TRANSCRIPT

"THE GLOBAL PAIN CRISIS: NARROWING THE GAP IN ACCESS TO PALLIATIVE CARE"

A conversation with Liliana de Lima, Donald G. McNeil Jr., and M.R. Rajagopal

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* * *TRANSCRIBER'S NOTE: DIALOGUE FROM VIDEO CLIPS NOT TRANSCRIBED.* * *

ANNOUNCER:

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JENNIFER RASANATHAN:

Good evening and welcome. We're very grateful that you made it, despite the impending doom of weather outside. We're delighted to have you, along with our wonderful panel of speakers here tonight to discuss the global pain crisis, and talking about narrowing the gap in access to palliative care. My name is Jenny. I'm a program officer in the public health program. And it's my privilege to be able to welcome everyone here-- and to engage our panelists in a conversation-- about driving change forward in this field. So OSF has been funding palliative care since 1998. (LAUGH) Which is a very long time. (LAUGH)

Our efforts started in the U.S., but soon expanded to begin to address some of the global needs for palliative care. And this is a tension that we'll kind of come back to throughout the course of the evening. The access that people in high-income countries have to pain relief and palliative care, compared to those in lower and middle-income countries. (SNIFFS)

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And those needs are great. Millions of people worldwide wife life-limiting illness live and die in avoidable pain and distress. In fact, 75% of the world's population does not have adequate access to medicines for pain relief, and suffer needlessly.

Palliative care is not only an issue of social justice and fairness. It's also a human rights issue. Denying access to palliative care violates the right of everyone to the highest sustainable-- or to the highest attainable-- excuse me, state of complete physical, mental, and social well-being, including access to medicines for pain relief.

And that has been equated to torture in some human rights courses. And in courts. So clearly this is an issue not only with respect to the right to health, but other-- human rights that are, of course-- universal. (HITS MIC) So though the global disparity and access to pain relief is well documented, in fact, thanks to many of our panelists-- neither the current (NOISE) unmet need for pain relief, nor the fact that each of us may likely need these services in the future, has been enough to stimulate broad public interest, or sufficient political will, amongst global health actors and implementors, to tackle this problem.

And, as we'll get to later in the evening, in fact, this is a tale of two opioid crises in many ways. While policy makers in the U.S. are alarmed by the rising rates of overdose deaths-- (COUGH) the majority of the world's population in need of pain relief-- cannot access medicines that have been available and cheaply produced for decades.

The Lancet Commission on Palliative Care and Pain Relief will be publicly launching next month. And we're lucky to be joined here by two commissioners on that report. The report itself is a significant effort to document and draw attention to the global lack of access to pain relief, to demonstrate that palliative care is an essential component of universal health coverage. And to identifying cost of package of essential palliative care services that could be implemented, given sufficient political will.

So, again, we're honored to be joined by three fantastic speakers who can tell the tale of the other opiate crisis. The global pain crisis affecting most of the world, and highlighting the abyss and access to these essential services, and the barriers faced in other countries. We'll explore the potential implications of U.S. policy on the overdose-- well, t-- policy reactions to the overdose epidemic for the rest of the world, and also describe some of the ways that advocacy groups have been chipping away at this issue.

And so I'm going to briefly introduce our speakers. Each of our speakers will talk for roughly ten minutes. And then I have a few questions that I will lead the discussion with. And afterwards, we'll open it up to the audience for questions. Just for everyone to note, this event is being recorded so that we can share it more widely. And, if you would like to ask a question when we reach that portion of this evening's event-- put a hand up. Sarah Party, (PH) my wonderful colleague who was essential to pulling this event together, will walk around with a floating mic. (COUGH) And please be sure to speak into the microphone when you ask your question. All right. So-- I'm gonna sit now. (LAUGH) Great. So Dr. Rajagopal, who is in the middle of our panel here, is a palliative care physician from India, the founder and chairman of Pallium India, an NGO that created two palliative care centers

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in Kerala, and established palliative care services for the first time across eight states in India.

He's also the director of the Trivandrum Institute of Palliative Sciences, and he serves on many task forces and boards-- to deliver palliative care globally. He is also, as many of you know, most recently, a movie star. (HITS MIC) He features in the new f-- documentary film by Moonshine Cinema, *Hippocratic*.

There will be a screening of the film-- the New York City premiere, tomorrow evening, at 6:30 PM at the Regal Union Square theater. So we encourage any of you who are still in New York and available to-- go to see the movie. It's nothing short of inspiring. (HITS MIC) Just to my left here, Donald McNeil, Jr., is a science and health reporter at the *New York Times*. He specializes in covering plagues and epidemics. Joined the *Times* in 1976 and has held a number of positions there, working his way up from being a copyboy, as I understand. Has reported on a range of issues. Served as a foreign correspondent-- for seven years. And has reported from 55 countries.

He's an award-winning journalist who's written stories about HIV, (HITS MIC) patent monopolies that keep drug prices high in Africa, and also about-- cancer patients in Indian and Africa, dying without pain relief. Many of you will be familiar with his fantastic article from this past December about "opiophobia"-- leaving-- the whole continent of Africa in agony without access to pain relief. (SNIFFS)

In fact, Don first interviewed Dr. Rajagopal as part (HITS MIC) of a series of stories on pain relief in 2007. So we're very excited to have him here, and to be able to get these two together again. And finally, at the end of the table, last but not least-- Liliana De Lima is the executive director of the International Association-- for Hospice and Palliative Care.

She has worked in palliative care for more than 25 years. Before assuming her role in IHPC, the acronym for her organization, she worked previously with the Pan American Health Organization. She developed a regional framework in palliative care for countries in Latin America, and was also the founder and coordinator focus the hospice, La Viga, in Cali, Colombia. And that was the first hospice in Latin America. So that's just really wonderful.

So, as I mentioned already, Liliana and Dr. Rajagopal are commissioners with The Lancet Commission. And Liliana will touch a little bit on the commissions' findings. And a brief summary of that report is also available-- just outside. Thank you all so much for joining us. We're excited and honored to have everyone here for this event. And, without further ado, we'll get started with two clips from the new movie, *Hippocratic*. Mark, thanks so much for queuing the second clip, and then we'll s-- and then, immediately after that, we'll go to clip number three. And then I will turn the microphone over to our speakers. Thank you everyone.
(VIDEO NOT TRANSCRIBED)

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JENNIFER RASANATHAN:

Great. Thank you. So we'll turn it over to Dr. Rajagopal.

M.R. RAJAGOPAL:

Thank you. Thank you very much for the opportunity. Good evening, everybody. And thank you, particularly, for giving me the privilege of meeting Donald again after a gap of 11 years. And-- Liliana, after a gap of l-- 11 days, I think. (LAUGHTER) (THROAT CLEARING) What-- what I would try to do-- in the ten minutes, is to present the depth of the problem, explain where we are now, and also briefly go into the opportunities for the future.
(OFF-MIC CONVERSATION)

M.R. RAJAGOPAL:

So -- Donald 11 years. Your landmark article in *New York Times* was something that gives-- significantly strengthened our hands. And so much of efforts by so many people. (SIGH) It is-- I saw the disappointment in your face when you talked about the current status. Unfortunately, though we are making progress, like the rest of the developing world, the progress is too slow.

Our state of Kerala in South India is supposed to have the most access to morphine and to pain medicines. And, in our hospital, that was just, oh, three years back. Well, almost four years back. Things have not improved. The-- a-- the parents of a ten-year-old boy killed their only son, and then hanged themselves in the hospital room, leaving a note saying, "I am doing-- we are doing this because we cannot bear to see our son suffering anymore."

I sometimes find it very difficult to think about that-- those few minutes when the child must have been struggling. And the man must have held onto that rope. And when he strung-- stringed the child up-- I think that child, and that family, and the millions of people in pain around the world, should be on our collective conscience.

We are allowing this to happen, to 80% of the global population, the global South. Next, please. One -- doctor of Indian origin who works in New Zealand now, wrote that sentence. "In India, the poor die in n-- misery and neglect. The middle class die in misery and ignorance. And the rich die in misery on ventilators. No one gets a pain-free and dignified death."

That's not an overstatement. I sometimes think the poor are better off. They may still be in pain, but they'll be with their families. And when the throat is parched, there'll be somebody to drop a few drops of water down the throat. Whereas the rich in our country, and in most of the developing world, end up in corporate hospitals, in intensive care units, separate from the families, and in-- when they-- when they want a few drops of water, what they will get is

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a suction greater down the endotracheal tube, which is dreadful agony. And they die horrible deaths.

Therefore, it is not surprising that-- (THROAT CLEARING) the-- the economist in the-- next, please-- economist Endel (PH) Jen's (PH) report classed India as one of the worst 15, among 80, countries to die in. They studied 80. And that's where India is. (INHALE) (THROAT CLEARING) We certainly have no reason to be proud of w-- that situation. Next, please.

We have been working at it for-- I mean-- my colleague-- colleagues and I have been working on it for more than a quarter of a century. In 2003, we formed Pallium India. And, in 2006, we set up the Trivandrum Institute of Palliative Sciences. Its objective is mainly-- to attempt integrational palliative care with healthcare in our country.

We are also at a place-- a collaborating center for training and policy on access to pain relief for southeast Asian radian. In Trivandrum, we provide palliative care directly. And we run an education center. As education-- palliative care education is in infancy, even today. And we get doctors, nurses, and social workers, from all over the country, to undergo our courses. And when we-- when we send them back, we try to catalyst the development of palliative care centers in the radius places.

These champions usually do not get enough support from the administration, or from the government, and therefore, they-- they need a bit of hand-holding. And a little push, too, as they're taxi, till they take off and can be independent. But one of our major roles, as we see it, is advocacy. I'm very grateful for the international media, and for the international organizations who give strength to our hands.

We advocate with the government for policies. We advocate with the public for improved awareness so that they can demand for something that we have failed to make happen yet. We, at the institution, also concentrates on palliative care education and research. And run a p-- information center, providing avail-- I mean, information about availability of palliative care as well as about-- the n-- needs of patients and what can be done. Next slide, please.

All the states that you see in color, and the stars, indicate places where we have set up projects. (THROAT CLEARING) This is not an easy task. I'm so sorry to see that so many per-- states are still in gray. Many of them practically have no access to palliative care at all. That is a sad state. But I am glad that there are some positive developments. I do hope that, finally, we seem to be moving towards a steep part of the growth curve. Next slide, please.

Some of the good things that happened recently was that-- the very draconian, Narcotics Drugs and Psychopotropics (SIC)-- Psychotropic Substances Act has been simplified by the Indian Parliament. It took-- took us 19 years to achieve this. It took us the-- so much of support from the international media. But, finally, it has happened.

We also got the government of India's Department of Health to form a national program for palliative care. And Medical Council of India-- which is a statutatory body which governs--

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governs medical education—approved of palliative medicine as a specialty. Started a post-graduate educational-- p-- education program. And many years back, agreed to include it in undergraduate education, also.

They agreed to do it. They have not done it. In each of these areas, unfortunately, we still have so much of work to do. (THROAT CLEARING) Most of you will think that, if a law has been passed, it'll be automatically translated to implementation. That doesn't happen in many of our countries. It still needs a lot of work. The central government formulated the law. Twenty-nine individual states have to implement it. It's all complicated. It's much easier not to implement it.

So we just have to go on hammering away at it. And Liliana, thank you for coming in and supporting this movement. There's a l-- lot of work to be done. The National Program for Palliative Care means that from Delhi, from the central government, they give money to the state governments for palliative care. But the state governments do not know what to do with it.

And, very often, the money is spent in useless fashion, so that it doesn't-- reach the man in pain. So they're also our catalytic action becomes very vital. And medical education still-- I have-- today's medical student, or nursing student, even today, does not know how to apply the World Health Organization's analgesic ladder. Next please. So a lot of work there yet. But-- I'm very grateful. There di-- that couple-- is Mr. Mike Hill and Sue Hill.

And the couple created a series of films which have been very powerful tools in our-- in global palliative care advocacy. They produced *Life Before Death*. They produced-- *Little Stars*, based on palliative care in children. And now they produce *Hippocratic*. I know that it was not easy for them to get funding for all this. I don't think any of the palliative care mo-- movies so far has made them millionaires. (LAUGHTER) But-- they-- they kind of knew to do it. I'm very grateful to them. Thank you very much for listening to me patiently. (APPLAUSE)

JENNIFER RASANATHAN:

Okay. Donald, we'll turn to you now. Thank you.

DONALD G. MCNEIL JR.:

Raja, I realized, as you were talking, and that you were describing my father's death. And one thing that struck me about is-- w-- my-- my father died in a hospital. A nice hospital in San Francisco. And would've died hooked up to a ventilator, but his biggest concern at the end, when-- when they realized that he had adult respiratory distress syndrome and he wouldn't survive, was that he-- one of the ventilator pulled out and he wanted a glass of orange juice-- (MAKES NOISE) before he died.

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And-- we-- we-- f-- fortunately, we were all there in San Francisco. So we were able to be there in the hospital room. And l-- let him take out the ventilator and-- and-- and get him the orange juice. And-- and-- and he was given a lot of morphine to help him with the-- what was going to be the choking that-- that come on once a ventilator was taken away. So I hadn't thought about, until you just said that, how much actually just the thought of liquid going down his throat would've meant that much more to him than-- I-- I-- I hadn't thought about how important that was until just now.

So-- I-- I'm-- I'm a-- I'm a journalist. So I talk about sort of (THROAT CLEARING) what I do and why I do it, rather than talking like an advocate, because I'm-- I'm-- paid not to be an advocate. I got-- I'm-- although what I do sometimes ends up being useful to the advocates, if you-- if I-- describe the problem correctly. I don't actually remember what got me interested in the question of palliative care for the first time in-- in 2007. I remember I read an article. I think it was one by David Joranson, who was then at the University of Wisconsin's-- pain and pain policy center. And-- and it described the situation-- the world. And I thought, "This is grist for a series." (MAKES NOISE)

Every reporters wants to-- want a-- wants to get a good idea that's new and-- and-- and he can write a series based on, hoping, pathetically, for some prize at the end of it. So I d-- I did write a series about the lack of-- of-- of pain medication for the world. And I started off in Sierra Leone, a country where-- no one had anything. There was no opportunity for pain relief, no matter what.

Even the army had just a small number of-- of-- pills for-- for coming. And-- and, of course, it had a huge problem with-- with drugs during the-- during all the warfare there. People often didn't know-- even know what the drugs were. They were just known as "brown-brown" or "gunpowder." Or things like that. But-- but-- there was a real fear of importing the drugs. And-- but I wrote about a woman dying of-- of breast cancer-- you know, with the tumor actually coming out of her chest.

And-- and no pain relief available to her at all stronger than-- than Tramadol, which is a-- equivalient of a-- (INHALE) cough medicine here. And I went to India to write about the-- the irony of a country that produced much of the world's morphine and that it grew opium f-- for-- sale. And that-- you know, in the fields of Rajasthan, the-- the poppies were growing, and there was a plant that chopped it up, and wrapped it up in big-- you know, the-- (COUGH) the-- the brown row of opium, which is sort of, like, a-- somewhere between molasses and chocolate fudge, was-- was being wrapped up and mailed off to St. Louis, Missouri, where it was being made into morphine.

(THROAT CLEARING) M-- mostly to be used by Americans. And-- and Indians had very little access to-- to-- pain as-- as Raj showed-- and where Raj worked, they had the best, and Kerala was the only state that had a real-- program. Thanks to Raj.

And then I did series -- the next part of it was in Japan, where lots and lots of people were dying of cancer. They had a extremely advanced healthcare system, and no official opposition to-- to painkillers, but nobody wanted to take them, just because of a

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longstanding fear of painkillers, and a-- and a-- and a sense that you don't show weakness even-- even the towards the end of life, you-- you grip on, and-- and-- and die in pain. People have various reasons for it.

And then I wrote a-- couple pieces. One about Doctors Without Borders changing their attitude about pain control. They had originally (THROAT CLEARING) condu-- conducted something, like, 70,000 operations-- or 7,000 operations using only ten vials of morphine. And they'd realized that they were not-- were not interested in the pai-- in-- in pain control for their patients-- for many years.

And they finally-- I said, you know, changed their-- changed their policies and changed their education. And then I wrote one piece about Afghanistan, and whether or not the-- the-- crops there could be used for pain control. We were-- you know, the United States Army was fighting a-- war against the opium trade, as well as against-- Al-Qaeda and the Taliban. And-- a great deal of effort was spent in-- in destroying something that could've been useful as medicine around the world.

I hoped the series did some good. Y-- Raja's very kind to write to me in-- was it 2012 or so? And say that it ha-- had helped pass the-- In-- India's palliative care policy. And, last year, I met Meg O'Brien of the American Cancer Society-- who started a group called "Treat the Pain"-- to try to bring pain relief to Africa.

And she said that she had started it, partially-- because she had been to an HIV conference. She was-- she worked for-- the Clinton Healthcare-- Clinton Health Access Initiative. And she had gone to an HIV conference and heard about how many HIV patients died in severe pain, especially if they had cryptococcal meningitis, or-- or some other-- opportunistic infections. And then-- and then she said she had read my series, and that h-- had helped convince her to leave-- leave HIV care, and-- and go into-- to palliative care.

But I-- I-- I wrote that article last year-- by chance. I was actually going to Africa to meet with-- with Meg O'Brien, because-- she had-- created a-- deal, under which cancer medicines would be available to Africa at 1% of their prices in the United States, a-- deal in which-- two drug companies, Pfizer, of the United States, and Cipla, of India, were getting together and agreeing to supply 16 different chemotherapy drugs to Africa at absolutely rock-bottom prices.

And the story about palliative care in-- in Uganda was essentially a story on the side. If I-- my bosses are happy when I can-- when I can get two stories out of a trip, rather than-- rather than one. And-- I had originally hoped to go to Ethiopia to write about the cancer story, but Uganda (NOISE) proved to be a-- well-- (HANDLES PAPER) easier to get in, partially because of profile I had written of the-- doctor who's now the head of the-- World Health Organization, which-- which-- they-- he was-- h-- he-- the Ethiop-- he wasn't unhappy with it, but the Ethiopians were (LAUGHTER) unhappy about-- about parts of it-- because it had also exposed that Ethiopia had covered up the fact that it had cholera for many years and was calling it acute watery diarrhea. And-- this nearly upended his chances of being elected.

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As I was writing that article-- the one about pain relief in Uganda, I had always w-- wanted to go to Uganda and write about the operation there-- the-- the-- the Hospice Africa, because it really was the first operation in Africa that was successfully bringing pain relief to any country in-- in the poorest parts of Africa.

There were some things in-- going on in south Africa, in the richer-- richer nations-- not that there are many rich nations. But-- what Anne Merriman was doing in-- in Hospice Uganda was really quite remarkable. And Meg O'Brien and the American Cancer Society had sort of stepped in and m-- brought the operation more to-- on-- on a more professional level. And it extended it. St-- sort of stop some of the infighting that was going on in the Ugandan government, and-- professionalized it so that it was always to distribute-- drugs to much more of the country.

And it was just my luck that the Lancet report came out at virtually, exactly the same time. I thought I was gonna have to slog through all the same documents I had worked on in 2007, and then called each one of the doctors and said, "What do you know about go-- what's going on in 2017?" And, instead, boom!

The Lancet comes up with this brand new report they've clearly been working on for years. And I was able to talk to-- Liliana and other doctors involved in it and-- and say-- you know, "Tell me about the situation now." But was has changed in the interim, and it's very sad, is that America has had its opioid epidemic, and a large number of overdoses. And that has changed the mindset of the world entirely towards pain relief, because back when I was reporting this, (HITS MIC) in 2007, it was more of a theoretical problem.

There were many naysayers who said, if you start handing out narcotics-- to poor people, you're gonna get an overdose epidemic. And, if we start handing out more narcotics in these United States, you're gonna get an o-- an overdose epidemic. And, sadly, sure enough, yes, that happened.

I mean, you've all seen how badly the narcotics were handed out. I think Meg O'Brien put it very well when she said, "Look, the problem with the overdose epidemic in the United States was not caused by the cancer wards in this country. It was caused by the dental practices and the orthopedics' wards."

You know, in-- in poor countries, you don't hand out Percocet for a strained ankle, or a pulled tooth. You hand it out at the very end of life when people-- but-- it was handed out way too freely in the United States. Originally, with good intentions. There was a l-- when I s-- first started writing about it, there was a lot of resistance to the idea.

And doctors-- doctors who were sophisticated about pain relief and-- and palliative care said that there was a giant need, even in the United States, both for patients to understand and not be afraid to ask for the drugs, and d-- describe their pain. And for doctors to be willing to prescribe it. And then, unfortunately-- you know, the whole situation went crazy. And-- mills developed where-- where drugs were being pumped out in enormous numbers. And

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that-- I can see the effect that that's had on-- on the world just from the reaction of my own editors when I talk about the story idea.

When I originally proposed the series back in-- in 2007, they said, "Gee, that's a good idea. 'Cause I had no idea that the problem existed. Sure, go ahead and write about it." This time, when I said, "I'd like to write about the need fo-- the successful use of pain control in Uganda without developing a gigantic opioid overdose problem," the reaction was, "Oh. Neat. What a counterintuitive idea. Who'd'a thought it'd be possible to hand out pain relief without creating an overdose problem."

(COUGH) And I'm afraid that's the mindset that is now controlling the debate. That-- "opioids" are a dirty word, and people are afraid to prescribe them. And people are afraid that-- people in other countries are afraid that, if they allow pain relief to happen, that the same thing will happen in their countries.

You know, they will fall-- if the United States can't get its act together, and can have an overdose epidemic, that it-- it seems to be unable to control, how is that our poor country will be able to control it? And I don't know how palliative care specialists overcome that. But it is a giant obstacle looming for the future. And-- with that, I'll conclude. (APPLAUSE)

JENNIFER RASANATHAN:

Thank you. And that is a topic we will certainly circle back to. Liliana, I-- I'm so keen to hear-- your perspective on this. We're gonna show a very brief clip to explain a little bit about what the International Association for Hospice and Palliative Care does, and then Liliana will-- talk a little bit about-- (MUSIC) the Lancet, and trying to simulate some change in this area.
(VIDEO NOT TRANSCRIBED)

LILIANA DE LIMA:

So-- that was just a-- short film that we did. We did a series of films-- in one of the regional congresses. This was the world-- Palliative Care Congress, which is actually run by the European Association for Palliative Care. But it has become quite large, and they have participants from all over the world. So now it's called the "World Congress."

And-- one of the things that we do is we bring participants from low-income countries who otherwise can't-- afford to go-- they have to have posters, and they have to have-- something to present during the conference-- some-- some kind of-- work that they've done. And, more and more-- it's also about advocacy. And how they're helping to change-- things, and matters, and policy in their own countries.

So we're hoping to-- teach them, and coach the-- the members of IHPC as well, that they are not just-- the clinicians caring for patients, but a-- also-- wonderful advocates, such as Raj. I mean, he's a shining star in the world. I think it's-- very difficult to follow-- his (COUGH)

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path. And-- but people can look up to Raj and think that it's a physician who also turned as an advocate, and changed the legislation. And we can do that.
So in the-- under that frame of mind-- we are working very hard to enabling-- the people who (COUGH) are working-- not just with the patients, but also with the governments and the policy makers. The quote from Martin Luther King that I mentioned-- actually, there's a-- there's another slide before that I had.

And these were the letters that he wrote from the Alabama prison. I don't know if you know-- if you're familiar with those, but there is a sta-- there's a statement that he says, that the statutory laws that-- discriminatory statutes-- give a false sense of superiority to the discriminator, and a false sense of i-- inferiority to the-- the person who was discriminated against.

And I thought, "This is the same that happens to patients who are incurable." Because the h-- the system is set up so that patients can't access care unless they're curable. If you are in a developing country and you go to see the doctor in one of the big hospitals that Raj mentioned-- he or she, the patient, may be told, "We're sorry. We don't have anything else to offer"-- if it's a poor hospital.

If it's a hospital that has resources and the patient has resources, they may end up in a ventilator, such as Donald's father, or-- or the patients that-- Raj described. So-- I think a lot of the patients-- and I was thinking, when I did that presentation, about a case of a patient we had in Colombia, when I used to run the hospice there. And it was a patient that we received who had developed-- cancer in-- he tr-- he had a tracheostomy. And he never learned how to use it. So he couldn't talk.

And he was illiterate, so he didn't write. And when he was brought in-- into the hospice, he was very-- unkept. He was dirty. He-- he had-- he had not eaten for several days. He was actually living in a-- in a barn with some-- chickens, and-- and animals in the farm. Because he was smelling so bad that nobody could resist him.

And he had asked a friend if he could stay there. So his friend brought him over. And we cleaned him-- and gave him, you know, medication. It was a weak opioid, what we gave him. A codeine, at that time. And the next day-- and we offered porridge. You know, something soft that he could swallow. And the next day-- you know, we saw him. He was a lot (COUGH) better. He had-- he slept on a bed. He had taken a bath. And clean clothes. And we-- had dinner, or had something to eat. And we kept asking-- you know, we saw that he was walking sort-- sort of in an awkward position. And we ask, "Jose, what's wrong?" And he said-- you know, he-- he just said, "No, nothing is wrong." And he kept kissing our hands.

His friend came over to visit the day after. And then we s-- we realized there was something wrong with Jose, but w-- we didn't know what was going on. And-- and we said, "Go and find out." And, "We think that he's still in pain." Well, he came back and he said-- "Yes, Jose's still in pain. But he's afraid of complaining, because he has been expelled from every

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other hospital that he doesn't want to be expelled of this place again. He thinks-- he doesn't want you to think that he's ungrateful."

So that's the extent of the suffering that we have to deal with, and the extent of not just that patient, but a healthcare system. The way that it's set up. And this is the purpose of The Lancet Commission, actually is to change-- the mindset of the healthcare systems in the world, so that care is provided since the moment you are born until the moment you die.

Every single instance of your life that you need healthcare, the system should be there, available and timely, to provide what you need in order to have good quality of life. Either-- could it be curative, or preventive. Rehabilitation. Or-- (COUGH) or palliative care.

I don't think we need to go into the slides because I-- that-- it does-- I don't think it merits, but-- basically, the slides will show, you know, some data that you can get on the paper outside. And I don't-- I think it will be much nicer to have the discussion going on-- that-- to go over numbers. But what the Lancet report right now, and-- and Raj is one of the commissioners-- and we are working-- IHPC is one of the organizations that will be in charge of the implementation, re-- resulting from the-- the recommendations resulting from the report.

So-- we'll have a luncheon next-- April in five and six, in Miami. And then, after that, we'll start with implementation and probably, we will select-- five to six pilot countries. And there's an essential package of interventions, medic-- medications, and-- a few things that we think are-- capable of alleviating that suffering that we've been talking about, in 80% of the cases. And that package has been costed-- it's not something that will significantly affect-- you know, the-- the GDP of any country. We've done the analysis. And I think-- we think it's doable. So that's it. Thank you. (APPLAUSE)

JENNIFER RASANATHAN:

Great. Thank you all so much. And we're happy to make the slide deck that Liliana was referencing available to anyone who's interested. So please-- just reach out to us for that. So I wanna start by asking Liliana and Dr. Rajagopal why aren't we closer to narrowing the gap? What, in your view-- and then, Donald, we'll turn to you, as well, from your perspective covering health issues for so long. Why haven't we been able to provide greater palliative care?

We saw in the IHPC video that there's a rising group of people who are being educated, clearly. Th-- Dr. Rajagopal's working tirelessly to bring education and broader access, in India. If you had to pinpoint the problem, w-- w-- what is it? And so we'll start with Liliana, and then Dr. Rajagopal.

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LILIANA DE LIMA:

I think it's the way the healthcare systems are set up. You know, we need to change the-- you know, (NOISE) the mindset of-- and that also affects how physicians and healthcare-- professionals are educated, how healthcare systems are funded, and how healthcare systems-- settings are developed, and-- and constructed, and built upon. If we can change that mindset that, you know, you-- you should receive the care you need regardless of the prognosis. That is-- that, to me, is the greatest challenge.

M.R. RAJAGOPAL:

So in addition to what you said, Liliana, possibly-- the advocacy efforts have been mostly by a few professionals. And not exactly from the people who suffer. (MAKES NOISE) I think their w-- their voices, if you could bring them out, really should be much more powerful. We are advocating something that's not very convenient for the existing system to follow.

It's so much easier to go on doing whatever they have been doing, that brings in more money for the healthcare industry. And the doctors feel safe. They don't have to see the suffering. You can turn away and concentrate the diseases. So we are advocating for something that's inconvenient for the system. And to-- we are unable to force them to do it so far. So that effort, I believe, will have to come through patients' families. Because patients themselves are suffering, and cannot raise their voice. So maybe-- I-- I strongly believe that a-- advocacy approach should focus on that.

Secondly, if it was, say, something as simple as polio eradication, the-- the procedure is simple. Easily understood. In palliative care, we can all just give a protocol to every doctor, and do palliative care. It means a change in the mindset. More of education is needed. And there, again, I still believe that there has been no specific strategy for developing countries in relieving suffering.

We have global strategies. Eventually, that ends up affecting changes only in the global). The problems are different, of course, from country to country. But there are some common problems. And everybody would say it's money, but it is not a cost of money. So maybe we also need a global strategy, specifically addressed to the global south.

JENNIFER RASANATHAN:

Interesting.

(DONALD G. MCNEIL JR.: INAUDIBLE)

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JENNIFER RASANATHAN:

Yes. So I'm going to turn to you, Donald, now. Given that amount of time you spent kind of covering this space-- is this kind of what you're seeing, too? The-- what's your take on why this problem persists the way it does?

DONALD G. MCNEIL JR.:

I think part of the problem is-- I cover a lot of diseases. And-- maybe 50. And some diseases are hip. And some-- I-- you know, like polio. (LAUGH) And flu. And Ebola. And plague. Because they have sort of hooks that stick in people's minds. And sometimes they have famous victims, or they have powerful spokespeople. Palliative care and the end of life do not have famous spokespeople, because, unfortunately, nobody survives it.

And the people who need the care most are often unable to talk, and-- and-- and-- and, very often, about to die. So we all know famous-- I mean, famous people who died of AIDS. Rock Hudson. Elizabeth Glaser. Kimberly Bergalis, and others in the-- and-- and-- and-- (NOISE) and hundreds of people in the arts-- and-- and theater in the early days of the epidemic spoke up loudly and eloquently for the disease, often as they were dying.

And some diseases have champions. Polio had-- had-- Franklin Roosevelt. You know, yellow fever had Walter Reid. You can sort of pick a disease, and there's somebody whose name is famously associated with it. You are the champion, but you're not a movie star, yet. (LAUGHTER) And hopefully that day will come, but you sort of-- in some ways, you need other well-known spokespeople.

You know, some diseases have-- you know, like malaria, get champions who speak up for them. And I think that make some a big difference, that-- that-- people associate ideas in their minds. And-- and-- I ha-- I have a story to tell that's probably unfortunate. After I wrote that series, I got called by a representative of a powerful, rich guy who was a former-- former secretary of state-- who was looking for a cause.

And called me and asked about, "What would you think of my taking this up?" And "What would it mean," and "What would-- getting involved--" and, I mean, he-- I'm not saying who the name is, 'cause he asked not to be-- talked about. But-- I said, "I think it'd be extremely useful. I think it's not just a question of money, but I think it's a question of advocacy."

And I sort of described the people that he might get in touch with. And-- and he said, in the end-- he said, "What do you think (COUGH) about it?" And I said, "I-- you know, I mean, look, it's not for me to tell you to what to do." And I'm-- you know, I-- I always try to make a point of being-- a journalist, and-- and staying back from-- from advocacy that way.

But I said, "You are gonna have to get used to the idea of being, basically, the world's biggest narcotics dealer." And there was a long pause on the line. And he said, "I'll think about it." (LAUGH) And-- and I hope I didn't discourage him from being the champion for

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the disease at the time, but the disease definitely needs a champion. I'm sorry-- not the disease, but the-- the-- the situation needs a champion. They-- th-- th-- there d-- needs to be (COUGH) a sort of-- and it helps if the advocate is rich. But it-- o-- or-- or popular.

JENNIFER RASANATHAN:

Yeah, please. Go ahead. And then I'm gonna turn to the final clip that we wanted to show from the *Hippocratic* movie. Uh-huh (AFFIRM).

LILIANA DE LIMA:

I was just thinking, as well, that-- that there's a lot of commercial interests in keeping treatments going on. And a lot of that happens in the decisions that are taken when futile things are-- implemented, or approved, or-- done to a patient, just because they keep the-- (NOISE) you know, the money kind of rolling in. So just wanted to...

JENNIFER RASANATHAN:

That was the perfect segue to the next clip we'll show. And then I'll-- turn it back to the panel.

(VIDEO NOT TRANSCRIBED)

JENNIFER RASANATHAN:

I see a lot of nodding heads. (LAUGH) And this is certainly something that we tackle-- try to tackle head on in the public health program, but thinking about the way the healthcare industry has become over commercialized. And I wonder if each of you could speak to the impact of the pharmaceutical industry, and the healthcare industry, on access to controlled medicines for pain relief. Liliana, I know you've done work around opiate pricing. Raj, perhaps, you can-- add a little bit more about, specifically, the role of the pharmaceutical industry. And, Donald, that will be the same question for you. Thanks.

LILIANA DE LIMA:

So we did-- we started a-- about four years ago-- a project called "Opioid Price Watch." I don't know if you are familiar with-- a report that is put out by the-- Health Action International. It's an NGO-- based in The Netherlands. And they always put together-- reports every ye-- every two years, in collaboration with WHO about the prices of essential medicines.

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And-- now, they've never included-- opioids. And, when we asked them, "Why are you not including opioids?" they said, "Well, opioids are a controlled substance. They have to-- you know, different things that affect the pricing. And we don't know anything about it. Blah, blah, blah, blah." So we decided to do it ourselves. And we started working with WHO-- sorry, that was in 2011. (LAUGH) We're getting older.

And-- so we've done three cycles. And what we do is-- we have now-- it's a project-- to monitor the-- the dispensing price. So, actually, the price that the patient has to pay at the pharmacy level for the opioids. And we looked at all the different prices of opioids. And-- it was striking what we found out. And we've done three cycles already. And the third cycle has proven exactly the same-- conclusion of the first one.

And it's that, somehow, when you look at the-- let me see if I can ex-- you know, explain this. But there's an international market. So let's say, a pharmaceutical company buys the raw product from a vendor in Australia. And then they mark-- them-- they manufacture the medication. And then they may be wholesalers, and sell it to a pharmaceutical company in-- in the U.S.A., or any other place. Or India. Or Colombia. Or Burkina Faso. And what-- we looked at the dispensing price, somehow, those medications that were higher in the international market-- as compared to morphine, when they come down at the dispensing level, they were cheaper.

How did that happen? So why are they-- government-- why are they subsidizing the more expensive formulations of medications? And not the cheap morphine? And, at the end-- what happens is that morphine is not available. What is available is the expensive fentanyl patches, the sustained-release formulations. And now the other things that are more profitable. We also looked at what is included in the essential medicines list in the national countries-- in the countries-- in the national medicines list. And we found out that, certainly-- morphine, they put it in there because it's in the model list. But all the other expensive formulations are also added. So automatically, they get funded by the government. Somebody-- somebody's getting favors.

And the way we-- looked at how that pricing affects the patient is we looked at something which is called affordability, and it's how much it would cost, in terms of days worked-- somebody who has the lowest wage in the country. And Bangladesh, somebody has to work 77 days to pay for 30 days of treatment.

In Mexico, they have to pay 190 days to pay for 30 days of treatment. In Honduras, 302 days to pay for morphine. One ampoule of morphine in Honduras costs $10. One-- in the international market, it's $0.03 of a dollar. Fentanyl patches? They're cheaper. So physicians get to prescribe this expensive formulations. They're taking over to conferences and meetings. And-- and-- you know, it's-- only those who can afford get access to treatment. So, in a nutshell, that's a little bit of the findings that we have.

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JENNIFER RASANATHAN:

Thank you. And, Dr. Rajagopal, where have you seen the indu-- the impact of the pharmaceutical industry on access to controlled medicines in India?

M.R. RAJAGOPAL:

Let me start with the positive. The industry-- i-- an element of the industry-- Dr. Hamied of Cipla, whom you mentioned, who made – of -- HIV medicines available at low cost to Africa-- who-- who changed the world. I mean, what would the world have been like today if that was not done? He also made low-cost morphine available in our country. I have in my state a commercial entity producing and selling at minimal profit-- ten milligrams of morphine costing less than $0.02 of your money.

So this is possible. But do we have a strategy for controlling the other elements? Oh, my God. I don't know. (LAUGHTER) I mean, this is-- this is a-- giant that is-- we can't even see its face. It's towering somewhere there. And I-- I have no clue how we are going to make-- I mean, like, limit their power. But, purely by making-- or continuing to support-- get the support of those elements of the industry, who have a philanthropic interest, and ensuring low-cost morphine, as quietly as possible, is something that I can think about. That's all.

JENNIFER RASANATHAN:

And, Donald, I'm curious, especially as you talked to the U.S. overdose epidemic, there have been more and more reports highlighting the role of the pharmaceutical industry in driving that epidemic, perhaps by-- marketing their products in a less than truthful manner. And I wonder-- from your perspective, what-- what role has the pharmaceutical industry played-- in driving both the lack of access in the developing world, but also-- in the ongoing crisis we have here in the U.S.?

DONALD G. MCNEIL JR.:

What I know about this is not from my reporting, but from reading the work of other reports, 'cause I didn't cover the epidemic in the United States. But it's very clear that companies like Purdue Pharma had a great deal to do with creating the overdose epidemic in the United States. And that they knew perfectly well that hundreds of thousands, or millions, of pills were being shipped to pharmacies in small towns, where they couldn't possibly be used more than 5,000 pills a year. Something like tha-- and-- and-- and, you know, was-- i-- it was clear that they were manufacturing and selling much more than is needed.

I think the report concluded that there's 31 times as much (HITS MIC) total opiate consumed in the United States a-- as the actual-- need we have. So the-- size of the illegal market is enormous. Whether or not they've conspired to do anything in poor and middle-income countries? I don't think so.

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I think they just don't care about poor d-- poor and middle-income countries. And I think one of the things that a champion, should champions emerge, should be doing, is making clear that, "Look, all of these drugs are off-patent. All of them are cheap." I mean, it-- (NOISE) morphine is dirt cheap. Heroin, invented by Bayer, back a-- over a century ago, was-- is-- is dirt cheap. Methadone is dirt cheap.

Codeine is dirt cheap. None of the-- all of these things can be made for-- for pennies. The-- the problem is controlling it once you get it close to the user. And the Ugandans have s-- come up with something that they hope is successful, and that-- they import the raw morphine powder. It happens they import it from Scotland, because they can get it cheaper there.

They can also get it from Hungary, a couple other places that-- that make it. And they make it in a drum that sells for not too much money. And the drum has to go through all the customs clearances, as you can imagine. But then, they mix it into pint bottles of water. Driving pint bottles of water around the country is a pain, but Coca-Cola does it, and (LAUGHTER) at larger bottle-- you know, successfully, without having to sell people an injectable form of Coca-Cola.

And without anybody turning it back into an injectable form of Coca-Cola. So there-- it-- so it-- it-- it's reasonable to think, that if you w-- wanted to imitate the Uganda model-- and-- and-- and, basically, it's made at strengths low enough to do some good-- not as much good as you could do with-- with a more concentrated form, but a no-- low enough to do some good.

But-- dilute enough so that you make turning it into a-- readily-abused, injectable form very difficult. And-- (NOISE) and-- and drinking enough morphine when it's-- when it's-- diluted is-- hard and bitter, and nauseating. And puts you to sleep.

JENNIFER RASANATHAN:

And I just wanna ask one more question. Then I'm gonna open it up to the audience. And I'm sure many of us have additional questions for the panelists. Liliana, could you please comment. In your role in the global organization, what have been some of the impacts that you're hearing from your members, and from-- the national places, where you focus on your work on-- some of the impact that you've seen already from what's happening in the U.S.?

LILIANA DE LIMA:

That's a very good question, Jenny. I think-- what we've seen-- and we've been doing-- workshops in Latin America and, more recently, in India-- on access to-- opioids and rational use of opioids. And we've seen now the fear-- and the reaction of the prescribers, and the drug regulators, on, "Oh, we can't let this become the U.S. problem."

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You know, "We can't--" but, when we looked at the data, that was one of the other things that we looked in the Lancet report. Most of the problem ha-- it-- it's the U.S. There's a little bit of issues in Canada. There's a little bit of-- abuse in the-- in Australia, and the U.K. Nothing in Germany. Nothing in Switzerland. Nothing in Austria. Nothing in France. Which have very high consumption of licit opioids. So it's not-- it's not the opioids themselves. But it's actually a m-- maybe more marketing strategy, and something that led to other things.

Now, just to clarify, that now the issue in the U.S. is not the licit opioids that are producing the deaths. It's the illicit fentanyl-- which is also carfentanyl, which is high-- very potent. And then, also-- the heroin laced with that illicit fentanyl. So it's not even the licit opioids, or if it's licit opioids, are opioids that were not prescribed, but actually taken from somebody's cabinet, or something else, and were used for a different purpose.

JENNIFER RASANATHAN:

Thank you so much. Okay. I wanna open it up to anyone in the room. Sarah will be helping me walk around with microphones. And, just for everyone's knowledge, when you get the microphone, just push the button until the light turns green. And then that will be on. So, please.

MALE AUDIENCE MEMBER:

Thank you very much for such a-- informative--
(OFF-MIC CONVERSATION)

MALE AUDIENCE MEMBER:

--a very, very interesting presentation. I think you-- all of you addressed, at some point or another, some of the possible solutions for this. And I think this has to be contextualized within-- a developing world where basic healthcare is-- is questionable, at best. Certainly, in the areas where I've worked, that's what I've encountered. But this sounds a lot like the mid-90s in terms of the United States, and the AIDS epidemic, and the HIV epidemic here. The best thing that I think you could do—I'd -- I would submit to what you alluded to, is-- the people who are suffering have to be heard. They have to be there. They have to be at the table. You can't ignore them. It's not gonna happen.

And that also reflects on the comment about-- physicians in general, because physicians are taught to fight disease. And certainly in this-- in-- in the developing world, and never give up. And we all know the sequela of that. And I think that this is just the beginning of a, you know, very long, uphill thing, as you alluded to.

But, attitudes will change. You know? And-- again, I can't emphasize enough the importance of bringing the people involved at the table. We're all gonna die. (LAUGHTER)

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You know? It's not like-- y-- you know, it's-- we're all gonna die. Get over it. And-- and-- and, you know-- thank you, again. Very, very informative.

JENNIFER RASANATHAN:

Thank you so much for that comment. Any other questions? (BACKGROUND VOICE) Yeah.

FEMALE AUDIENCE MEMBER:

Thanks. Yes. I agree it was a very-- informative-- presentation. But I do have a question about the healthcare system, as you described-- that it's sort of a free-for-all, or that there's-- there-- there was little guidance. Could you give a little bit more clarity about how the healthcare system operates-- in the area that you were talking about? I think that would be helpful, and enlightening.

JENNIFER RASANATHAN:

And, are you asking specifically about India?

FEMALE AUDIENCE MEMBER #2:

Yes.

JENNIFER RASANATHAN:

Okay. Great. Let me take one more question if s-- if there's another question before we go to the answer. Yep. Uh-huh (AFFIRM).

FEMALE AUDIENCE MEMBER #2:

Just in regards to India. (HITS MIC) Dr. Raj, what is your thoughts about the availability of education of palliative care in the medical schools and post-graduate courses, where people already struggling, leading to a brain drain?

JENNIFER RASANATHAN:

Great. So two questions for you, Dr. Rajagopal.

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M.R. RAJAGOPAL:

In response to the first question-- (THROAT CLEARING) it is really not only India. In most of the global south, treatment costs are out of pocket. So in my country, for 80% of people, they have to find the money themselves. It's only 20%, ou-- out of its many, are funded by the government, because they are government servants. Or a small minority who have an insurance system.

All other 80%, they have to find the money. That is-- that is the usual system. So the healthcare system, theoretically the government, has a system at tertiary, secondary, and primary level. But-- in my country, only-- like any civilized country, would have 5% of their GDP spent on health. Whereas, in my country, it is still only at one-- 1.25%. By 2022, it is planned to go up to 2.5%. Let's hope that happens. Even then, that's so little. And so having a reasonably robust healthcare system-- like we learned from our grandmothers that, without health, wealth is of no importance.

So giving that importance to it is key for many of our countries. The palliative care education is the one thing-- I mean, if a fairy came to me and asked me to make one wish, it is that introduction of palliative care into the undergraduate medical and nursing education that I would want.

They have started a post-graduate course. So, for our country, with 1.25 billion, we have four seats (NOISE) a year for a post-graduate course in palliative medicine. That's because the basic facilities need to be-- s-- s-- so many professors, so many beds, and so many facilities, which are not available in the university hospitals. For many of the-- the problems, we can at least see a solution in sight. But here, I fear, things are going to be delayed much. We are actually working within the individual medical colleges-- the individual universities, because the medical council is not re -- responsive.

JENNIFER RASANATHAN:

There's a qu-- there are two questions. Uh-huh (AFFIRM). Three. And we'll take-- this time-- yeah, t-- we'll stick with two questions, and then-- have the panel respond. Thanks.

FEMALE AUDIENCE MEMBER #3:

Dr. Rajagopal-- first, I heard your name and your work ten years ago. It's amazing. Congratulations. And I can't imagine the hardship that you came across in your group. It is hard to say that, you know, opioids are c-- culprit, or panacea for suffering, you kn-- or related, you know, issues. The treatment of suffering is not-- related only for cancer. For all-- other-- you know, disease groups. And we forget to-- prevent disease in the world, right? As you said, disease is the-- is-- causing sick people. And that's the-- the-- the base of-- healthcare industry. That's how we became corporate.

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We are selling the education-- medical education. We are selling drugs. We are selling, you know, the services. And it's-- e-- especially worse in developing countries, when they pay out of pocket. Then you will g-- come across more blocks, you know? When it comes to palliative care. Because then the-- the goal is to s-- sell the-- expensive treatments.
So during this time, you know, on last ten years-- when you were-- working on-- advancing palliative care in India, did you come across with this, you know, corporate kind of-- healthcare system-- blocks that you had to-- sort of, like, fight against?

JENNIFER RASANATHAN:

Great. Thank you for your question. And did you s-- yeah. One more question before we turn it over to the panel.

FEMALE AUDIENCE MEMBER #4:

Hi. My question is slightly different. I wanted to ask about the m-- relationship between the global war on drugs and the lack of access to palliative care. I was wondering what role, if any-- Dr. Rajagopal touched on-- touched on this in his presentation when he spoke about making drugs the law that made drugs illegal in India actually led to a massive-- drop in legal access to mo-- to lifesaving drugs.

So if I wanted to ask, a-- according to you, if-- if there's any role for global drug policy reform a-- advocates-- to help narrow the gap in access to palliative care. Is it useful, or is it harmful, especially given this context of this hysteria. And-- fears created by the overdose crisis in the U.S. So just wanted to know you all thoughts (HITS MIC) on that.

JENNIFER RASANATHAN:

Thank you. So Dr. Rajagopal, and then maybe Liliana, (UNINTEL) will you take that question?

M.R. RAJAGOPAL:

Maybe I'm here and able to answer your question because I have not had the courage to take on the industry and fight it, face to face. It is too l-- huge-- force. (THROAT CLEARING) Very unfortunately-- we have not worked out a system to convince the corporate sector that it is in their industry to start providing palliative care.

It's happening more and more, especially people coming from the West-- Indian-American or Indian British teachers coming back for the treatment of their parents or on demand pain relief. And that is slowly causing an impact. But then, the fact remains, as Liliana said, that it is more profitable for them not to provide palliative care. So, unless there is that public awareness, and public demand, things will be hard to change. Attacking the industry's not

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easy, because we do not have the strength to do that. Maybe the public awareness is the answer to prevention of exploitation by them. You want to ans-- try to answer the second question then?

LILIANA DE LIMA:

You're right. It's all related. And we're in this mess, (LAUGH) actually, because of the-- s-- the convention-- it is a called the Single Convention on Narcotic Drugs. I don't know if you are familiar with that. But it-- this was signed back in the 1960-- 1961.

And it came from-- as a result of the opium-- wars. And it was the first opium convention. And then that led to another several conventions. And that was joined in one single document, which is why it's called the "Single Convention," because all-- all-- it was formed by different conventions from Asia-- Europe, Latin America. So they all joined together in th-- the Single Convention. Now, the Single Convention is a legal framework that all the United Nation member states-- all the countries that are-- legally abide-- they have to abide to it. And-- we have obligations as countries, to meet those-- th-- you know, the-- the-- the statements.

The conventions have a preamble, both-- there's another con-- convention that was-- adopted in 1971, which is called the Psychotropics Convention. And both the 1961, which is the Narcotics, and the '71, which is the Psychotropics address the need and recognize the and need to ensure access to these medications for the relief of suffering.

And that's in the preamble. So it recognizes that this is a public health issue. But then it goes on and on and on about the r-- restriction on the use. On the importation. On the certification. On the processing. Licensing. Blah, blah, blah. So how-- you know, we have been working together with the international-- you, with the help of-- OSF and many other organizations that have a lot of the human rights-- background, and legal background, to raise the issue of these as a-- public health issue. In – in -- Vienna where the narcotic-- the-- CND convention-- the c-- Committee on Narcotic Drugs meets-- all the other-- meetings that are relevant to those, like, the WHO in Geneva.

And, basically, what we're trying to say is, there is-- there's the issue of, "Yes, preventing abuse. Diversion. Non-medical use." But also, "What about the patients who need it for legitimate medical purposes?" Now-- the good thing, as-- as Raj likes to say is that, (UNINTEL) which happened-- two years ago w-- will-- now-- has a chapter related to access, which didn't have before.

So now the countries that-- actually, Mexico, Colombia, and Guatemala joined together and wanted to d-- dele-- you know, get rid of the-- the conventions and do a new one. But you need-- to do new conventions, you need 100%-- consensus. And there's several countries in Vienna that are very hardliners, and they-- you know, they kill people who are drug users. We know cases.

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So they are not willing to do that. And the conventions will stay and will remain. But (UNINTEL) was able to develop a framework and new recommendations that has now a chapter that recognizes the use-- the medical use for-- people who have-- dependence problems-- medical needs for opioids. So this is a very important issue. And I think a-- very positive-- step ahead.

JENNIFER RASANATHAN:

Great--

LILIANA DE LIMA:

But more needs to be done.

JENNIFER RASANATHAN:

--thank you. Yeah. Yeah. Absolutely. And it remains to be seen as to wh-- how that chapter on access can, and will, be actually used. So much of what we're talking about is moving from policy to implementation. Any other questions? Did you-- yep. There's one in the back, Sarah. And then-- a gentleman here in the middle.

FEMALE AUDIENCE MEMBER #5:

Thank you. Yes. This comment and question comes-- I'm a professor at John Jay College. And I'm also an ethnographer. And I'm beginning to do my research on-- in Latin America, with regards to drug addic-- addiction and pharmaceutical and historical memory. Liliana, what you said about mindsets, and changing the mindsets-- I'm so inspired by you acknowledging this, because, in Latin America, at least places like Chile, to change the mindsets-- I mean, right now, in Chile, as a country-- you know, as a case study-- mental health and addiction is governed by the Ministry of Security.

It's a security issue. It's not a mental health issue. How do you change this mindset of institutions? Let alone civil society. That's another ballgame. (LAUGH) What strategies would you suggest, in the case of Latin America? Yeah. Thank you.

JENNIFER RASANATHAN:

We'll take one more question. I know. (LAUGH) She threw you a softball. (LAUGH)

MALE AUDIENCE MEMBER #2:

So my name is Dustin--

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(OFF-MIC CONVERSATION)

MALE AUDIENCE MEMBER #2:

Dustin. I'm a geriatric palliative care fellow at Mount Sinai. So (NOISE) taking a step back, you know-- and having no knowledge about developing countries and how the mindset is in care, is there-- is there more of a-- paternalistic care, versus a care where, you know, we individualize patients' care and align with their values. And is that-- is that also a gap that maybe can be, you know-- narrowed just aligning with patient values and-- and-- and family values? And-- and is that some s-- like, do you see that in the teachings, for example, in-- India, where, you know, t-- is it more paternalistic-- views?

JENNIFER RASANATHAN:

So we'll start with Liliana, and then turn to Dr. Rajagopal.

LILIANA DE LIMA:

(LAUGH) That's the million-dollar question. "How to change mindsets?" I think we always go back to the-- to the campaign-- the HIV/AIDS campaign. That, to me, was a wonderful way to show how you can change-- mindsets. And changing something which was very discriminatory-- very denigrating to the empowering of the people-- who were living with HIV/AIDS and making decisions, and accessing care, and demanding-- from the governments.

When-- you-- you cannot-- you cannot-- n-- sorry. My Spanish brain. (LAUGH) You cannot do anything unless you have a local partner. And the national palliative care societies, and the national mental health societies, those are your strongest allies. And they should be. Because they are the ones who can make demands from their government. As international organizations, we can't do that. We have to go through the diplomatic process. So the people who elect the governments, those are the ones who make demands.

But we can coach them. We can teach them. We can give them the resources. We can-- show them how it's done. So you need to-- I-- I would say-- my suggestion would be, start to identify the local partners that could be the strength of your voice with the government. And then, you know, you stand behind them. You keep support. And you provide guidance.

I think that, also, what has been mentioned, and Raj also-- was underscoring is the importance of the voices. And you have a very strong voice, because these are not the palliative care people who have very, very low voices, and they're end of life, sometimes, so very weak. Mental health can have very strong voices. And I-- you know, I've seen them. So you can have very good, strong voices from the ground. Those would be my suggestions.

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JENNIFER RASANATHAN:

I'm gonna take the moderator's privilege to also turn to Donald quickly, and to also answer some of that question on strategies. And I wonder, in particular, what role can the media play-- in national level advocacy around palliative care, but also globally?

DONALD G. MCNEIL JR.:

Okay. The first observation I might make about your question-- you know, I get all my medical care at Mount Sinai, and I would not declare Mount Sinai a-- paternalism-free zone. (LAUGHTER) So I wouldn't-- I wouldn't put all the onus on-- on the developing world-- to worry (LAUGHTER) about-- paternalistic medical care there.

I mean-- I think the answer is that each country needs its own advocate, because every country has its own situation. Every country has its own attitude on the part of its doctors. Attitude on the part of its patients, which really surprised me, in Japan. Because in-- in Japan, there was a s-- great reluctance on the part of people, to take the drugs that were available, to them.

And-- and-- and I think each country has a very difficult situation as far as-- as-- drug smuggling-- drug-- you know, drug abuse. We-- the-- the smuggling-- the-- the overdoses of-- Liliana explained the difference between, you know-- same drugs in-- in United States, and-- and Canada. And-- and available in western Europe. And some countries have a big abuse problem, and some don't.

It's a-- it's a bad idea to generalize about all these things. And-- and the role of the media is gonna have to be the role of the media in each country. And somebody-- I mean, I find it s-- it-- it's good to take journalists by-- by the hand and explain to them why something is a problem, if you can. I get 300 plus emails a day from people trying to do that, to me. I read-- (LAUGHTER) I read some of them. And-- and it's-- you know, i-- the role of the media in changing people's minds is very important, but you have to kind of find the right reporter, and explain to them why opioids are not the end of the world, and inevitably going to lead to overdoses in the street-- and why there are people who they probably don't know about, suffering, who badly need those drugs.

Going back to earlier-- and, I mean, th-- unfortunately, the people who need the relief are not able to speak for themselves often, because they are at death's door. But people have to come up and speak for them. And reach the media. And-- and also help to find a way to tell those stories. I think *Hippocratic* did a very good job of showing Raj visiting patients.

And that's the way you make a story compelling. Get people involved. Don't just announce principles to somebody. And my experience-- with doctors-- (THROAT CLEARING) is usually-- I mean, doctors, as a journalist, is usually that, when a doctor wants to me to write about something-- I'll say, "Okay, I understand the principles. I understand, you know, what you're-- you're thinking about." But I-- I need to speak to some of your patients.

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And, almost always, the first reaction is, "Oh, my God. No. I'm not letting you jackals of the press near (LAUGHTER) any of my patients." You know, "I know the way you would v-- avoid people in-- you know, d-- in-- invade people's privacy. And, besides, I have, a hold in the United States, we have all those HIPAA problems." And—and I'll inevitably say the same thing, which is-- which is, "Look, doc, do me a favor. Ask them.

"And-- and ask a bunch of them." Because my experience is-- is-- is that a certain number of patients will go, "Oh, my God. Keep those vultures of the press away from me." A certain number will say, "All right. I don't necessarily want to be poster child for this disease and have my suffering made public-- or my photograph out. But if my suffering will help other people from having to suffer similarly, okay. Go ahead. You can speak to me. Take my picture. Talk about my life. Show how I'm suffering."

And there will be a few who say, "Oh, my God. The *New York Times* wants to talk to me? This is my 15 minutes (LAUGHTER) in fame? Bring it on." You know? And you-- you can't know, (LAUGH) until you ask them. And I find that, whether-- you know, whether I'm writing about flu in Pennsylvania, or leprosy at-- Bellevue Hospital. Or-- or-- HIV in-- in Africa. It's-- it's the same-- the same sort of-- dichotomies. And-- and also, th-- the attitude of the indi-- individual doctor is what makes the biggest difference in-- in-- i-- i-- in-- both (HITS MIC) the patient care and in the ability to translate that idea to a greater audience.

JENNIFER RASANATHAN:

Raj?

M.R. RAJAGOPAL:

Let-- let us learn from the past. We people who advocate for access to pain relief maybe made the mistake of making your arguments too one-sided. We wanted all pain to be treated. We wanted the message that opioids were very safe. Maybe we needed the balanced approach. The Lancet Commission gave us the concept of serious health-related suffering as the-- as-- as what should be our objective. Not just life-threatening diseases.

Suffering is our focus. The person who gets hooked to a m-- medicine also is suffering, that also we accept. So, I mean, maybe we will-- we should, hereafter, advocate for safe treatment of pain. And wherever we are advocating for pain relief, we should also be advocating for putting in the safety net there. My second point is our attention is always s-- too concentrated on the hardliners. The hardliner pain therapist who wants opi-- opioids everywhere, and the hardliner who doesn't want opioids anywhere in the world. And this is a-- both are small minorities. There's the chunk of people-- Liliana and I were two of them.

And Jenny wanted a place of meeting, where this fun was happening. It was so much a fight. And others were looking at-- (LAUGHTER) this group. And then looking at this group. And that's the majority. Maybe 70% or 80% of people who are not talking, but listening, and

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forming an opinion. We should be talking to them. But that change of the mindset is going to take time. And we will simply have to be patient and keep on trying.

JENNIFER RASANATHAN:

Thanks so much. We are very nearly out of time. I wanted to thank our panelists so much (APPLAUSE) for your time and energy-- for sharing your insights and experience with us. Thank you so much to our IT support staff-- for helping the videos run smoothly. Biggest thanks to my colleague Sarah Party, who tackled all logistical issues, and made tonight's event a success. Thank you so much. (APPLAUSE) And last, but not least, huge thanks Alyssa Sadler, our fearless communications officer, for inviting all of you, and for making this event happen. Please help yourself (APPLAUSE) to food and drinks-- and enjoy for another ten minutes in the lower lobby.

* * *END OF TRANSCRIPT* * *

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