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The Campfire

Transcript of Episode 2: Social Stigmas and Social Barriers in Health Care, With PhD Students Amay Singh and Rebecca Ingrim

Max Benavidez: Welcome, I'm Max Benavidez. This is Episode Number 2. Today we have two guests with us from the school at Claremont Graduate University, the School of Community & Global Health. And these are two PhD students. We learned about them because their work really exemplifies what students are doing here at Claremont Graduate University.

Our first guest is Amay Singh. She's a doctor of public health student at CGU. She was raised in El Paso, Texas; received her bachelor of science from George Washington University in Washington DC; and her master's of public health from Tulane University in New Orleans. She worked for two years in Houston before coming here to California and now she's at Claremont Graduate University.

Our other great guest is Rebecca Ingrim. She graduated from Portland State University with a bachelor's of science in political science and economics. She's now a doctoral student at Claremont Graduate University, working on independent research about tuberculosis causes and disabilities, and is awaiting publication of an original study on chronic disease outcomes. Her interest are infectious diseases and environmental hazards.

Amay and Rebecca, welcome to the podcast.

Rebecca Ingrim: Good to be here, we're so excited. This is really good for us to start our platform talking about what we're interested in and how Claremont has really sort of shaped what we're going to be doing in the future and … what we're doing now. So I think we're really happy to be here and talk about this. It's been a good experience so far.

Benavidez: One thing that I've been struck by in talking with the two of you before is about the personal side of this. So Amay, when we originally talked and you said you wanted to study stigma in public health, you talked about some of the things that happened to you in your life, you know, around your culture and your background, that influenced you to want to come here to CGU and study this. Can you talk a little bit about that?

Amay Singh: In terms of stigma, so–growing up in an Indian family I would go to India every year. I've seen how women are treated over in India, especially considering women's health issues, so for example menstruation, like, it's a pretty squeamish topic wherever you go, but

especially in India. Many girls drop out of school because they start their cycle and they don't have access to proper sanitary pads or tampons or whatever, they use an old rag, which is not hygienic. They are embarrassed. A lot of, I think 23 percent of girls drop out of school because of that. Some girls are actually even, not just girls, I mean women, as long as they're menstruating, they're sent out to little huts that are set up in these isolated parts of the field, like it's in the middle of the woods. They rely on family members to come in and bring food to them and clean water. But that's not always the case and if it's bad weather they're out there, they're cold. It's not the greatest.

And then there's other topics, there's widows for example–they are considered pariahs in society, they're considered bad luck so they're not allowed to really attend anything.

Benavidez: So they're isolated–the widows are isolated.

Singh: They're isolated, there's actually like entire buildings just, I mean it's almost like a fortress, where you just keep women or widows in. And it's especially unfortunate for girls, young girls who are married off in child marriage. And so they're really doomed to this structure.

Benavidez: So if their husband dies and they're still young, they're going to be widows for the rest of their lives.

Singh: Remarriage is taboo for a lot…

Benavidez: Those kinds of experiences that would influence you. I mean, I didn't realize that 23 percent of young girls are dropping out of school due to the fact that they're having a menstrual cycle. And so they're being ostracized and stigmatized because of that.

Singh: Well, one, there's not proper bathroom facilities so in a lot of places to go to the restroom they have to go to a field. And so, one, they have no access to the material, like no access to pads. And even if they did, there's nowhere to really like maintain their cycle… if you're going to school with boys too, you know girls tend to be self-conscious and it's just easier to drop out. Some girls, they try to keep up the schooling by going, by just missing the week that they are on their cycle. But that adds up.

Women in India … Part of the custom is that if you're menstruating–and again, I don't really know how they would know this–but like, so you're not allowed in the kitchen, you're not allowed into places of worship. You're, I mean, essentially banned from a lot of places just because you're considered impure just for having a natural human body experience as a woman.

Even selling like sanitary pads or whatever, if you go to a store over there they have it hidden away in the back. And then when you ask the shopkeeper to get it for you, they kind of give you a look. They go in the back and then they wrap it in like newspaper and then black paper and

then like in this bag so no one knows what you're there for. It's like a weird little drug deal or something. They're like, "Here you go," and you're like, "OK."

Benavidez: But actually that shows in a physical way how people see their bodily functions.

Singh: I mean it's …but there's nothing wrong with that. All girls normally go through it. So it's, why should a woman be a social pariah just because of that, you know?

Benavidez: So Amay, if you can talk a bit about the connection between those experiences that you've had with women and widowhood and menstrual cycles, et cetera, and how it's stigmatized people and what's the connection between those experiences and what you're doing now and why you want to study stigma and public health. Can you talk about that a little bit?

Singh: Yes, so with stigma, I'm really interested in policy because I feel like that's where you can enact the most change. And our school, we're really lucky with some of our faculty there… amazing connections. I would like to work in global health, obviously, because India is like, it's still home for me. So I'd like to help my culture in any way I can. And so I feel like the best way to get involved with that is working with maybe like the UN or one of the entities there, and by doing so, maybe I can help influence policy that passes stuff that just can decrease stigma, increase health equity.

Benavidez: You want to create awareness about this, so that people say this doesn't seem humane.

Singh: I mean that's the best way to battle stigma, is awareness and education.

Benavidez: Rebecca, you know, when we were talking you had said that you had seen your mother go through an illness, she passed away, et cetera. You spent time, I guess, when she was in the hospital, in the hospital setting. And at that point you began to feel that the area that you're interested in, which is infectious diseases, was something you wanted to study and be involved in. Can you talk about that, first the personal side, but then, you know, talk about why you're studying infectious diseases now here at CGU.

Ingrim: Yeah, absolutely. When I was about 10 my mother was diagnosed with ovarian cancer and I spent a lot of time with her going through the battle and really thinking about at a young age, really thinking about what happens to your body chemistry when things like that, you know, happen, and you go through some pretty serious changes and sort of what your cells do or don't do. And I became really fascinated at a very young age with the battle that she was facing. I went to chemotherapy treatments. We went to Mexico and she was stung by a thousand bees, and we were really searching for all these alternative methods.

Benavidez: A thousand bees?

Ingrim: Yeah. In Mexico.

Benavidez: Oh, it's one of those methods of healing.

Ingrim: Well, they thought it would work. I don't really know if it helped out too much. She was pretty–even more, even more ill afterwards. But you know we were on this journey together, my family and I, to sort of do whatever we could to save her life. And so going through that with her and seeing the surgeries, I became very connected with the human body, immunology, and sort of what cells do. And from there you know, about 12 or 13 is when I became really interested with infectious diseases because on a different level–just as terrifying, but I get to take two steps back from something that's really personal but still be interested in something that kind of excites me. And I think my favorite question is sort of, Why did this happen? What's going on and what you can really do about it?

And so from there on out I became really interested in things like HIV and AIDS. I'm working a lot right now on tuberculosis. There's just something really exciting about me being able to combat things that are really terrifying, but that they're, you know, we're working on cures for these things. And you know honestly, I was reading a study the other day that said about... in 2015, about 10 percent of the population in America had tuberculosis during that year. Which is just, you know, something that we can really avoid.

Benavidez: TB is something we can avoid?

Ingrim: I think so. I definitely think so.

Benavidez: Why do you say that?

Ingrim: Well, I think a lot of it really comes from sort of sanitary conditions, people not living too close to each other, and really focusing on, you know, it’s the No. 1 killer of people with HIV AIDS.

Benavidez: TB is?

Ingrim: Yeah. So when you focus on that population, specifically, you can sort of try to combat it from there. And so that's what I've been working on at the clinic that I've been doing my research with, is focusing on HIV/AIDS-infected individuals and tuberculosis and syphilis and other types of things that I really believe that don't need to be such a burden on society. But my interest started very young. You know it's a scary thing to talk about chronic disease, infectious disease, communicable diseases, it's really scary. But it’s also really interesting, because we have a lot of ways right now are sort of watching the development, the life of these diseases. We can really reduce them if we tried to, and in different ways, of course.

But you know, it's exciting for me. I mean Hepatitis B is the No. 1 infectious disease in the world and it kills more than it needs to. And it's a terrifying disease, and you can get it from water and unclean food. I mean we can really prevent these things.

Benavidez: . So a lot of these are preventable. What exactly… you know, for both of you to consider, what exactly will you do when you finish your degree here? Let's start with you, Rebecca–what would you do with a PhD from here? And you're interested in infectious diseases, what's the next step? Because a lot of people ask that, you know, in today's world, you know. They, you know, go and get an education, and I think given everything people say, what's the practical outcome here?

Ingrim: For me my PhD is in biostatistics. So I'm focusing on statistical analysis of these things, so I'm mapping out these diseases. I'm watching the trends, I'm watching how different types of vaccinations and or other type of preventable, or you know what not… things we can do. So basically for I plan on doing is I plan on mapping out these diseases and determining where can I intervene. I'm also very interested in clinical sort of trials and things like that. I mean, to be honest with you, the more we practice prevention and curing of these things, the more we can sort of figure out what's going on. So I know that for me, and I've… I've already been doing a whole bunch of research on these diseases. For me it's mapping them out… an epidemiological model allows me to.

Benavidez: When you say mapping out, what is it–what exactly does that mean? I mean you literally draw a map of it, showing statistics, and say, here's where it's going up, here's where it's going down? And then it's like a geographical locator as well? You could say, this is really big, say this part of the country right now. What can we do there, so it doesn't spread? Is that what you're talking about?

Ingrim: You could do it geographically, which I have some background in. And geographically mapping out STDs specifically, but I also do graphing of, let's say, that you started out with a population of 100,000 people, and you put 60 people in it with tuberculosis. How long would it take for the entire community to be infected? I also map out diseases like that as well. So there's a lot of different ways you could really map it out, depending on the research that I've read.

Benavidez: So you learning that here?

Ingrim: I did. I learned GIS at Claremont.

Benavidez: What is GIS?

Ingrim: It's Geographical Information [Systems]. So basically you do map out different diseases geographically. and you put percentages of where things are, and sort of, and it's you know, it's really helpful for everyone to see where things are clustering. Then you get an idea of maybe the demographics of the population, the characteristics of people that live there, things like that. And then aside from that, I'm also doing graphing based on the life of a disease, how long it takes for a disease to show symptoms, and then how long it takes for a person with symptoms to pass on that disease. I'm doing that as well. So there's a lot of different ways, statistically, you can do it. For me, my main focus right now is probably literally looking at the life of a disease, an infectious disease–how long it takes to give it to someone.

Benavidez: So this is something you would do out in the world.

Ingrim: Yes.

Benavidez: Like would you work for a government agency or something like that, doing that? And Amay, for you, what's the practical outcome, what's the result of you studying about stigma in, you know, in these settings …like you go back to India or whatever, I mean… Are you going to work in India, are you going to work here? And what kind of job do you get doing that?

Singh: My ambition, like you mentioned before, lies with the UN. But I would like to focus in on India, but I don't plan on limiting myself there, because there is a lot of stigma just around the world. For example in Malawi, they have these older gentleman called hyenas. And so basically when a young girl, either to go through a coming of age ritual, or if a woman, say like she just lost her husband, and as a sexual cleansing, they'll have them sleep with this man. and he's usually an older gentleman–I'm using gentleman very liberally here. And unfortunately a lot of times he has diseases so that this could tie into what Rebecca was talking about like HIV/AIDS. And sometimes they are aware of their status, sometimes they're not, but they're sleeping with loads of women. And so it's just spreading like crazy… And it's disgusting too. I mean it's just...

Benavidez: Well let me ask you this though: You talk about stigmas, and you know like something like this, but that's kind of bred into the culture that you have. I had never heard of this before–these hyenas who are doing this–and I put big quotes around it–"sexual cleansing." But also when you're talking about India, these are things that are embedded in the culture. I mean how do you change that? I mean this isn't just policy. These are cultural practices and we see that a lot of times. There's something that happened I think it was in Pakistan where you know some family stoned their daughter.

Singh: Honor killings, yes…

Benavidez: Honor killings. And so those are things that the government is trying to stop it. But it really applies to you. Like if you're dealing with stigma. How do you actually begin to dispel stigma. I mean this is something that's deep.

Singh: It's education. One of the issues there, you could pass policy in India, but it's such a diverse country–there's so many rural areas where they have like a tribal chief who's really regulating things like who's…

Benavidez: Who's marrying who etc.

Singh: Yeah. So I believe if you work with them and try to educate the community about what's going on, maybe they'll have a greater awareness.

So I actually know a close relative who went back to our ancestral village in India, and they had a child who was born here in the States and they were just visiting India. This little girl, she was

three years old. She had ice cream I believe over there. And so it was contaminated somehow. She became very sick. So, and all the men in the village, they had gone to a wedding in the neighboring state. And the women in the village…so the mother of this child, she was really upset, really scared. And the women around her were mocking her. They're like, Oh, you know, it's like typical for kids to get sick, why are you freaking out? And unfortunately that little girl did not make it.

Benavidez: She died?

Singh: Yes. But up to that point, that mother was being mocked, and no one was really helping her. So it's ignorance. Well, her immune system isn't adapted to Indian diseases. She grew up in the States …she was only three years old. But it's education. It's the best way to combat it.

Benavidez: OK. But that's going to be a long process. You know, with stigma. So would you want to…your fantasy is to work for the United Nations and in an educational capacity. I'm talking about stigma… I have learned about it because we see a lot of this information out there.

So the reason I ask is because like, really how do you do it? I mean you can educate people… we pass laws here, too. You know it isn't just India or other countries like Malawi or whatever, it happens here. We pass laws, you know, and things don't change. necessarily. So it's more than that. It's something about, changing customs and practices, isn't it? So do you study that here?

Singh: Well yes, studied that here. But speaking as someone who comes from that culture, this is a culture that's persisted for thousands of years. So in order to normalize or to combat stigma in a culture like India… it's pretty patriarchal. I think we have to get the men on board. And so for example with these women's issues, usually the men are just kind of like left out. We're like, oh, women rally together, but that's not enough.

Benavidez: Well it sounds like a really big job. I mean to be honest, because you know you're going there as a female in a patriarchal culture trying to change these stigmas. You're a transplant. They're going to say, you're really an American.

It's very personal for you, your work is very personal.

Rebecca, you know, talk about what can people do though about these infectious diseases. Isn't it something like more about really getting government agencies to really be aware of this? Because people say that we have more infectious diseases now than we had say 25 years ago. What happened in that ensuing period?

Ingrim: I would argue, and I know this is a very controversial sort of topic, but the less vaccinations communities take, the more diseases seem to sort of spread and come about and things like that. It's also living in really close quarters with animals, or consuming food and water that's not prepared properly–those things, you know, create infectious diseases. But the biggest thing really is, you know, hygiene, vaccinations. And although people maybe disagree

with vaccinations, it is a proven fact that they have really sort of curbed a lot of the spread of these things.

But sort of like what Amay was saying, you know, education is really the most powerful thing. Resources are the most powerful thing. You know if we could really convince people to sort of look out for certain signs and symptoms, maybe stay away from certain areas during certain times of the year… A lot of infectious diseases really can be attributed to different seasons. So if you're really aware that, hey, it's spring, it's humid, there are a lot of vectors out there, maybe you should steer clear of those areas. You know if people knew those things believed that they were true, you know, hazards, maybe the spread would be a little bit less. But it's also, in America it's different. We're combating these things. You know there's over 200 different infectious diseases, according to the APHA.

Benavidez: What is the APHA?

Ingrim: It's the American Public Health Association, and I think we're both we both members this….yeah. They say that there's about 200 different infectious diseases.

Benavidez: You mean in the world?

Ingrim: But if you were to Google, it would say there like something like 50, or 80. Because I was looking at that, there's a really big difference there between what people believe and what they don't believe. So I think that a lot of people don't believe they're at risk. That is a really big problem.

Certainly things like Lyme disease, the reason why that's sort of spreading is that people don't believe they're at risk, but they are. So basically just getting awareness out there…there's a lot of things that we're trying to do with regards to research that are preventable measures because it's hard to fix something that's already been done. So we can sort of get vaccinations out there or treatments out there before an infectious disease really takes over a body, before things can start spreading. We're in good shape and I think there's a lot of research being dedicated to that especially with regards to clinical trials. Pharmaceutical companies are really trying to create these preventable mechanisms. It's expensive, it takes a long time, and a lot of people are really against it. So it's a challenge.

Benavidez: Let's talk about what you're doing here at the University, and each of you think about what has been the experience here, that, you know, stays with you, that resonates … whether an experience with a professor or a fellow student, or some kind of the work you're doing off campus.

Amay, I mean what is it for you? Is there something that just sticks out in your mind and you say "I'm glad I'm here. I had this experience." Is there something like that for you?

Singh: The professors here, the faculty here, they're all extremely passionate about whatever they are studying and they seem extremely invested in their students. You're not just like another number, like, they're actually emotionally invested in you.

I went to, as you had mentioned in the intro, two other schools, and they were great, I had a great experience there. But here it's very unique because it feels like you're really adopted into this community and they're really invested in your personal success. So that's really refreshing. And professors seemed to be willing to use their connections to try to help you try to get where you want to go. So it's really refreshing.

Benavidez: So they really see you, that's what you're saying. Is that true for you too, Rebecca, with your experience here? Is there something that resonates, that happened while you were here, like this, that, you know, kind of illustrates this?

Ingrim: Absolutely. My first term in my Master's of Public Health program, I took biostatistics and I was absolutely terrified. I had no experience doing that, didn't think I was really much of a math girl to be honest with you. That's all I do now, is just statistics. So I was very, you know… I was… That's how good the experience was. My teacher, Professor Bin Zi, was probably the most amazing person to teach something that complicated, and was really able to get you excited about it. But I had a TA named Hillary and she recently finished her PhD a couple of weeks ago, I think, and this woman inspired me to work so hard because it was just going to be absolutely worth it.

Benavidez: And how did she inspire you to work so hard? She just was… by example?

Ingrim: Yes. By example, she was, and you know what's funny about her is that she really wasn't there to teach me, she was more there to support me and inspire me. She just talked to me about some of the projects she was working on, which was all statistical sort of analysis-type projects, and she really just sort of convinced me that this was maybe the best place for me to be, and to do that. And her and I had such a connection from the beginning, that I continued with statistics because I had her support, and she was there for me my whole two years in the master's program, and she was a GIS PhD. So she focused on the sort of informatics part of it.

But I've just never been around such supportive people [who] really said, “You know, if you don't get it today, you'll get it tomorrow. And I'm here you know to help you get this.”

Benavidez: So there's kind of two things going on: You're learning something–in your case, hard data practices, you know, biostats–you're learning that but then you also have the support. So it's sort of like a combination of really learning something that's useful for society, because you both talk about that a lot, how you want to contribute something to society. But at the same time you have this personal connection where you get the support and they really see you as individuals, so you're not just a number like you said, Amay.

Singh: You’re family.

Benavidez: OK. That's really great to hear.

Singh: Our policy professor, Dr. Heather Campbell, she is amazing. She is very passionate about her field. She's very intelligent and she's very inspiring to be around. So I came into this program not really knowing anything about… not *anything*, I mean I knew the political system… but she really put policy in a perspective, that kind of dissected into a way where you can…

Benavidez: And how did that connect for you? That's what I'm trying to get at. What's the personal thing here that happened, what was the spark? I mean, was there a spark and you saw something. Because you've said that before about, you know, Dr. Campbell and that she's really great. But then what was the thing that actually did it? Was there something that happened?

Singh: Well I don't really have a lot of background in policy. And she it seemed like she really, it's going to sound lame but she sounded like she really believed in me. So and that really resonated with me because it's not often that happens especially when you're so new to…

Benavidez: So then you saw the connection between what she was doing in the classroom with your desire to work in the area of stigma in health.

Singh: Yeah. OK. And just like policy in general. I think at first she thought was a policy student. She's like, oh, you're here for your policy degree. I'm like, not quite, kind of integrating that into public health. And so yes, she's an inspiration.

Benavidez: You're both biting off a lot, you know, in the areas you're talking about, and so like I said before it would be helpful if you could just talk a little bit, you know, before we close out, about how do you relate to other people outside the program who aren't specialists, who aren't in the university? What do you tell them, you know, you're doing? I mean do you ever have that experience. Well, say, with your family…

Singh: Well with family. So I bring up a lot of the topics I mentioned so stigma is something I think goes across all cultures. I already mentioned stigma with women's health. But I'm also interested in stigma in mental health because from my personal experience what I've seen is that a lot of people there, they either think you can pray away disease or mental illness which isn't the case all the time, I mean, it works for some people. Or they just they just pretend like mental health is not a thing. And so I've seen people with mental health issues in India, again, get mocked because they're different or if they try to see… and you see that here, too, it's not just India. Someone's like seeing a therapist. So some people are like, Ooh, you're unstable, or ooh, you're crazy. So there's a lot of stigma.

Benavidez: I just read something about Lady Gaga. She had had a sexual assault and then she went through therapy. And then the one that really struck me that I didn't even know about was Prince Henry, because as you know…

Singh: Prince William, they're both working together…

Benavidez: But Harry, I mean, he had a real issue with his mother's death and didn't deal with it and then partied out through his adolescence, but now he says all of the support he got really helped him. So he used the word stigma too. Yes. It was interesting. And what about you Rebecca, talking about people beyond the campus environment?

Ingrim: Well, I spent almost a year at this public health clinic, so I see a lot of patients that are very unfamiliar with the health care system, in sort of what's going on in public health and things like that, so I kind of bore them with my details of what I think is important and interesting. They seem to really get a kick out of it because a lot of these people… first of all, English isn't their first language. You know health care, navigating the health care system, can be very challenging. And when you have someone that can sit down and sort of explain it to them in a way that makes sense and is interesting to them, you know… and I got a lot of that from Claremont–how to break these things down and explain them to a person who may not be familiar. A lot of the training that I had here was sort of you know breaking things up into pieces so anyone could understand what you're trying to talk about. I do a lot of that at the clinic. I talk to my dad; he's an architect so he's completely unfamiliar with the public health world.

Benavidez: So that's good, that's really what I was looking for–can you talk to people about what you're doing? You sound really excited about it.

Singh: Well, I mean, public health too, it's such a broad area, so you can really find almost anything to connect with someone with. I mean someone has an experience with something health-related, somewhere along the line.

Benavidez: It touches all of our lives, it really does, whether it's stigma or infectious diseases–the whole field.

Singh: Anything, really, you can be like, well in public health, this is how we would try to address it. And so it just kind of connects the dots for people.

Benavidez: Well, great. Amay and Rebecca, thank you for being on the podcast. I wish you the best of luck as you finish your studies, et cetera. We'll hear from you again.

Singh and Ingrim: Thanks. Thanks for having us.