



Presidential Commission
for the Study of Bioethical Issues

TRANSCRIPT

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SESSION 4: HISTORICAL, SOCIOLOGICAL AND LEGAL PERSPECTIVES ON U.S. POLICIES INTENDED TO PREVENT EBOLA IN THE UNITED STATES

DR. WAGNER: This is the final panel of today, and it's to discuss the historical and sociological and legal perspectives on U.S. policies that are intended to prevent Ebola in the United States. Our first speaker will be Dr. Howard Markel who is the George E. Wanz distinguished professor of the history of medicine and the founding director of the Center for the History of Medicine at the University of Michigan.

He's also there a professor of pediatrics, psychiatry, health management and policy, history, and English literature and language -- he has a large business card -- and an acclaimed social and cultural historian of medicine, public health, and epidemics.

Dr. Markel is the author, co-author, or co-editor of ten books, including two that we point out -- want to point out to you here, the first entitled "Quarantine: East European Jewish Immigrants in the New York City Epidemics of 1892," and a second book "When Germs Travel: Six Major Epidemics That Have Invaded America since 1900 and the Fears They Have Unleashed."

It will be interesting to hear from you. Professor Markel has served as a historical consultant on pandemic influenza preparedness planning for the U.S. Department of Defense and currently serves as the principal historical consultant on pandemic preparedness for the CDC.

In 2008, Dr. Markel was elected to the Institute of Medicine, which cited his influenza work among, and I quote, "The most novel and potentially practical applications of medical history research ever conducted." His historical work served as the evidence base for community mitigation strategies employed by the WHO, CDC,

and the Mexican Ministry of Health and numerous state, provincial, and municipal health departments around the globe during the 2009 influenza pandemic.

Very much looking forward to hearing from you, Howard. Please.

DR. MARKEL: Well, my charge is to talk about the vast history of epidemics in America in ten minutes. Actually, 9.45 minutes, so I'll try to do that, and what I'd like to do is actually instead of speaking of individual epidemics is try to give you some major leit motifs of epidemics. I wrote that slide when I was listening to the opera. A better metaphor might be the ingredients of a cake.

So when you make a devil's food cake, you have many of the same ingredients that you might have with a red velvet cake or a carrot cake, but they are slightly different. But these ingredients do appear again and again and again not just in the American context, but across world history.

So the first one that's very important to note is that epidemics are almost always framed and shaped, sometimes advanced and sometimes hindered by how a given society understands a particular microbe to travel and infect others. So in this slide it's from the 1600s during a plague epidemic.

This is a plague doctor dressed -- actually looks like he's wearing a hazmat outfit -- but because miasma theory, the notion that rotting, organic material would somehow pollute the environment and cause disease makes a lot of sense as to why that health practitioner would garb himself in that way.

Economic losses are typically associated with epidemics and pandemics, and they can have a strong influence on public responses as well as public policies. And so you see this is just a clip from The New York Post during SARS where \$30-odd-billion were lost, and you can see those two -- that graph that shows the stock market and how

it plummeted during SARS and again during 2009 during the flu pandemic. So people do react, businessmen, commerce reacts in a way that's generally negative to epidemics and pandemics.

A very dangerous theme of epidemics past in terms of worsening spread is their concealment or delays in reporting them or delays in understanding their severity being ignored or underestimated by the world at large. So that top picture shows the cholera pandemic of 1892 as it played out in Hamburg, Germany. Hamburg was the leading port of the world at that time, and the Hamburg government did not want to publicize the fact that they had cholera in their midst and kept sending goods and people and ships out because of that.

As you recall during SARS, even though there were cases as early as November of 2003, it wasn't until April of 2004 that China admitted it had a problem and largely for nationalistic or political reasons. And of course, Ebola, the topic of today's conference is it was not underreported as much as underappreciated by those who were reading or glazing over articles about it much earlier than the summer of 2014.

Now the movement of people and other living beings and the speed of travel are essential factors in the spread of infectious diseases. So back 100, 125 years ago when people traveled by ships, you had a certain length of time, seven to eight days if it was an Atlantic crossing, and generally 10 to 20 days if it was a Pacific crossing. So you had time for the diseases to incubate on shipboards. And that's why a lot of quarantine stations were developed at various ports, because they could easily pick off those people who may have become ill before they came into port.

Now that all changed, of course, with jet planes, and just to give you an example of this, the quote of the day -- I'm not trying to be vain here -- but the quote of the day,

October 9, 2014, was by me. It was, "Germs have always traveled. The problem now is they can travel with the speed of a jet plane." Well, this floored me for many reasons. Why anybody would quote me generally floors me, but the idea that this wasn't inherently obvious to everyone.

And I think that's a very important point, that it is not inherently obvious until it's too late, the notion that an epidemic anywhere can go everywhere is something that we really do have to think about not just for ethical reasons or humanitarian reasons, but also for issues of national security and good business and good commerce and the flow of goods and people. So it really makes good sense to think about that, that epidemics anywhere can travel everywhere quite quickly.

Now we talked a little bit in the last session about media coverage, but widespread media coverage of epidemics is hardly new. And since there's been a printing press, people have been reporting on them, and it's an essential aspect of any epidemic. Some of the reporting is quite good. Some of the reporting is not. There have always been snake oil salesmen in every newspaper I ever read, and I go back a couple hundred years of looking at newspapers during epidemics.

So we really do have to worry about how information is spread. And in this era of amplification of information through social media and Twitter and blogs and the internet and so on, that spread is even faster making the old Mark Twain line about how a lie travels across the world before the truth even gets its boots on in the morning, he may have underestimated the speed with which that can happen.

Now this is something that I find troubling is our fascination with the suddenly appearing microbe that kills relatively few in spectacular fashion often trumps our response to infectious scourges that patiently kill millions every year. Think SARS,

think Ebola, think bird flu, when you really have to think about the things that do cart us off on a daily basis, and this was a piece in The New York Times years ago that I did, but tuberculosis is really one of the number one killers, as is AIDS, as is malaria.

If you look at the little, tiny, right-hand corner, because this was written during the SARS epidemic, there are only about four or 500 cases of SARS when that piece was written. And yet, if you read the newspaper at that time, you would think that the leading health problem in the world was SARS when it really wasn't.

Poverty, we were talking about this. Poverty and its attendant evils often fuel the fire of an epidemic, and we have learned that in west Africa. One of the previous guests said what a perfect host Liberia, Sierra Leone, and Guinea were for this, perfect in sense of how impoverished it was. These were actually photographs taken by Jacob Riis for his famous book "How the Other Half Lives," which comes from an axiom, a French axiom is that half the world doesn't know how the other half lives.

And that book was so successful because flash photography had just been invented, so he could associate his prose with these wonderful photographs. Well, now we have many more multimedia presentations of poverty -- television, movies, and so on -- and yet we're not doing enough to think about these two partners in crime, poverty and disease. And licking one might help the other, but you really have to start with the structural problems long before you take care of the epidemic.

One of the saddest themes in the history of epidemics is the tendency to scapegoat or blame individuals or a social group for the importation of infection. This is during the cholera pandemic of 1892 and you see coming into Ellis Island a shrouded, Asiatic cholera with an immigrant -- Russian Jewish immigrant and a Dutch immigrant. They come hand in hand.

The newcomer, the marginalized, the threat, whether real or perceived, of contagion in laws governing migration, individual liberties, and movement are uniquely tied and intimately tied, and sometimes many times civil rights, civil liberties are trampled on, and for a much broader group than those are truly effected with a particular disease. And of course as we learned -- we mentioned, the good Governor Christie who has suddenly become an expert in public health in so many levels that there's interlacing rivalries and disputes between local, state, and federal government and international government, so that these fights really do prohibit the good conduct, the good concerted effort you need to fight off an epidemic.

There is one slide I forgot to put in, but I think it's very important as we're talking today is that perhaps the most common final act to a pandemic is what I call profound amnesia. SARS, what's that? We're not yet at Ebola, what's that, but I guarantee you we will be there. And that's the real problem beginning with what Commissioner Guttman began with is that we don't want to plan for epidemics as they're going on; you want to do it in between. And yet, history shows time and time again we just move onto the next issue.

Well, years ago, Time Magazine called me. I was actually working on some flu work for the government, looking at some 1918 papers in the National Archives, and this was during the height of the bird flu scare. And the reporter kept asking me over and over again, "When do you think the next deadly pandemic will be, and how will it unfold?"

I didn't want to answer it, and I hemmed and I hawed, and I said, "Well, sir, I'm a historian. I'm uncomfortable with the future as a definition." And he said, "Well, you're also a doc. Give us a prognosis. What do you think?" And I was just stammering and

stuttering, and finally I said, "No one really knows what's going to happen. Anyone who says they do is either a fool or lying." And that's how I was quoted in Time Magazine.

So you have to be very careful what you say, but the reality is that these themes always occur and reoccur, but the exact mix, whether we're getting a chocolate cake or a red velvet or what have you, that's the trick. But what's also important to, in part to the American people or any other public at a time, is that when public health officers change their path in midstream, it's not because they're flip-flopping as politicians are often accused of. They're actually being good doctors.

When you're seeing a patient individually at the bedside and something goes awry from one hour to the next, you change your plan. And similarly, public health is patient-doctor relationship writ large. And when you see new data coming in, you change your plan, and then you move accordingly. So I'll stop at that point.

DR. WAGNER: Thank you. Our next speaker is Dorothy Roberts. Welcome.

MS. ROBERTS: Thank you.

DR. WAGNER: She is the 14th PIK professor, Penn Integrates Knowledge professor, George A. Weiss University professor and the inaugural Raymond Pace and Sadie Tanner -- is it Mossell?

MS. ROBERTS: Mossell.

DR. WAGNER: Mossell.

MS. ROBERTS: I've heard it pronounced different ways.

DR. WAGNER: Okay. Great. Alexander professor of civil rights at the University of Pennsylvania where she holds an appointment in the law school and departments of Africana studies and sociology. Internationally recognized scholar, public intellectual, social justice advocate, she has written and lectured extensively on

the interplay of gender, race, and class in legal issues and has been a leader in transforming public thinking and policy on reproductive health, child welfare, and bioethics.

Professor Roberts is the author of an award-winning book -- of award-winning books, including "Killing the Black Body: Race, Reproduction, and the Meaning of Liberty." She serves as chair of the board of directors of the Black Women's Health Imperative, on the board of directors of the National Coalition for Child Protection Reform, and on the Advisory Boards of the Center for Genetics and Society and The Family Defense Center. She recently received awards from The National Science Foundation, the Robert Wood Johnson Foundation, and the Dorothy Ann and Clarence L. Ver Steeg Distinguished Research Fellowship.

Welcome to you.

MS. ROBERTS: Thank you. Thanks. Well, thanks for inviting me to join you today to talk about sociological influences on the U.S. response to Ebola when it hit the United States, and I really appreciate that the committee is interested in the social context in which ethical principles are established and interpreted and applied.

When Thomas Eric Duncan entered the United States from Liberia infected by the Ebola virus, the media, public, and politicians responded in panic way out of proportion to the risk that he posed to this country. And as we heard in the prior panel, there were calls to close U.S. airports, to impose travel bans, and as the nurse mentioned, also to place quarantines on healthcare workers returning from west Africa even when it wasn't medically warranted.

Now what caused this exaggerated response, a response that far exceeded the risk, contradicted public health experts' advice, and linked the disease to political

debates about immigration and even terrorism? This question goes to the heart of my work over the last 25 years on biological claims rooted in race and gender assumptions that help to shape public policies and debates about social equality.

But I also have a personal stake in the Ebola panic. My sister, Helen, has lived in Liberia, where she was born, for the past five years, where she's helping to rebuild the education system there after 14 years of civil war. She visited me last September during the Ebola crisis shortly before Duncan died. And then she returned to Liberia to continue her work in November, and she's there now preparing children to go back to school on the 16th hopefully.

I didn't worry about having her in my home, because I knew she hadn't been near bodily fluids of anyone suffering from Ebola, and she had no symptoms herself. But what worries me more is the impact of the panic over Ebola and what that might have on her health back in Liberia and her ability to travel back to the United States.

Now I want to pick up what Dr. Markel said about marginalized groups being blamed for epidemics, and I'll focus my remarks on how race and gender influence the response, particularly on the way biological engendered concepts of race intersect with concepts of a disease and contamination.

An online commentator objected to playing the race card in analyzing the response to Ebola, writing "if a very Caucasian, Siberian Ebola patient presented at the ER in Dallas, he would have gotten the same treatment as Duncan." And I want to explain why I think it did matter that Duncan came from Africa.

The concept of racial diseases combined with stereotypes about black bodies help to construct Ebola has a black disease that was especially frightening because it's so contagious, contaminating, and uncontainable. Perhaps the two words Americans

associated Ebola with the most were Africa and fear. Granted, Ebola is contagious and often lethal, though not as lethal in the United States as it is in the few west African countries where it is now. But the extent to which fear "outweighed" the scientific evidence of risk was determined by racial disease concepts, stereotypes, and assumptions.

Behind the conflation of Ebola with black people is a racial concept of disease. There's a long history in the United States of understanding diseases in racial terms and racial differences in terms of disease. The notion of racial diseases that people of different races suffer from peculiar diseases and experience common diseases differently is centuries old. Originating in slave medicine, doctors today are still trained to identify their patients' race immediately and to take their race into account when diagnosing and treating them.

Countless research projects going on right now at universities and biotech firms around the country are studying racial differences in disease and searching for the genetic causes of racial health inequities. This racial understanding of disease has been an essential part of a biological strategy to legitimize racial inequality and has served to mark black people in particular as naturally fit for an inferior social status.

White slaveholders, including Thomas Jefferson, argued that the biological peculiarities of blacks made them unfit for citizenship and made enslavement the only condition in which blacks could be productive and disciplined. Shortly before the Civil War, Dr. Samuel Cartwright, a University of Pennsylvania Medical School graduate and well known expert on negro medicine championed the claim that slavery was beneficial to blacks for medical reasons. He coined the term Drapetomania combining the Greek

words for runaway slave and crazy to describe the mental disorder that caused blacks to flee plantations.

In his book, "The Protest Psychosis," Jonathan Metzl traces how schizophrenia became known as a black disease in the 1960s when psychiatrists began to explain black urban unrest as a symptom of mental instability.

Defining racial disparities in biological terms makes them seem natural, the result of inherent racial differences instead of social inequities. It blames the very people who are disadvantaged by inequality instead to avoid structural changes needed for good health and more broadly for a just society.

The U.S. response to Ebola stemmed not only from viewing it as an African or black disease, but also from a fear generated by stereotypes about black bodies and minds. Compare the result as -- to the response to the measles outbreak, which has come up a lot today, that began recently in California's Disneyland and quickly spread to about a hundred cases in eight states.

As far as I can tell, all the photos and interviews in media reports have shown white children and parents. Although there's concern about parents who refuse to vaccinate their children, who are often presented as hippy -- former hippies -- former white hippies, we don't see the type of panic that attended to a few easily contained cases of Ebola on U.S. soil. In fact, last Saturday, a New York Times article on the measles outbreak referred to measles anxiety, a far cry from measles hysteria or panic.

The myth that black people are exceptionally violent and out of control and therefore frightening has long circulated in dominant U.S. culture. It's recently been in the spotlight because so many police officers repeat it when they explain why they shot, choked, or beat to death an unarmed black person.

For example, Officer Darin Wilson testified before the Ferguson grand jury about 18 year-old Mike Brown, "It looked like a demon." And another quote, "When I grabbed him, the only way I can describe it is I felt like a five year-old holding onto Hulk Hogan."

Another longstanding stereotype is that blacks are less intelligent, irrational, and superstitious. The media portrayed African culture as characterized by witchcraft and distrust of western medicine and cast it as a risk factor for Ebola and an impediment to controlling the outbreak. In an August 2014 cover of Newsweek magazine, there was a large photo of a chimpanzee behind the misleading words, "A Backdoor to Ebola: Smuggled Bush Meat Could Spark a U.S. Epidemic."

Ironically, while policymakers in several African countries had successfully eradicated the disease -- and you've talked about survival stories, positive stories -- there's one that should be in your report that there was a successful -- in Mali and Nigeria. But at the same time, U.S. politicians were advocating hysterical measures contradicted by scientific evidence.

Black women have been subjects of degrading stereotypes based on myths about their uncontrolled sexuality and procreation. Attitudes originating in slavery have painted black mothers as reckless reproducers who transfer their degeneracy to their children. And I could go through lots of stereotypes. So let me move forward to the beginning -- beginning in the late 1980s when these stereotypes helped to turn the health problem of substance use during pregnancy into a crime.

Policymakers and the media located the problem in black communities and created a panic of gestational crack cocaine exposure. The pregnant crack addict was added to the mythology of depraved black maternity as the media depicted mothers

addicted to crack cocaine as monsters who, because the drug, it was claimed, chemically deprived them of maternal instinct. And this was only supposed to happen to black mothers. No other mothers had this chemical reaction in their bodies.

The media also created the so-called crack baby typically assumed to be black, although use of crack and other illegal drugs crossed racial categories, who was predicted to suffer not only permanent physical damage, but to become a social pariah. In fact, medical research, some of the best at University of Pennsylvania Medical School, has since discredited the stereotypical portrayal of the crack baby as scientifically unfounded.

As important as the stigmatizing stereotypes was the structural context in which they operated. Testing for and reporting of positive infant toxicologies was performed almost exclusively in public hospitals that served poor, minority communities. Private hospitals were less likely to have drug screening protocols and rarely if ever reported their patients to the police.

So let me conclude by saying that one of the most unethical aspects of the racialization of disease is that despite being identified as naturally prone to contracting the Ebola virus, blacks in America are less likely than whites to get treatment that will best insure their recovery. The deep inequities and access inequality of healthcare both in the United States and globally which were obscured by the Ebola panic are ultimately what an ethical approach to this disease must challenge. Thank you.

DR. WAGNER: Thank you, Dorothy, for interjecting that important perspective, which we'll work on a bit later.

Our final speaker for the panel is Dr. Unni Karunakara. And Dr. Karunakara has been a humanitarian worker and a public health professional for two decades with

extensive experience in the delivery of healthcare to neglected populations affected by conflicts, disasters, epidemics in Africa, Asia, and America. He was medical director of the medical humanitarian organization, Médecins Sans Frontières, Doctors Without Borders, campaigned for access to essential medicines, and later to MSF's international present -- excuse me. Let me run at that again. And later was the international president until 2013.

Dr. Karunakara was deputy director for health of the Millennium Villages Project at the Earth Institute of Columbia University, served on the board of directors of the Drugs for Neglected Disease Initiatives, and is currently an assistant clinical professor at Columbia University's Mailman School of Public Health and a senior fellow at the Jackson Institute for Global Affairs at Yale University.

And last but not least, Dr. Karunakara was part of the Bioethics Commission's own international research panel subcommittee, which provided advice to us in 2011 regarding current U.S. rules and international standards for the protection of human subjects research in scientific studies supported by the U.S. Government.

Welcome, again.

DR. KARUNAKARA: Thank you. Thank you for having me back. Much of what I want to say today has already been said, so I'm the last speaker of the last session, so a lot of things have already been covered. So I'm still going to soldier on. I've got some personal observations over the past two decades and some of my experiences, and then also coming to some perhaps ethical sort of issues that we need to perhaps look at as we consider future epidemics and future outbreaks.

So my first experience with Ebola began on February 26, 2002. I received a call from the MSF team, Doctors Without Borders team in Brazzaville in the Republic of

Congo. My colleagues told me that people were dying of fever in the remote Mbomo and Kelle Districts bordering Gabon and the Odzala-Kokoua National Park. It's a huge national park that straddles the border of Congo Brazzaville and Gabon.

Ominously, the field team had earlier received reports from forest rangers of massive ape die-offs. The rangers were concerned that the human outbreak was related to the deaths of the apes, potential carriers of Ebola. Within 24 hours, I was on a windowless chartered plane from Ostend, Belgium accompanied by another doctor and a logistician. We also had an Ebola kit onboard.

Now a kit is not a box. It contains everything you need to respond to Ebola from pencil to four wheel-drive vehicles. So that's a kit. So I was, in fact, in a plane sitting inside the car because we didn't have seats to sit on. It took us ten hours to reach Brazzaville and then another six days for the kit and the vehicles to reach Mbomo. I'm trying to paint a picture of the terrain here.

So it was easier to get to the capital, but took us six more days to get to the place where the outbreak had happened. It took us close to seven hours to drive the six miles from the forest airstrip to the village. So these -- it gives you an idea of the kind of places we're talking about, not the current outbreak, I'm talking about in 2002.

By the time we had set up an isolation ward in a local school, much of the damage had already happened. Not surprisingly, the villagers were wary of strangers walking around in white protective gear. The resistance to engaging without outsiders extended to fellow Congolese. So it was not just white people they were afraid of, but they were afraid of outside Africans as well.

The fear was not without reason. Family members showing signs of possible infection who were taken away to an isolation ward would rarely be returned alive.

They had no faith in medical care. As for them, health and illness were mediated by ancestors or spirits, not microbes.

As Emmanuel d'Harcourt of International Rescue Committee recently pointed out, however, superstition alone does not explain the difficulties in halting the spread of the Ebola virus. In the Congo, I witnessed deep mistrust and distrust and an inability to communicate between the communities and the institutions charged with providing care. The locals justifiably asserted that year in, year out, more children died from preventable causes such as measles and malaria than all who died from Ebola. And they wanted to know why the Ministry of Health had done nothing.

They aired conspiracy theories and recounted stories of bloodsucking and experiments by outsiders who had long preceded us. So this is going back to the colonial times as well sometimes.

Ebola allows no time for such mistrust. Speed is of absolute importance in an outbreak response. Management of cases essentially involves isolating patients in order to break the chain of transmission. We now know that in the Ebola outbreak of 2001-2002, the first case of animal-to-human transmission had actually happened as early as in October 25, 2001.

So the Pygmy people that inhabited these parts are hunter-gatherers and live in or around the rainforest that provide them the sustenance. Animals such as monkeys and porcupines were part of their diet. In fact, the virus had moved from animals to humans six different times in the four months prior to my receiving the call in February. So it's not just this outbreak. In previous outbreaks we've had this lag time between the first case and international response.

The fact that there were six separate transmissions of primary sources of infections points to the fact that Congolese Ministry of Health was unable or unwilling to mount adequate control measures or even to advise communities that they should avoid contact with sick or dead wildlife.

Given that there were very little understanding of what was going on, fear of course reigned. An epidemiologist engaged in contact tracing was chased out of town and harmed. Attempts to cordon off certain areas and limit movements had little effect. Families evaded health workers by hiding infected relatives in forests. No wonder then that the mortality rates were high, 89 percent, one of the highest recorded mortality for an Ebola outbreak in the past two decades.

Coming so late in the outbreak, our case management efforts, MSF, doctors, and nurses out setting up isolation wards had very little impact. Fortunately, the remote geography and the diminishing virulence of the virus over time limited large-scale infection and mortality. No thanks to us, the virus just died on its own.

What struck me during this outbreak was our absolute inability to communicate key concerns and to work with the community to control outbreaks. We lacked the vocabulary and the tools to negotiate culture, superstition and distrust. Moreover, the fact that it took four months for the information about the outbreak to travel from [Africa] to Geneva and then to Amsterdam indicates how broken the national health system and indeed the international response mechanism was.

Twelve years later, not much has changed in the national and international capacities required to respond to such an outbreak. Several factors led to loss of control of the current Ebola -- loss of control of the current outbreak in west Africa. Ebola erupted first in a region of Guinea that borders Sierra Leone and Liberia.

Unlike most outbreaks in the past, this one occurred in a region that was densely inhabited and by people who were extremely mobile both inside and across porous west African borders. To quote a colleague, "Even the dead move," because dead bodies were taken across borders and to other parts of the country for burials.

Several strategies failed, including attempts to engage affected communities in Guinea. This resulted in satellite outbreaks across the three countries, all of which had highly dysfunctional health systems with no prior experience in confronting Ebola.

For the longest time they thought it was Lassa fever. It's only much later that they sort of came to the conclusion that it was Ebola. The international response has been tepid and anything but timely and adequate. Though the first transmission of the disease occurred in a two year-old child in Guéckédou in southern Guinea on December 6, 2012, it was not until August 8, 2013 that the WHO declared a public health emergency of international concern, an eight-month delay. Longer than in the Congo outbreak, but hardly inspiring confidence in national and international outbreak response mechanisms.

National systems have suffered from the lack of investment and capacity. One MSF doctor illustrated the diagnosis of the situation. When one MSF health worker in Liberia puts on -- dons their protective gear just for one hour with the patients, he said they have spent the equivalent of what the government spends on healthcare per citizen for the entire year. So we're talking about per capita expenses in healthcare if you want to talk about health systems.

As the outbreak spiraled out of control in west Africa, fear and ignorance again dictated the course of the disease. To give one example, rumors in Liberia asserted that Ebola was a ploy to increase foreign contributions in order to increase health worker

salaries. In Liberia there was a strike going on just before the outbreak where health workers were fighting for increased pay.

Pervasive distrust can undermine even optimum medical care. Ebola transmissions occur in the hospital, but also in the home and at the burial ground. If we are to effectively reduce transmissions in these settings, we must accompany case management with equally important public health efforts in the community. We must educate the public about the nature and spread of the disease.

It is almost as if we have not learned lessons from the past outbreaks. AIDS and MDR-TB experiences tell us that outbreaks cannot be controlled without the understanding and the willing engagement of effected communities. Buy-in from the community depends on appropriate, fair, and just implementation of infection controlled policies.

We also know that coercive policies have been remarkably counterproductive in transmission control. For example, there have been reports from Sierra Leone that checkpoints and roadblocks meant to limit or control movements have been a disincentive for seeking care.

In the United States, as in West Africa, fear and politics played a big role in how infection-controlled policies were implemented. Effective protocols such as the one developed by CDC were implemented erratically. States and counties were free to impose isolation and quarantine on asymptomatic individuals without legal or professional oversight. Such inconsistency in the application of protocols served to stoke fear, propagate erroneous public health messages, drive individuals underground, and dissuade healthcare workers from volunteering to fight the epidemic.

It also didn't help that the returning healthcare workers were criticized and vilified rather than supported for their decision to treat Ebola outbreak -- Ebola patients. Travel restrictions that sought to limit travelers from affected countries have not been successful. Passengers have resorted to paracetamol or ibuprofen to suppress fever so as to escape detection at airports.

In addition, fear of being quarantined has made passengers less than forthcoming about having been in west Africa or about their exposure risk. If quarantine laws are unreasonable, then the likelihood of passengers lying about their travels increases. CDC Director Dr. Thomas Frieden recognized this when he said that a restrictive approach to travel could make the Ebola outbreak harder to contain.

Now I'm just going to go straight into the last bit, which is international human rights instruments do recognize the rights of states and legitimate agencies to limit the rights of individuals during public health emergencies. Section 25 of the Siracusa Principles states public health may be invoked as a ground for limiting certain rights in order to allow a state to take measures dealing with a serious threat to the health of population or individual members of the population. These measures must be specifically aimed at preventing disease or injury or providing care for the sick and injured.

With this right, however, comes the responsibility to ensure that the implementation of social distancing measures such as isolation and quarantine are necessary, that they are carried out in a manner that is legitimate, non-arbitrary, and cognizant of the social implications of such measures. National and international responders must recognize the tension that exists between the biomedical ethical principles of beneficence and autonomy.

The drive to control the epidemic should not come at the cost of an individual's right to autonomy. Arbitrary and unnecessary imposition of isolation and quarantine policies though legitimate can be at odds with ethical principles.

Now the last bit. The ethicist and a friend of mine, Jerome Singh, has proposed a set of questions that can be used to evaluate an ethically justified public health containment strategies. One, what are the public health goals of the proposed interventions, modification of what Nancy Kass presented earlier? How effective is the intervention known to be in achieving its stated goals.

What are the known or potential burdens of the intervention? Can be the burdens be minimized? Are there alternative approaches? Is the intervention implemented fairly? Can the benefits and burdens of the project be fairly balanced? And are the individuals affected by intervention adequately supported? No one gets counseling. None of these patients who are expected to be in isolation gets counseling. So these guidelines provide a tool.

So in closing, I just want to end by saying something, something I feel very strongly, that I want to reject the label of physicians being heroes. As I see it, physicians are fulfilling a moral obligation. Being a physician has a moral obligation by responding to Ebola. And being a physician also means the recognition and acceptance of reasonable risks associated with care.

Now the risks associated with Ebola are reasonable. We know how to prevent it. We know how to train people for it. So this should be routine work for physicians in the U.S. and in Africa, provided they get the right training and the right support.

DR. WAGNER: Thank you, Unni. In fact, I especially appreciate your penultimate points about guidelines. Up to that point, what we had been hearing from

you three was pretty difficult to swallow, that the life cycle of an epidemic has been, to begin with, denial and neglect and to end with amnesia, and in the middle to be marked with disparity and human rights restrictions, mismanagement and misinformation.

And if you hadn't rescued us with a few possible guidelines that could give us some hope, I would despair of this conversation. You may want to comment on that timeline, but are there comments also from -- sure.

DR. GUTMANN: Just along those lines, I think -- look, I think it's really important to hear what the history and sociology of -- that fuels. We have to understand what fuels the lack of attentiveness to what good medicine and good care and an ability to overcome a treatable disease, what the barriers have been, and they've been historical.

So you, Dr. Markel, said 12 years later and not much has changed. Those are -- what -- oh, Unni said 12 years later and not much has changed, but you've also done historical patterns, so --

DR. MARKEL: I would say 200 years --

DR. GUTMANN: Exactly, thank you. So 1,200 years later, 200 years later, you name it. So that said, my question -- I'll just tee you up -- is: How can we aid change? Because while not much -- I agree on the Ebola not much has changed. We can point to areas where there's been great discrimination historically where things have changed, and I'll give you the most apparent in our time.

Attitudes towards gay and homosexual individuals in our society without a doubt has changed dramatically, and you can look at the demographics of change, you can look at the politics of change, you can look at the sociology of change, and so on. It's change, and it's change in no small part because there have been movements for change.

Now that's a totally different area than the area where we can look at medical treatments and see how those have changed over time. I'm just teeing it up to -- I know we can't change everything, but how can we change something from your perspective of looking at all the things that are broken and have remained broken in the treating of Ebola and in epidemics and the discrimination that fuels it. Simple question with a difficult -- just how can we aid change?

And you can use any "we" you want. I mean obviously our commission is a "we", but it doesn't have to -- how can we aid change in what we recommend, an open-ended question, but to get out of the -- you know, informed by what you have seen historically, sociologically, and on the ground in the last 12 years.

DR. MARKEL: I didn't realize I was being such a downer, and I apologize. My daughter accuses me of that all the time.

In fact, a great deal has changed, and so, as -- as I was hearing about the concepts of beneficence and autonomy in relation to quarantine, that is an earth-shaking change in the long history of quarantine.

So, as recently as 100 years ago, when the commissioner of New York City was testifying before Congress on a typhus epidemic, he said, Senator, if I wanted to shut down City Hall and make it a contagious disease hospital, I could.

And the laws are quite clear, and you could yank somebody out of their home and put them on an island or a lazaretto, far away from where they lived, no questions asked, and so, the concept now that our public health officers think very hard about, even if there was to be a quarantine, how would you provide food, entertainment, phone calls, even though it never minimizes the harshness of quarantine, I realize that, and I've spent a lot of time writing about it.

But those types of concerns just simply wouldn't exist 50 or 75 years ago. So, that's something we should say is a good thing.

DR. GUTMANN: The public scrutiny and the questioning of it has really heightened --

DR. MARKEL: And that, too, so that the idea of --

DR. GUTMANN: -- and we can use our voices --

DR. MARKEL: Yeah, the whole notion of authority, in this country and elsewhere, that you would have to follow what they say.

The other issue has to do with stigmatization and discrimination. It has not gone away, but it has been attenuated somewhat.

And so, that -- we still have a lot more to go, but when you think of how immigrants were stigmatized 100 years ago, and for how long, and their fellow people who had nothing to do with the particular epidemic in question, that seems to have been attenuated somewhat, but we still have a long way to go.

But the idea that people no longer just take the public health officer at his word or her word and say yes is a big change.

MS. ROBERTS: Well, one question that comes up is whether it's better to ignore the racist and sexist attitudes and the stigma, and -- because maybe that will -- either people will reject what you're trying to say -- and of course, there are ways that are more palatable to people than others, ways they'll hear and -- versus ignore, or to highlight how these biases affect the way in which ethical principles are interpreted, the way in which scientific evidence is interpreted, the way in which we decide what's needed, what's a reasonable response, in order to get to a better response both in terms of justice and in terms of what's better for our health.

And to me, I think it's useful, which is why I made the statement I did today, to point out to people -- I'm not saying it always works, but for many people, if you point out to them that bias is actually causing a worse response that's going to harm people, they may change their minds about the irrational response that they have.

It doesn't always work, but I think it's better to highlight the way that bias is pushing toward the wrong response in terms of health and in terms of justice than to ignore it.

I have to believe -- and I've seen evidence where it does change people's minds, and so, certainly, if we're all perplexed about this crazy response to Ebola that even leads politicians to recommend measures that we know scientifically are going to make the epidemic worse, in the U.S. and abroad, than I would think we want to look at these biases as one explanation.

DR. GUTMANN: I think that it's very important to recognize that there has not been a rush to quarantine measles, you know. It really -- it's quite a -- now, there are differences, but there are -- there are also differences that speak -- because measles are much more contagious -- somebody who is asymptomatic Ebola is not contagious, period, full stop.

MS. ROBERTS: Exactly.

DR. GUTMANN: Measles are highly contagious, and there hasn't been a rush to quarantine, to isolate, and so on.

However, here's my question back to you.

MS. ROBERTS: Okay.

DR. GUTMANN: There's also evidence -- convincing people that it's wrong and counterproductive to do it is what you said, which I think is absolutely right. The more

you tell people that a lot of people have this prejudice and discrimination, there's evidence that that actually fuels -- people feel that they're in good company rather than that this is counterproductive.

So, how we communicate this is going to be critically important.

MS. ROBERTS: I agree. That's -- that's just a persistent problem when it comes to talking about racism. It's how do you keep -- tell the truth but not make people so defensive they won't listen at all? That's sort of a classic tension that comes up. Unfortunately, there are people who go all the way to the extreme of not talking about it at all, and what I'm -- I'm suggesting here is that it can make the discussion more rational if you note how biases have made it irrational.

So, the discussion about measles -- there's been some irrational things said about it, as well, but it's being conducted in a much more civil and considered way.

So, I think the ethics of, for example, whether a school should bar children who haven't been vaccinated because one of the students has leukemia and is extremely vulnerable to measles but hasn't been able to be vaccinated because the child has leukemia -- I heard a debate about that carried on in a very rational way.

You could imagine instead one saying get those children out of the school, their -- their parents are killing -- threatening to kill children.

You know, if you could just map on -- map on the kinds of things that were said about Ebola onto measles. To me, making that comparison, and really honestly asking yourself, do you think race has something to do with this? I definitely do, but I think -- I think you're fooling yourself if you think it doesn't, and then what are the consequences, then, of recognizing that bias and seeing if you could change the way in which the debate is being conducted.

I want to just mention two other things in answer to your question about what do we do? Another is that -- to try to also focus on the -- the stories of positive interventions, especially by people in Africa.

I find that so many of the stories are negative stories about African people or people of African descent that just perpetuate preexisting stereotypes, and as I mentioned, the work done in African countries to eradicate the virus in some of these countries is a very, very positive story that challenges the stereotypes that there's something, as the speaker in the prior panel said, as if there's something innate, you know, in so-called African culture that perpetuates epidemics.

No, as he also pointed out, which is my -- my final point, is that structural changes not only improve people's health but they also change people's attitudes.

So, if there is a concern about some of the misunderstandings of Ebola in Liberia and Sierra Leone and Guinea, what changed those misunderstanding? It was a change in the way in which the health care system addressed the disease and the recovering of people from disease.

So, it's not just -- I'm not saying that educating people, you know, through training sessions and those sort of things aren't important. A lot of what I said today was about changing misperceptions. I think education is important.

But more important, I think, are the structural systemic changes, which are what perpetuates these diseases in the first place and also create misunderstandings.

So, I would strongly recommend a focus on addressing the structural inequities that are tied to these biases, as well. I think it works both ways. Improving structures to create more equality, I think, improves people's attitudes about them, and vice versa.

Identifying and changing biases brings more willingness to change structure, but to me, the structure, I think, at bottom, is what is the most important and what I would advocate recommending to improve.

DR. WAGNER: Unni, I saw you take a note or two. Do you want to respond to Amy's challenge?

DR. KARUNAKARA: I just want to start with what you ended with. Absolutely. Let's forget Ebola for a moment and look at the health system. Years of under-funding and IMF policies and lack of donor stamina to see through changes have led to the situation where we are.

So, there has to be some real collective thinking about, okay, is it something we are going to take on and support and do?

So, that's nothing to do with Ebola. It's just you need those structures in place if you want to respond to any future eventualities.

Second is -- I think it was Dr. -- Professor William Foege who mentioned that -- perhaps a possibility of an African CDC.

This is something we really need to take seriously, and if at all it's something that we can get off the ground, then this should be supported, because they are the front line responders, and they have the -- you know, the capacities will be built in the continent closer to home.

It takes a long time to -- because a lot of our response also depends on domestic pressures and domestic concerns. So, you want people to be able to respond without all of those pressures.

So, I think an African CDC or some such would definitely be a good idea and should be supported.

Third is implementation of policies, and we talked about it. Why is it that a county or a state can just go and implement what they want even in the -- even when it is in opposition to CDC guidelines, right?

So, where is the professional oversight? Where is the legal oversight?

I think every isolation order should have some sort of oversight either by a judge or by CDC. This is something that the Americans have to figure out, but you have to figure out how to do it the best way.

Third is information, information, information, and how do you get communities to work with you?

So, I told you the story about my first outbreak experience, but the second time we responded, we had learned a few things.

So, the first time we set up an isolation ward, it was a school that we had taken. It had thick walls. It was opaque. You couldn't see what was going on inside. We had high walls.

So, bodies went in, dead bodies came out.

The second time we set it up, we changed it. The perimeter wall was transparent, so we had plastic materials through which the communities could actually see what was going in, and they had walkie-talkies where they could actually talk to their family members, who could then report back about the care they were getting, about the food they were getting, etcetera.

So, this might just one small example, but we need to work on -- to borrow a term from the military -- hearts and minds strategies to sort of work with communities.

DR. WAGNER: That cultural component.

John, do you suppose your question is going to be covered in roundtable?

DR. ARRAS: I wanted to engage you on the notion of heroism, but I don't want to get us un-tracked.

DR. WAGNER: I appreciate that. So, I tell you what. We will ask all of our presenters to reconvene around the table at 3:30, so we can have that roundtable session.

Thank you all. Another wonderful presentation.

(Applause.)