay out. It is a phrase that points to an American reality. Some people are taken care of and others are not. A choice is made. The great epi divide sounds more accurate to me than the more ubiquitous phrases like disparities in health care, which suggests that a terrible thing has happened, but without active participation on anyone's part. Disparities arise and inequalities exist. These words trouble, but at the same time offer a reprieve, no one is implicated. The same is true of the word poverty, that knife of an abstraction. A phrase like diseases of poverty obscures the degree to which we have made choices about funding for public health."

Garry [00:20:44] Daisy, how has access to care changed in the United States since the time your Aunt Theodora arrived in the 1980s?

Daisy [00:20:53] It's a very complicated question about care today in the United States. Your access to care really is determined by where you live. So when my auntie was here in the 1980s, she came on a tourist visa, she pursued medical care at a clinic that apparently provided care for low income community members. It does not seem that they ever asked about her citizenship status. Today in the United States, for someone who's an immigrant, for someone who's undocumented, it's going to be largely determined by where you live. So some of the patients that I talked to that were in the Washington, D.C. area, they were able to access certain levels of care. I interviewed a doctor whose patient I did not get to meet. She was someone in a different situation, a legal permanent resident, but in that part of Texas, there are some very intense limits on what kind of treatments doctors can provide. So they could provide a defibrillator, but not a heart transplant, for example. The patient that I include in the book was able to actually get a heart transplant, even with Medicaid dollars. So it really, really depends on where you live in the United States and also what the health care providers are doing behind the scenes. That doctor in Texas shared with me that even getting State Medicaid dollars to pay for the defibrillator was something that she and doctors and medical care health professionals had to fight for that at the State level. Your life is just completely different if you live in Iowa or if you live in Washington, D.C., it's night and day in terms of care.

Garry [00:22:45] And even when it comes to health workers or doctors actually knowing about Chagas disease, I think it's better in terms of the global kind of exposure to different things, to those trained in the north now is different from maybe what it used to be. But it's still complex in terms of they're not even looking for a parasite, they are looking for another condition before they even get to understanding that it's actually an infectious disease.

Daisy [00:23:20] I agree with you, I think, because I worked on this book for about seven years and I saw a lot more awareness just even in those like 7 to 10 years in the United States, it's been really incredible to see awareness among health care professionals. I keep saying still a long way to go, but again, it's also really determined by where you live. There's been a lot of activism in L.A. County, and so I think if you're in L.A. County, everyone knows, oh, there's a particular cardiologist who's devoted to this. The same thing right now in Florida, we have an infectious disease specialist who's been working on Chagas disease. So people, within the community they know, and then the upside, of course, is, I suppose Google. People get online and you can track down folks that way as well.

Garry [00:24:07] Daisy Hernández, your research took you across the United States and Colombia. You describe how pathogens don't care about bank accounts, national boundaries, tax returns, yet not all health care systems are equipped to deal with a disease such as Chagas. How do you see this playing out across different places and maybe even in Colombia? How did that play out?

Daisy [00:24:32] Yeah, I did get a chance to go back to my auntie's home country and I was actually surprised when I went to Colombia. Obviously, they have a much greater awareness than in the United States about Chagas disease, I would say, in general, but I was still surprised to find that there was, similar to the United States, really a divide between the rural areas and cities. So I met this doctor, a young, young doctor right out of medical school, born and raised in the city, in the capital, and he was doing his one year commitment of going out into rural areas to provide care. Chagas disease was completely new for him, and he made such an impression on me because he was so eager to learn everything. He basically created his own textbook on Chagas disease that he showed to me and had a number of patients infected, was really resourceful, a really incredible person. But it really also reminded me of what I was seeing in the U.S., which was the individual doctors ending up with their patients and realizing like, okay, I didn't learn this in medical school 20 years ago, in some cases, 30 years ago or longer, I need to learn about it now and taking the initiative to learn about the disease, to educate their colleagues as well, in some cases to go out into community to do testing as well. I think that actually a lot of what I saw in the United States around COVID was what I had already seen around Chagas disease. So here in the U.S. in the early days, we didn't know where to go get tested. We had testing sites that sprung up in very wealthy neighbourhoods when we desperately needed them in very poor neighbourhoods where people had to go to work and couldn't work from home. So a lot of the disparities that we saw with COVID I had already seen with Chagas in terms of not knowing which lab would test for people struggling. Doctors themselves hustling to figure out who would test for it. But I think I was actually surprised being in South America to see a certain number of similarities, which I think is true around the globe, right? We make choices about who we take care of, and we make choices about who we neglect.

Garry [00:26:55] So in reading the book or the work that you've done, what really helped me is to understand that between humanities and public health, what advice do you have to our listeners who are mainly global health professionals, about how this complementarity could enhance the impact of their own work?

Daisy [00:27:16] It's a beautiful question. I think people really understand stories about people, and that is the entry point to understanding the larger conversations and the larger concerns. I would say it's even the entry point to understanding the data fully are those human stories. I would say that's true when, from the perspective of wanting to reach people and wanting people to understand the work that you're doing in public health. I would also say maybe talk to the other side of the conversation, which is like kind of what does it mean for someone who's working in public health to either start writing stories or poetry or a documentary video. I think that, and again, I don't work in public health so this is my observation as an outsider, is that the work is very intense. The work can feel very urgent, is very urgent. It can also be insular. You're often talking with one-another with others who know about your field. And so I think that taking the time to pause and allowing even yourself to connect with what is the narrative of the work that I'm doing, I think that can be very powerful in giving you like an opportunity to look at your own work from a different perspective, one that's not necessarily driven by what you learn to do as a public health person. But like, how does this connect with the human condition? How does this connect even with your own heart and with your own work? I was remembering that when I started this process, there was a doctor that I had interviewed who I was trying to hoist meaning onto her own life, and I was like, why did you get so involved? Tell me about your life. And she was like, no nothing about my life. But in fact she is someone who grew up with a single mom. She's somebody who understood what it was like to not have so easily. She understood neglect, I think, in a very particular, visceral way. She cared about people because of the kind of, I think, struggles that her own family faced. And that was like a beautiful part of her story. And I think it adds another dimension and ultimately that actually does bring other people into it as well, when we understand what are some of those emotional ties. And again, I have to say, I've met many people in medicine and science who are like science no, no, no emotional ties, nothing. Even entomologists. I did this because I've always been fascinated with blood. And I'm like, take me back to when you were a child. What made you so fascinated with the natural world and say, I think there's another layer there. So I think telling stories, we're not only telling stories to others, we're telling stories for ourselves as well.

Garry [00:30:31] Thank you, Daisy, for joining us today and having this fascinating conversation.

Daisy [00:30:37] Thank you for having me. I really appreciate it.

Garry [00:30:41] Daisy confronts Chagas disease not as a public health study, but as a human story. By speaking to a vast range of experts and people affected by Chagas across different health system settings, Daisy's book paints a comprehensive picture of a disease through its multiple realities. Daisy's approach and influence can inspire us, those working in global health, to go beyond our public health silos and to present our work in a way that motivates expert policy and lay audiences towards greater action.

[00:31:19] To learn more about our Dialogues series and the content of this episode, visit the episode web page where you will find additional readings, show notes and translations. Don't forget to get in touch with us via social media, email or by sharing a voice message with your reflections on this episode.

Elisabetta Dessi [00:31:43] Global Health Matters is produced by TDR, a research programme based at the World Health Organization. Garry Aslanyan is the host and executive producer. Lindi van Niekerk and Obadiah George are content technical producers. Priya Joi is the curator of the Dialogues series. The podcast editing, communication, dissemination, web and social media designs are made possible through the work of Maki Kitamura, Heather Paterson, Chris Coze, Elisabetta Dessi, Izabella Suder-Dayao and Chembi Collaborative. The goal of Global Health Matters is to produce a forum for sharing perspectives on key issues affecting global health. Send us your comments and suggestions by email or voice message to TDRpod@who.int, and be sure to download and subscribe wherever you get your podcasts. Thank you for listening.