

**DD: Can you describe yourself in three words, please?**

RD: The first word is 'reader'. I love reading fiction. I think it's a route into other worlds, which is important. My second word would be 'enthusiastic' and I hope that comes across in this podcast. My third word would be 'tenacious', in which I try to get on with things, even if they're setbacks.

**DD: Hi, everyone. Welcome to the Global Health Lives podcast. I'm Delan Devakumar and today's guest is Dr Rageshri Dhairyawan. She's a consultant in sexual health and HIV medicine in Barts Health, NHS Trust and an honorary senior lecturer in Queen Mary University of London.**

**Rageshri is a clinical doctor, a researcher and an advocate for sexual health rights and violence against women, in particular minorities to women. Rageshri, thank you very much for joining me today. The kind of work you do is so important and I was super keen to have you on the podcast.**

RD: Oh, thanks so much for the invite. It's really exciting to be here.

**DD: So we first met through your partner, Darren. Darren was helping with the project that I was running, migration and xenophobia in schools, and I'm happy to say that through him I met you. Then we've been working together on race and health group and on sort of different issues. So your work spans a few different fields in HIV, medicine and sexual health, violence against women and issues of racism and xenophobia. I'm really interested in how you got into these fields.**

RD: I think I've always had a bit of an interest in women's health because my mum was a GP who specialised in family planning. So I think she really instilled in me a kind of interest in women's health. That kind of led on to sexual health and then further on to HIV and matters related to that.

**DD: You have a medical family, mum in particular, then your dad is a dentist, your sister a doctor as well. But you started off life wanting to be an astrophysicist and then it all changed. Can you tell us what kind of influences you had in your family and childhood?**

RD: Sure, so I was born in Bombay and we moved to Essex when I was two. My parents have kind of moved back and forth before that. So they settled in Essex and that's where I grew up and went to school. It's a very medical family. So as you said, my dad's a dentist, mum's the doctor. My sister went on to be a doctor. So the NHS, I think, has had a real influence on my life. We used to spend our evenings sitting in our parents' surgeries, waiting to go home. We'd be doing homework and then the surgery, so I felt like I pretty much grew up in the NHS and I wasn't that interested in medicine. I kind of saw what it was like in the NHS and working, although I thought it's a great job for me.

I was really interested in astronomy, so I found space really, really interesting. I think I had this one book that I read maybe 100 times when I was small that really made me want to think about that as a future career. But I have to say, I don't think my physics and maths knowledge was probably good enough to be an astrophysicist, I think it wasn't quite what I envisaged. But I do remember people saying to me, are you sure it's an astrophysicist you want to be? Are you sure it's not an astrologist? I used to get really offended, because of course, I knew what the difference was.

**DD: I was interested, before you told me how your parents told you to not go into medicine. Why was that?**

RD: I think partly from their experiences of working in the medical field. I think they worked really hard. That's one of my main memories, is just how hard they both worked in order to have enough money. As immigrants here, they're very keen that we would attend- we had a good education. I was very lucky and privileged enough to go to a private primary school and then on to grammar school. So for them, education was key and they really sacrificed a lot, so I think they wanted to put me off and my sister off actually. Because while it's a great job, which they enjoyed, it was a lot of hard work and they wondered if there were other fields that we could look into. So my mum was keen for me to be an engineer, which I have to say, I never showed any interest in it at all, but I don't think they're disappointed with the choices that we've made.

**DD: You talked about coming to the UK as young child. So, I similarly was born in Sri Lanka and came here. But my grandmother, who lived with us was from Bombay. I remember going to Bombay as a child now, now in Mumbai. Did you have close connections with Bombay, your family in Bombay?**

**RD:** Yes, definitely. So we used to go every summer and on my dad's side of the family we owned a plot of land in Bombay. There was a building there for many years which was knocked down and the six storey block of flats was built in the end of the seventies. So essentially everyone on my dad's side, had a flat. So every summer we'd go back and my cousins would be there, either the ones who lived in India or the ones who lived in America or elsewhere they'd be visiting. So kind of all my summers were spent- I remember running up and down the staircases of this six story block of flats. So I really got to know my cousins, which was great. We had such little family here as well, so it really felt- India felt very familiar to me. That's been interesting for me, because when we think about identity and being British, Asian, my family's Marathi and we have a very small community here in the UK. So I never really felt that sense of being British, Asian where most of the communities here come from Gujarat or Punjab or other big groups. For me, it's always made me feel a little bit separate. That's really made me think about how British, Asian as an identity is large and very varied. Thinking about what it means when we think about health - the health of these communities - we need to ensure that we realise it's a diverse community. It's not just the obvious examples.

**DD:** **Yes, absolutely. I mean, categorising all people from Asia into one group just doesn't work, does it? I had a similar experience. So my family's from Sri Lanka and I grew up most of my childhood in Wales. So there weren't many Welsh Sri Lankans. What was it like going to school in Essex?**

**RD:** I grew up in Chelmsford and I was one of only two children of colour in my class. She is still a very good friend of mine, this other girl. We both had elder sisters. I think when we started primary school, we were both bullied a bit, actually. I think that's probably related to our race. We just remember being kind of protected by older sisters. When they left, they kind of had made enough impact that no one wanted to bully us further, so that was quite a big thing. But thinking about it over more recent years, so a school friend of mine has recently written a book about Essex girls. We had a conversation about did I ever feel like I was part of the stereotype. I said I didn't at the time, but actually as I'm growing older, I kind of want to embrace it. But more because there's something about the Essex girl being able to speak her mind and not be scared of what people might say, I think that's something to aim for and perhaps something I'd like to do more.

**DD:** **Then you decided to go to medical school, and you went to Guys and St Thomas'. When we were speaking before, you described how you weren't very political initially, but that kind**

**of changed during your university time. Were there specific things or major events that happened?**

RD: So I think yes, at medical school, one of the first things for me was having come from a very white area in Essex to medical school in London. Half of my year were from Asian backgrounds, so that was quite a big change for me. I have no regrets saying this, but at university I studied hard but I also had fun with my friends. I do remember kind of a bit later on towards the end I went to New York and bought a book there which was about women's rights and about abortion rights across the world, and kind of how precarious they are. That book really made me realise that actually all these rights that I took for granted, perhaps weren't always be there and still need to be fought for. So I think that was a kind of great introduction into feminism for me. That was towards the end of medical school. Then further on in personal events and events in my career have made me think more about how politics affects health and the other way around, I guess.

**DD: Health is very political, despite government proclamations that it isn't. So then you went into these fields, sexual health initially. Can you talk about the process and what you sort of learnt and how you developed two interests within those fields?**

RD: Sure. So I think I've been very lucky to do all my sexual health and HIV work in East London. Actually, I've lived in East London from well beyond that, from when I was a medical student, so feeling lucky enough to live in East London and work there and really understand the communities has been great for me. I think sexual health is an area of medicine where you get to work with people from very different backgrounds. Perhaps it's a speciality where we challenge stereotypes, we try not to be judgemental. Social justice is a big thing. So for me, I feel very lucky, I kind of fell into it, with my interest in women's health. Discovered there was so much to this speciality that I was really passionate about. I think initially- At the moment, I focussed more on HIV as a consultant, but as a registrar, I did a lot of sexual health as well. Some of the topics that have come up have been around gender and around race to do with sexual HIV and the inequalities there.

**DD: Yes, just on the topic, can you describe how those fit together? HIV, medicine, race, I guess coming at it from a feminist background as well.**

RD: Yes, so with regards to HIV, obviously there's been so many success stories around HIV in the last decade and more. So we have such successful treatments and people living to normal life expectancies, etc. But I have to say, in my clinical experience, when we see people on the wards, people are still having AIDS defining diseases. We're still seeing things like cryptococcal meningitis, we're still seeing all these diseases that I thought I would only really read about in medical school. They're still there on the wards. These tend to be people who are diagnosed late or not in care anymore for various reasons, so they have lots of challenges to staying in care. I began to notice that it was often the people on the wards were people who were from ethnic minority backgrounds, for example, and many of these people were women. So for me, I became very interested in women living with HIV because they're not seen as much and not heard as much. In fact, a really recent big study into them was called 'Invisible No longer', because people don't talk about women living with HIV in the UK so much. So that's really been my interest, I think. Actually, if you look at numbers, women make up the global majority of people living with HIV. But in the UK, they make up a third. I think a really striking statistic is that out of all women living with HIV in the UK, 80% come from ethnic minority backgrounds. That's something that often is not acknowledged.

**DD: Yes, I know. Can you describe some of the research you've done on this topic?**

RD: Sure. So when I was a registrar, I remember - I can actually picture in my mind - I went to a conference and I heard Professor Charlotte Watts, who's an international experts on violence against women, give a talk about the links between violence against women and sexual health. I remember sitting at one of my consultants and we both sat there like completely in awe, having never heard of these facts before. Just how violence against women is linked to poor sexual health and increased risk of STIs and HIV.

We went back to work, had a chat and thought we need to find out what's going on in our clinic. So I did a bit of reading and found out that violence against women is one of the leading drivers of HIV transmission globally. But there were no studies looking at this in the UK. So we basically did a small study in all our HIV clinic. We found that over half the women had experienced intimate partner violence in the past. Which is double the UK average in the general population. So that was quite a big finding. It went on to be cited in three national guidelines, it was presented nationally, it was published and ended up having quite a big impact - especially for the community of women living with HIV, who felt it was an important topic that wasn't talked about. That led on to me being on a national board to do with sexual

violence in sexual health and getting to do a lot of work around that. It's still an interest of mine, highlighting those links between poor sexual health, health and violence against women.

**DD: So it's must be great to see your work translate into actions and changes at a national level. So, I work on similar topics in a way, in terms of violence against women. We have a project in South Asia. I remember learning about some of the statistics around this, just how shocking they are. The international WHO surveys cite one in three women are survivors of violence. If you look at childhood abuse, that's a UNICEF statistic saying that a billion children have experienced physical, sexual, emotional violence or neglect in the last year, which is just staggering. We don't talk about this stuff. So tell me a little bit more about your advocacy work, because I know you're on a lot of boards and lots of groups. Why is that important to you and how have those things progressed?**

RD: Yes, I think advocacy has been really important to me. It's really enriched my clinical work in my research, but I think it's really important to make sure that we're also doing stuff for people living with HIV in the community and working with them. I think HIV actually has been a great example of patient activism. They (patients) are very much, things mustn't be done *to* them. They must do things for themselves. We must work with them, that's really important.

So my work has been around women living with HIV, I chair a steering group of a community interest company called 4M. Basically, this is about peer mentoring. It's a network of peer mentors in the UK who are what we call mentor mothers. So, they're women living with HIV who have experienced pregnancy and parenthood, there's a network of them who've been trained around the UK to peer mentor other women living with HIV. We know that's really important. So we know certainly in terms of policy, women living with HIV are often only be looked at with regards to pregnancy. So, they get a lot of intense care during pregnancy, then afterwards it kind of disappears. We know that's often a time for when women fall out of care, so they stop engaging with clinics, so this is really about keeping them in care, keeping them well and just really prioritising their health and wellbeing as well as that of the baby. So I've been lucky to be part of their steering group for a few years, which I now chair. I think I'm really proud of the fact that it is run by women living with HIV, it's run by black women living with HIV. We are there just to help and advice. I think that's very important.

Another role I do with regards to women living with HIV, I'm a trustee of another community interest company called Swift. Which is basically a network of clinicians, academics and women living with HIV. We want to use research and education to improve the knowledge and the lives of women living with HIV in the UK. I've run a couple of workshops for them, we did one this summer on racism and health outcomes. I've also done one on violence against women and HIV as well. So, that's another way of trying to advocate for this issue and improve the lives of women.

**DD: It is a perfect example of how things should work, really. So you described a little bit about your work with Naz. Can you tell me a bit more about that?**

RD: Sure, I've been lucky to be on the medical board of Naz, which is a London based sexual health charity for ethnic minority communities. I've been on the board since 2013, I think that's also been kind of one of the influences in terms of my interest in racism and xenophobia in health. I've had some really just some really great opportunities with them. So, we've been working on several projects to look at innovative ways of reaching ethnic minority communities, to talk about sex and sexual health, which are obviously quite taboo topics. A couple of my favourite - one was we actually made a film called Faces, which you can see on Amazon Prime. That is basically to get discussions about sex, sexuality and HIV in African populations in the UK. So I helped to advise on the script, they filmed some of it in our clinic and then they needed someone to play a doctor, so I ended up acting in it. I have a very brief scene where I play a doctor with my name, who sees someone who's been sexually assaulted. So I now have an IMDB page where I am down as an actress playing a character with my name. That's been quite funny. Actually the film has done well, in terms of kind of raising discussions. There's been screenings done with community, panel discussions afterwards, and it actually won a prize at the Durban International Film Festival. So that's just been an example of a different way of kind of approaching, reaching communities.

One of the other things I've done has been just help Naz with a project they're doing called 'Show They Love,' which is about trying to raise awareness of HIV amongst South Asian, gay and bisexual men in the UK. That's led to me doing more work around that. I led on the study at Barts Health, looking at all South Asian men and women living with HIV. This was the first study looking at this group since 2004, just a really kind of overlooked group, both in the HIV world and again probably in the South Asian communities as well, because people don't talk much about HIV.

Since then, again, with some other clinicians and academics and people living with HIV, we've been able to create a group called SAHAR, which is the South Asian HIV advisory Resource. We're really aiming with this to raise HIV and sexual health as an issue in South Asian communities in the UK and get people talking about it. But more importantly, get people testing, because we know that people often present late, because they don't go to sexual health clinics, they go to their doctors when they're unwell and get tested. So that's been a passion project for me as well.

**DD: Brilliant. So not only are you a researcher and clinician and advocate, also an actor.**

RD: I know, I keep offering myself up to other things.

**DD: No takers?**

RD: No takers.

**DD: So you've had your own experiences of the health system as well. I was interested if you could talk a little bit about them and kind of how they've influenced your work as well.**

RD: Yes, definitely. So, when I was training as a registrar, I was married, we were trying for children and I became diagnosed of endometriosis. Endometriosis as you may know, is a really, really common menstrual disorder. It affects one in 10 people who menstruate. The main presenting symptom is pain, it's something that that people often are ignored when they go to the doctor with symptoms and told your period pains are normal. This is just a women's problem, for example. We know that on average in the UK, it takes eight years for someone to get a diagnosis of endometriosis.

**DD: That's incredible.**

RD: I know it's incredible - even for me! So, when I was diagnosed I had bad pains, I went to the doctor, I had a scan that was normal. Then I was discharged. Then I ended up self-diagnosing myself a few months later and went specifically to the GP and said, I think I have endometriosis can you referred me to a gynaecologist. I did really reflect at the time that if I wasn't a doctor, if I didn't have a medical background, how easy it would have been for me not to be diagnosed and just how most women have difficulty getting diagnosed. One particular episode for me



was when I was having fertility treatment and I ended up being admitted to hospital with pain. That was basically because the fertility hormones had really exacerbated my endometriosis symptoms. I was admitted to hospital, and it was the hospital that I'd worked at as a registrar, so I knew quite well. I had very bad pain and I was treated as if by asking for more pain relief, that I was a drug addict. I remember being incredibly shocked at just the way I was made to feel, as someone who's a known medical professional- And again, it made me think about how other women are treated, how other people treated. So from the patient experience point of view, that was really important. So, I think for me, that kind of early experience, and that was about maybe over five years ago, that made me really think about how patients experience care. That's been important for me.

I think the other thing that's interesting about that, is although endometriosis and women's health and reproductive problems are so common, the amounts of funding that goes into them is really miniscule. So, again, whose health problems get more attention? Whose are seen to be more important? Then who gets the funding? All things we need to discuss more in medicine and research.

**DD: Can you talk a little bit more about the racialisation of this? Because endometriosis is almost one of the classical examples - the lack of pain relief, particularly to black women. I wonder if you could expand on that a little.**

RD: Sure. So I've actually recently written a piece on this for the BMJ leader. Actually, this comes from a conversation I had with my husband, Darren, you actually said is a philosopher. So I had this experience this summer where I'd tweeted, a very well referenced list of racial health inequalities in the UK. All reference to a link to the paper and the actual study. One of the first responses I got on Twitter was, is this correct? Has this been medically fact checked. Even though there I am on Twitter with my doctor name, my position, all the references. I remember saying to Darren 'I was a bit annoyed'. I wasn't very annoyed, but it was a bit irritating. I just said to him, "What's happened here?" And he said, "oh, I think you've suffered a testimonial injustice." This is an issue that I can't say I know lots about, because I'm not a philosopher, but it is a type of wrongdoing related to knowledge. So it's essentially when a speaker is not taken seriously due to aspects of their social identity. This can be, for example, their gender, their ethnicity, their age, their sexuality, their class, lots of different things. So in my case, perhaps because I didn't look like what a consultant might do on Twitter, because of my race and my gender, perhaps I wasn't taken as seriously.

So I wrote it I wrote a blog about this for the BMJ leader. Having read this excellent piece by Gallagher et al in BMJ Ethics, who did a much more detailed philosophy paper on this. It really looked at how when patients experienced testimonial injustice. So that is when they complain about symptoms and they're not believed by their doctors, it has an impact on them. So, for example, with endometriosis it tends to happen more to women. It tends to happen more to ethnic minority women. How all these factors and their social identity go together to make them less likely to be believed. I think we talk a lot about bias in health care now, so implicit bias. But I think, this is related, isn't it? Why is it that our societal prejudice- Why is it that we view some people as being kind of less credible when they talk?

**DD: Yes. We have this image of who the expert is. If the person doesn't fit that image, I guess these differences result. What can we do to fix this?**

**RD:** That's a big question. I think sometimes just being aware. I think it needs to be systematic. So I think it needs to start with- Obviously trying to change societal attitudes is a big thing. But there are things that we can do on smaller levels in healthcare and in medicine. So that could be around our training, making sure that we have more reflective training. People talk about implicit bias training, which I think is something, although it's not always. It's not been shown to definitely been effective and obviously the focus is on the individual. There are other things that we can do. So, again, lots of talk about diversity and inclusion on boards, but I don't think that's enough. I think there needs to be really proactive ways and making sure that voices are heard on these boards. In my piece of BMJ leader, I gave an example, it's one of the British philosophy associations, it's one of the women's ones. They have some guidelines for chairing sessions, which I think could easily be used in other settings, like in healthcare or conferences, for example. So when someone doesn't talk instead of saying, "Raise your hand if you want to ask a question." It suggests various ways in which we can try and get quieter voices to speak. So that the most obvious ones aren't always heard. So, for example, that could be giving a gap, between the talk and the questions, so people have time to think about what they want to say, maybe discuss of the neighbour. Things like making sure that people aren't always asked first. It's something about I think making sure that we reflect and acknowledge these kind of prejudices that we all may have. Which are ingrained in the systems that we work in. Also but trying to change our strategies and policies around that, to actively work against them.

**DD: Yes, it's so important and it's not just about diversity and inclusion, it's going a step further. As you say, to acknowledge people's views, opinions, to act on them, to build your strategies, policies through inclusive voices, really.**

**So, my last question is looking forwards, so within the fields that you work in, HIV medicine and sexual health and violence against women and the racism, xenophobia, work or anti-racism, anti-xenophobia work - what's your ideal view of the future? Given everything that's happening currently. Given the pandemic and the political state that we're in. If you were to look forward optimistically, how do you see that?**

**RD:** So I think this has been a particularly interesting year. I think, particularly with Covid really highlighting some of those racial inequalities, that I think we've known about in different disease areas for a long time. But Covid has really brought them about into the public arena in the discussion. That, I think along with the Black Lives Matter protests have really focussed people's minds. That I think is a good thing, because people are talking about it. It doesn't always mean the action happens, but I'm hopeful that there may be action, not just talk.

I think what has been really exciting, has been some of the work that we've seen from medical students. So, for example, in the United States, we know, for example, at the University of Washington, there was a campaign by the medical students there, to try and get rid of the race correction, when measuring estimated glomerular filtration rates, so kidney function. So that's an equation that we commonly use, where we use race as a factor. What it essentially does is, it means that we underestimate renal function in people who are racialised as black. So we may therefore miss early deterioration in kidney function. So that has important effects on health and kidney health in the long term. What these medical students did was to create a campaign about this. They've managed to get the race correction taken out of their medical curriculum so they're not being taught to do that anymore. I understand that in some hospitals in the US as well, they're taking it out of their clinical algorithms. Seeing that on the other side of the Atlantic and seeing a lot of activity in the UK as well. So medical students are really interested in social justice, they're really interested in, for example, I've seen campaigns to decolonise the medical curriculum. I just think there is a lot of political energy there, much more political than certainly I was and some my colleagues at medical school. I think it's very exciting to see and I think they are doing great things.

**DD:** Thank you, Rageshri for telling us about your journey, how you got to do all the amazing things you do and being a full time clinician and an advocate and a researcher and bringing all these fields together in these super important topics. It's wonderful to hear that story from you. Thank you.

**RD:** Oh, thank you so much for the opportunity to talk about it, thanks.

**DD:** Thank you to my guest, Rageshri Dhairyawan. The episode was produced by Priscila de Morais Sato, Amaran Uthayakumar-Cumarasamy and myself. Artwork by Beth Stinchcomb. The theme song is Paper Stars by Liam Aidan. This is a Global Health Lives podcast. Thank you for listening.