

## Episode: **Ethics Talk: Public Health Messaging Design and Epidemic Management**

Guests: Olivia S. Kates, MD; Monica Gandhi, MD, MPH

Host: Tim Hoff

Transcript by: Tom Wagner

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TIM HOFF (Host): Welcome to Ethics Talk, the *American Medical Association Journal of Ethics* podcast on ethics in health and health care. I'm your host, Tim Hoff.

Managing an epidemic well requires clear, concise public health messaging. Distilling complex clinical scientific facts into easy to understand and easy to follow health advice is a skillset that public health officials must master. We rely on public health officials to elicit concern without causing panic. Corraling adherence to guidelines in ways that preserve solidarity is a key feature of what it means to govern well during a health crisis.

In an article published in the New York Native in 1983, author and LGBT rights activist Larry Kramer argued that gay men should be scared and angry and if they weren't they would face extinction by Acquired Immune Deficiency Syndrome or AIDS. Others believed that fear-based messaging was inherently stigmatizing and that it would threaten social advances LGBT communities had found to be hard won. Jim Curran, a Centers for Disease Control official who coordinated an AIDS taskforce, believed it necessary to avoid panic and stigma by delivering public service announcements that clarified how Human Immunodeficiency Virus, or HIV, which causes AIDS, could *not* be spread.

Even in 2021 public health messaging must still avoid introducing stigma into campaigns to help people living with HIV. Dr Olivia Kates, the editorial fellow who led the creation of this month's issue on ending the HIV epidemic, recalls her realization that stigma can creep into even the most well-intentioned public health messaging. U=U or Undetectable=Untransmissible is a public health message that aims to promote the fact that those who achieve and maintain an undetectable viral load by taking anti-retroviral therapy daily cannot sexually transmit the virus to others.

DR OLIVA KATES: And I was interacting with the person living with HIV via Tweeter who actually expressed sort of the first negative opinion toward U=U as a mass campaign that I had seen really at all, and it was a person who, because of their HIV treatment history and resistance was unable to become undetectable, and they brought up the issue that there are a lot of people living with HIV in that circumstance and there are plenty more people living with HIV who are making the choice not to be undetectable, and that this messaging actually might have different meaning for people who don't fall into this celebrated undetectable group.

HOFF: Tension between avoiding panic and conveying truths about real health risks persists in messaging around HIV, obesity, smoking, and recently the novel coronavirus pandemic. Dr Monica Gandhi joins us to discuss lessons HIV experts offer to help us design public health messages today. Dr Gandhi is a Professor of Medicine at the University of California, San

Francisco, and she is also the Director of the UCSF Gladstone Center for AIDS Research, and the Medical Director of the HIV clinic at San Francisco General Hospital.

Dr Gandhi, thank you so much for joining me.

DR MONICA GANDHI: Thank you for having me.

HOFF: To begin with can you tell us a little bit about yourself and the work that you do in HIV research?

GANDHI: Yes. I'm an infectious disease doctor, but I went into infectious disease because I really loved the field of HIV. It overlaps for me sort of social justice, stigmatization of key populations, it's an incredibly important and interesting medical questions that come up with HIV, and so I consider myself really a HIV doctor. And now being in that clinic for a number of years since – for the last six I've been directing this clinic, [been the] the medical director of the clinic, which is called Ward 86. And Ward 86 is likely the oldest clinic in the world for people living with HIV. It opened its doors in January 1983 because San Francisco was the epicenter of the epidemic of HIV in the United States, and so we opened up our doors first. And so Ward 86 has reputation of being on the cutting edge of thinking about innovations of care for people living with HIV.

HOFF: The first living donor kidney transplant from a person with HIV to a person with HIV was performed in the summer of 2019, as you obviously know, while this innovation expresses advancement in our understanding of antiretroviral drugs and transplantation, a big part of the success of this operation is its potential to help reduce stigma towards those living with HIV. What role does stigma reduction have in ensuring equitable care for people living with HIV and for ending the HIV epidemic?

GANDHI: Yes, I think stigma has one of the most important roles actually. It's why I went into HIV. So specifically, what happened at the beginning of the HIV pandemic is that, at least in the United States, it was an infection that was disproportionately effecting men who have sex with men and gay men – lesbians to a less degree but they joined the gay men in the fight. And it really was a very stigmatized illness to the point that by 1985, four years after we had even talked about HIV in this country, still hadn't heard from the President of the United States at that point even speaking of it. And beyond that there was a lot of concern that this is just an anal-intercourse disease. It wasn't – there was really quite a bit of stigmatization about the more, the easier spread with men who have sex with men.

And then worldwide where the stigma comes in because it is a heterosexual epidemic worldwide meaning it is equal between men and women. If we think about sub-Saharan Africa, for example, the stigma comes in from sexuality in general. That girls are unfortunately – younger girls – are less able to negotiate their own often sexual debut or their own sexuality. There is an informal way that girls are simply not as safe as young men are from older men, and so all of that has led to this becoming a disease that occurs with a layer of stigma over it. The problem with any disease that has stigma – I would include COVID-19 actually in this – that any disease where there is, quote, "an element of human behavior," end quote, so sexually transmitted disease the

element is sexual activity, and with COVID-19 that element is masking or distancing or being around other people – there is always populations that end up getting blamed. There are actually a blamed-based messaging that occurs towards populations when all they are doing is anything that anyone else is doing which is being human.

And so, I am very concerned and obsessed with the idea of stigma and infectious diseases. I've seen it with poorer populations in COVID-19, I've seen it with racial and ethnic minorities, I've seen it in people after work, and I've seen it with HIV from the beginning. We have an initiative here in San Francisco called "Getting to Zero" and there are three goals of this initiative: to get zero deaths from HIV, zero new cases of HIV, and zero stigma from HIV. Because that is how important stigma has in a role to play in the spread of infectious diseases including HIV and COVID.

HOFF: Does public health messaging around vaccines and masks and social distancing during the COVID-19 pandemic suggest any lessons for HIV health promotion? What do you see as some of the most and least successful messaging strategies? And specifically what lessons does harm reducing messaging have for the success of COVID-19 precautions and vaccine participation?

GANDHI: Yes. I think that we have . . . I think there are a lot of public health messaging in COVID-19 that is not being informed by our long experience with HIV, and I think if we could actually draw back on our HIV history, we could be doing a lot better with COVID-19 mitigation. So what I mean by that is, going back in time, right? The HIV pandemic the first reports that we ever got of HIV were in 1981 – June 5, 1981 – the CDC's *MMWR* put out these reports of these terrible infections occurring in young gay men in Philadelphia, Miami, LA, San Francisco, New York, around the country and describing these terrible opportunistic infections that can occur when the virus targets your immune system. There was quickly a movement by public health to use stigmatizing language – "this is the price you pay for anal intercourse" – and also the second stigma is, "well, we know how to keep HIV away from everyone – abstinence only." So the message that was originally peddled, often by conservative lawmakers – and the opposite is true with COVID, so I'll talk about that in a minute – was abstinence only. "If you just stay away from other human beings, this can be combated, and we'll get rid of HIV."

Obviously to tell someone that a human need and behavior and a desire for intimacy cannot be part of their life because they have a viral infection is extremely stigmatizing, doesn't work, is completely non-compassionate, and it led eventually to layers of messaging, what are called harm reduction layers of: "No, of course, this is part of life, how do we keep you safe, how do we message how to tell you to be safer in your interactions?" And harm reduction was about condoms, or eventually pre-exposure prophylaxis, or treatment is prevention, or other ways to message to people who could have a risk for HIV that these are human activities, this is a human need, and how do we message appropriately so that we tell you how to keep safe and safer within human activities.

And so then what happened with COVID-19, fast forwarding there, is it was really scary when it was first happening, no one knew how it was spread, why was it spreading so quickly. And there was immediate shutdowns. That was indicated, we didn't know if it was spread from surfaces,

we didn't know how transmissible it was from people who feel well – so-called "asymptomatic transmission," which by the way there is – and then after a while measures came about and got recommended that could mitigate the risk for people, which is making, standing further apart from each other, and ventilation – these three so-called "non-pharmaceutical interventions."

Then, as we've been messaging as this pandemic has gone on and on, especially in the United States where we've had the worst pandemic unfortunately COVID-19, the lessons that we could have learned from HIV are not informing us. For example, there's still blame-based messaging going on right now. What I mean by blame-based messaging is – "if the public would just be more responsible, if they would just understand that they have to stay home, none of this would've ever happened." That's blame-based messaging because of course people have to work, people have desires to spend time with another person, loneliness is a big part of this pandemic, and this virus is very transmissible, and you may not have known at all what happened that you contracted COVID-19. Second problem with messaging on harm reduction is that it really hit me over the holidays is that a stay-at-home message is exactly like abstinence, and it did belie people's needs to see their loved ones or to see family members. And instead, we could've had a different way of messaging which is: "let's keep it safe, let's do masking in the household, keeping two families in two separate rooms if you're going to eat, keeping the windows open or at least cracked if it's really cold, and keeping it as small as possible, and we can't guarantee there is no risk, but these are all the latest ways to keep safe." And the reason that could have been more effective is, paradoxically, harm reduction messages – it's not even paradoxical but people will think it's paradoxical – actually reduce transmission more because it brings in human needs, human behaviors, human longings, into your public health messaging. It acknowledges human behavior. And there're many different ways we could have messaged differently through this pandemic that wasn't fear-based, blame-based, or used harm reduction that I think would have served us in better stead in the United States.

HOFF: The stigmatization of public health messages like, "this is the price of anal-intercourse," or things like that seems apparent, but stigma can work also through seemingly harmless or less apparently stigmatizing messaging, and I'm thinking specifically of U=U or Undetectable=Untransmissible. One of the articles in this month's issue argues that this messaging can exclude those who either can't or who choose not to pursue the goal of undetectability. Can you speak a little bit more to this kind of insidious role of stigma that isn't so apparent and "in your face?"

GANDHI: Yes, I mean, that's a great question. Just to remind us of what you U=U is, is essentially that after years of observational studies that showed that you are very unlikely to pass the virus on to another through multiple activities including sex including even other things like sharing needles, if you are undetectable if your virus is undetectable in your blood stream, there were three very large observational cohort studies where there was these were called partners and opposites attract studies and in these studies – very large studies – they enrolled couples and of the couples one was positive, one had HIV, and one was living without HIV. And all the people living with HIV were taking medication, antiretrovirals, and had their viral load less than 200. And out of hundreds and thousands of self-reported condomless sex acts either vaginal, receptive anal, insertive anal, there was zero new infections that occurred to those living without HIV. And

thus, the messaging arose, undetectable = untransmittable – that if you take your medications and you have no virus at least detectable in your plasma that you will not pass it on to others.

And U=U become a very large public health campaign of... the CDC pushed it out, advocates pushed it out, patients pushed it out because it was meant to be destigmatizing. It was meant to say that there should never be an element of people living with HIV having any questions about their having a healthy and happy sexual life; that they should be able to, even without condoms, given this incredible advocacy of treatments and prevention, be able to negotiate their sexual life without stigma. There's no Typhoid Mary, there's no... there should be no issue linked to someone living with HIV. However, like you just implied, there is a catch and there is one requirement of this messaging which is that those who don't pass it on to others usually through sex, need to be undetectable by these studies and by this messaging. And what does it take to be undetectable? It does take usually daily adherence to antiretroviral therapy. So the reverse stigmatizing that you're implying absolutely occurs because then what happens is [that] there are many reasons that people can't achieve undetectability, most notable among them usually social determinates of health or psycho-social barriers. So the various reasons why it is hard to take a pill every day is mental illness often, substance use which can interfere with pill taking, social determinants of health, food insecurity, housing insecurity, being homeless, not having the ability to even have their medications be somewhere, stored somewhere where you can take your pill every day. And thus it became – you're getting at very important issues – that it almost became stigmatizing for people who are poor or people who are struggling that – boy you can't even stay undetectable that must mean that... you should not be engaging in sexual activity or you don't care about others.

You're absolutely right that that's... bringing that back to COVID then, it would be almost like, and I really think of this as the *stay-at-home* message that we continue to message to this day – California just lifted stay-at-home orders another round of stay-at-home orders yesterday which was January 25, 2021, so we're really in still this *stay-at-home* messaging – belies the conditions of people's lives like essential work. I have to put food on my table, I have to go to the grocery store, I have to help my very struggling lonely neighbor; even that messaging, it didn't mean to be maybe stigmatizing, but of course it is stigmatizing, and it is something that is a privilege of the rich.

We need to look back on what we did during COVID because we learned a lot from what we did during HIV and they're still learning, and I think it's a brilliant point that U=U we thought was meant to lift stigma and it can put the veneer of stigma on some. One thing I want to say before we go on to the next question is, it is up to us as public health messengers and infectious disease doctors and all of that and politicians even, the onus is on us to message appropriately. To say later when we look back on COVID or HIV, "well, they didn't know any better," that is not accurate in the sense that we've had plenty of lessons from centuries of infectious diseases on how the poor have gotten blamed, on how the vulnerable and the down and out has gotten blamed for the spread of infectious diseases to the privileged. We have had decades and centuries of experience, and we need to know better when we message and we need to take a hard look before we put any public message out there to ensure that we are not doing harm.

HOFF: Is there such a thing as a "stigmaless" message or is it a matter of diversifying public health messaging so that we're not relying on single dogmatic phrases or things like that?

GANDHI: Well, I also think that's an excellent question because there's a tendency especially in the United States to use sound bites. A good example is not thinking critically. So, we like to say... we messaged a long time ago "no child left behind." That sounded really interesting and what a cool statement, whereas in Europe there actually was a lot more nuanced messaging about "let's work as hard as we can economically to increase the income level of the bottom ten percent of our society in the next year."

Do you see how one's really long and not sound-bitey [laughs], and the first one actually is really sound-bitey and may sound good, but it actually could be profoundly stigmatizing? What I mean by that is nuance, longer messaging, tailored messaging, messaging bringing in community members when you message are important for public health. One size fits all has never worked for public health. For example, pre-exposure prophylaxis in PreP – shouldn't we be done? We have a pill you can take every day. Shouldn't we be done, isn't it that easy, just take your pill every day, just take it. And of course, inaccurate. It's when we brought in community messengers meaning Latinx communities messaging to Latinx men who have sex with men, young women and adolescent girls in sub-Saharan Africa messaging to young women and young adolescent girls; and that message is totally different than a message to white men in the Castro district of San Francisco. We need to be a little bit less afraid of nuanced, tailored, chiseled, directed messaging to different communities bringing in our community members when we are trying to combat an infectious disease. Again, what happened with COVID-19, the phrase "stay at home" *literally* could be perceived as insulting – "where am I supposed to go, I have to go give food to the people who want to say at home and stay on their computer, so I have to go and deliver food" – it actually ends up shaming and stigmatizing, these types of easy to say sound bites. No, I think that's a very important point and then bringing in the community could not be any more important when you message.

HOFF: Great, thank you. The stated goal of the Ending the HIV Epidemic plan announced by the US Department of Health and Human Services in 2019 is a 75% reduction in new HIV infections by 2025 and at least a 90% reduction by 2030. This priority of reducing number of HIV infections is key but is it enough to, quote, "end the epidemic?"

GANDHI: Yes, I mean it's a great question. There is a tendency to put in aspirational goals. So these were aspirational goals that were put in by the End HIV Epidemic. I do believe that some of these goals and messaging may change in our new administration, that's first. The HIV directive was put out in the former Trump administration and Biden administration will have its own ideas. However, on the other hand, there are literally two simp... two ways to get the virus – I shouldn't say simple though, so I'm going to stay away [laughs] from the "simple" messaging – but there are two ways to get the virus to go away essentially. One is to bring the community viral load, the viral load circulating in existence, down as low as you can and the way to do that is to expanding treatment to those who... and tailoring treatment and figuring out what's keeping people out of care or what's keeping people from taking a pill every day, and figuring out an appropriate method of care that will help them take a pill every day to get their viral load to undetectable. And then the second is for those, while we're waiting for the virus to go down to

almost undetectable levels in the community, for those who could be at risk to take pre-exposure prophylaxis. Those are the two main ways that we can combat this virus.

And the funny thing is that we've had the tools for a long time, we keep on saying that's a "funny thing," but we've have had the tools for a long time, meaning highly-active antiretroviral therapy has been out since 1996 and pre-exposure prophylaxis was approved by the FDA in 2012. But it's not about having the pills and the tools right, it's about all the overlapping aspects of health like poverty, like stigma that we've already been talking about, like substance use, like loneliness, like social isolation, everything else that makes it so hard to just use these tools and make it go away. That's why these are aspirational goals and what I'm impressed by is that there's a real focus in the HIV epidemic on two goals; one is to go to high incidence HIV regions in the country so go to the counties that have, quote, "carried the most virus," end quote, have the highest incidences and focus resources on those counties as opposed to a county that has a low HIV incidence, and the second impressive goal of the End HIV Epidemic or impressive tenet that I think will help us achieve our goal is a focus on poverty, is a focus on social determinants of health. There is a true turning of our conversation to substance use, mental illness, hunger, poverty, housing, all of that, why can't people... why is it hard to take medication every day and how can we address it. And so, actually I admire the End HIV Epidemic Initiative. It's aspirational, it's exciting, it puts a name on it, it puts a framing on it, and I do think COVID is going to set it back, but if we can get through COVID I think all of us HIV researchers and doctors are going to turn our attention back. And do I think we are going to get there by 2025? I don't, but I think we could get there someday.

HOFF: Speaking of COVID setting it back, obviously the pandemic has drawn the attention and resources of the health professions community to exhaustion, can you talk a little about how that's affected gains made to end HIV epidemics?

GANDHI: Yes I mean it's literally just a matter of a limited number of people, researchers, who work on one problem and then turn to another. So HIV doctors and researchers because they have a lot to say and they have a lot to add to a new viral illness have been turning to this. Money got deflected from HIV to COVID overall. And then health systems... it was more difficult for people living with HIV to access healthcare systems because one strategy was to close off healthcare. So, I genuinely, genuinely think that we are going to be set back. There is a very disturbing model by UN AIDS that COVID will set us back to the point that we may be leaping up to the number of AIDS-related deaths by next year to one million as opposed to 500,000 AIDS-related deaths. We have not seen one million deaths from AIDS in this world since 2008. So that is a terrible, and I hope not true, prediction, it was not meant to be a prophecy it was just warning us that unless we turn our mind back to access to antiretroviral therapy, to keep on rolling out Prep, that we're going to see some major backslides.

So the way I think about COVID-19 since November 9th which is the first day that we got amazing brilliant news from the first pharmaceutical company that said – Pfizer, in this case – that said we have a vaccine that is this effective is that the best way to get out of the COVID-19 pandemic that we have to get out of it is mass vaccination. And so, now that we have the tools we're no longer in this point where, "oh, how are we doing to get out of this;" we know how to get out of this and it means putting all of our attention to mass vaccination hoping that we

do it as quickly as possible so that we can get back to the goals. There is no doubt that HIV has been affected by the COVID-19 pandemic and our goals to getting to zero.

HOFF: The rampant inequity in COVID-19 infections and deaths have revealed how closely linked a nation's public health infrastructure and capacity is for responding well to infectious diseases of all sorts. What should health professions students and trainees learn for this as they develop in their careers?

GANDHI: You know, what they should learn from this, I think, is that when you look back to what was happening earlier in 2020 with the very visible racial inequities that occur in our country with the police brutality being exhibited on TV for everyone to see with George Floyd and others, there was a moment of reckoning where the conversation turned to, "actually, we'll never get out of this until we go back and reckon with our racist origins and with our ongoing racist policies," and there is nowhere else to go but up from here and students and actually luckily people who had never talked about it even before started having that dialogue.

It is the same thing with infectious diseases and public health. That, in infectious disease like HIV, like COVID-19, like the bubonic plague, all of them are stemmed in inequities, in one group of people having to work, in one group of people needing to put food on the table, in one group of people not getting enough support from our governmental policies when we go through economic downturns (which is also part of public health), and I urge our students to realize that we are in... that unlike HIV which arguably people could say, "well, it didn't affect me I didn't know anyone who had HIV," and unfortunately people were still able to silo the infection, though that of course isn't true. With COVID-19 every single person on this planet has been affected by in some way by SARS COV 2 either by lock down, by economic downturn, by COVID-19 itself, and that entire planet being affected and then understanding how much inequity drove disparities and us in the United States being a country of inequity and us in the United States being the global center of the pandemic, COVID-19 pandemic since March 26<sup>th</sup>, I think it means that as students we turn our minds to it's not about knowing the drugs, it's actually not about understanding which drug works in what part of the pathway, but it literally is figuring out that our entire system of public health has to be redone, rewrought, and rethought of in a way that goes back to fundamental issues of inequities, disparities, redistribution of wealth, and everything that economists have been talking about for many, many years. So I guess we'll never get away from it again, we'll never ever pretend that inequities don't drive poor outcomes now that we've seen what happened with COVID-19, and it will revamp curriculums and it will revamp the way we think.

HOFF: Dr Gandhi is a Professor of Medicine at the University of California – San Francisco, she is also the Director of the UCSF Gladstone Center for AIDS Research, and the Medical Director of the HIV Clinic at SFGH.

Dr Gandhi thank you so much for joining me and for sharing your expertise.

GANDHI: Thank you for the privilege of being here.

HOFF: That's our episode for this month. Thanks to Drs Olivia Kates and Monica Gandhi for joining us. Music was by the Blue Dot Sessions. To read this month's issue "Ending the HIV Epidemic," please visit our site, [JournalofEthics.org](http://JournalofEthics.org). For all of our latest news and updates follow us on [Twitter](#) and [Facebook](#), @journalofethics with an episode exploring transgenerational trauma.