

Lynn McPherson:

Hello. This is Dr. Lynn McPherson, and welcome to Palliative Care Chat, the podcast brought to you by the Online Master of Science and Graduate Certificate Program at the University of Maryland. We have a real treat today, not only one person that we're interviewing on this podcast, but four of five authors from a very important paper published in The Lancet. The first is Dr. Lukas Radbruch, who tells me that's close enough for somebody from the U.S. to pronounce. He is the Chair of the Board of Directors from the International Association for Hospice and Palliative Care and he's a practicing physician in palliative care. Also, we have Dr. Felicia Marie Knaul, who is a professor at Leonard Miller School of Medicine, at the University of Miami. Director of the Institute for Advanced Study of the Americas and a full member of the Cancer Control Program at the Sylvester Comprehensive Care Center. She's also President of a Mexican NGO, that I cannot pronounce, Dr. Knaul bail me out here.

Dr. Knaul:

Tómatelo a Pecho works on women's health in Latin America in particular.

Lynn McPherson:

Okay, well that was my next plan on how to pronounce it, but thank you for bailing me out. She's also Chair of the Lancet Commission and in fact, all of our authors have been involved with the Lancet Commission for Global Access to Palliative Care and Pain Relief. A very important effort.

Lynn McPherson:

Ms. Liliana de Lima, who is the Executive Director of the International Association of Hospice and Palliative Care. Dr. Afsan Bhadelia, Research Associate Harvard, TH Chan School of Public Health and not present, but also an author on the paper, Cornelis de Joncheere, who is the President of the International Narcotics Control Board. Welcome everyone. I'm delighted to be with you today and thank you for taking time for us.

Lynn McPherson:

So the article that you all authored that caught my eye is titled, The Key Role of Palliative Care in Response to The COVID-19 Tsunami of Suffering. Published in the Lancet May 2020. Wow, that looks like an important paper. Let's start with Dr. Knaul. Dr. Knaul, the tsunami of suffering, that sounds pretty impressive. So, what does this mean and who is feeling this most?

Dr. Knaul:

Well thank you so much for having us here. All of us who worked initially on the Lancet Commission for Global Access to Palliative Care and Pain Relief that really gave rise to the comment that you mentioned, that we published together recently. But we're so thrilled that you have this concern. Particularly for access in low and middle income countries. This is the moment to be speaking, very sadly, about Latin America. Eight percent of the population is in Latin America, the world's population, yet they are now concentrating well over 40% of daily COVID deaths and we're seeing a huge upswing, particularly in Brazil and Mexico. So that there are now more deaths in Brazil and Mexico in the upswing, but more deaths in Brazil every day than we're seeing in the United States.

Dr. Knaul:

This is happening in a region of the world where health systems are weak. Much of the population, in my countries at least, half are employed in the informal sector. Non-salaried workers with no kinds of social protection. Nothing to do, they can't get work so they have to go outside, and living in conditions where they're very close one to the other. So that physical distancing is really very difficult and so that just gives rise to what we call the tsunami of suffering. When we published this paper we were worried about it. We are now seeing it happening in real time.

Dr. Knaul:

Again, I spoke about Latin America, but we can speak about Asia, and to some extent Africa as well. The tsunami of suffering means that countries and regions of the world that were not prepared to begin with, to satisfy need for palliative care and pain relief, have now received an onslaught of need. I'm sure that Dr. Radbruch will speak more about this, but we know that just essential services around palliative care support and bereavement support, but also opioid medicine were just so lacking and now when we speak about excess mortality, we're speaking about both the need that existed before for serious health related suffering that's associated primarily with chronic and non-communicable diseases, but in addition, the need associated with COVID and COVID deaths.

Dr. Knaul:

So, what we knew before was, if we take the issue of pain relief medications, these countries only had enough to satisfy about one third of palliative care need before COVID. And only four to 5% of overall need before COVID. Now with COVID, how are they going to manage to satisfy this need? We have some very specific recommendations that I know we'll speak about a little bit later, as to how we can strengthen the health system of low and middle income countries in the face of this and hopefully in ways that will strengthen them overall in terms of meeting palliative care need and need for pain relief medications, and certainly have them more prepared for future pandemics.

Lynn McPherson:

And it seems like with their limited health care resources, people who have non-COVID illnesses are getting squeezed even harder. Can you drill down any further on the specific implications for these low income and middle income countries you've been speaking of?

Dr. Knaul:

Yes, absolutely. Thank you for insisting on that point because that's really where the tsunami is in fact happening. One other issue we want to highlight is something that we never saw in high income countries with this onslaught of this pandemic. Painful as it is, and continues to be, the majority of people were dying and are dying in hospital. That's very painful for their loved ones who can't be there often and that's what's led to these issues of complex bereavement. What we are going to see in low and middle income countries, where hospitals simply cannot meet this need, even under the best scenarios and I'll get back to that in just a minute, they can't meet this need. So patients are going to be dying in their homes. They're going to be dying in their homes from COVID and from other diseases, illnesses and conditions.

Dr. Knaul:

Both require palliative care, both kinds often require pain relief medication, but what is going to be happening in low and middle income countries is that their caregivers are force into situations where they have to have their loved ones die in the home. They have to give unprotected care giving. So, their

risk of COVID is going to increase exponentially as a result of all of these individuals suffering this disease, dying or not dying, in these conditions where they are not going to be able to get access to hospital and medical care.

Dr. Knaul:

Then, the added piece that I think we just need to say is, at least and I will only speak for Latin America where I actually have my permanent residence there, in Mexico, we have seen very poor leadership. Extremely poor leadership. Some of it has been, let's be generous, ignorance. But some of it has been truly going against what science and evidence have told us about protecting people from the onslaught of this disease and health systems. So, they've done anything but flatten the curve, which would have allowed us to be able to have health systems better managed. Both the NCDs, the non-communicable diseases and the chronic illnesses that give rise to palliative care need, but also COVID itself.

Dr. Knaul:

So we have leaders in Brazil, in Mexico, and in several other places that really acted very late, telling populations not to worry about it and some, in the case of Brazil, that continue to do so. We are generating a tsunami because of very poor leadership in some countries and they're large countries and it's causing a series of issues for those populations and/or around the world, but specific to palliative care. It's a surge of need in places where there was always a tremendous lack of access. Again, this is something about which we have some concrete suggestions and recommendations.

Lynn McPherson:

Before we get to those, I'm almost afraid to ask, if you look in your crystal ball, how is this going to ultimately play out? Will it just be a matter of people who survive having had the illness do you think?

Dr. Knaul:

So, I am not a physician or an expert on this pandemic. So let's just play out what could happen under the best case scenario. So, that also the audience can hear some positive ideas. We've actually developed a state level observatory of public policy and public health around physical distancing in Mexico and Brazil and expanding into the region. I want to say that the state level is so important. Because in places and countries, and we also saw this in the United States, where federal or national leadership is lacking. There is an opportunity for state level government, civil society and the private sector to step it up and to realize that they can improve the situation of their population and they can step it up in terms of access to palliative care as well within their health systems.

Dr. Knaul:

We are beginning to see this. We see some much better performing states, some worse performing states and so a little bit of naming and shaming I think is going to help to improve the situation in many of these countries. Now, the best time to plant a tree, was 20 years ago. But the second best time to plant a tree is now. So, now is the time to help populations to meet this need.

Dr. Knaul:

There's a tremendous tension between people suffering the economic suffering that's associated with this pandemic and the loss of life. So we also know that there are some important public health recommendations this is not specific to palliative care, but it will certainly help to reduce that excess mortality and excess need, when governments decide and people decide to open it up and relax the

physical distancing, we need to help people to understand use masks, maintain the six feet. Wash your hands. And we need to insist on tracing and we need to insist on testing. Testing, testing, testing is the message and going back to palliative care, that's so that we can help to flatten the curve. Flatten the curve means also, access to palliative care, pain relief medications and for breathlessness in particular and complex bereavement support.

Lynn McPherson:

Any other comments on palliative care's role in COVID? Overall even, but particularly in these underserved countries?

Dr. Knaul:

I really want to let our other panelists say something here, but what I want to highlight is what an opportunity I think we have to leapfrog over an obstacle that we've been facing in palliative care and pain relief, I think probably for decades. There is a tremendous lack of access to opioid medications. Really because of misinformation. It isn't about the money. It's about better decision making and we were really so pleased that the President of the International Narcotics Control Board co-authored the paper in Lancet with us because they have made huge steps forward in encouraging countries to do the right thing to have a balanced approach to access to opioid medications.

Dr. Knaul:

What we are really hoping is that this desperate need that's being created by COVID-19, will help countries to realize that they can do aggregate purchasing, for example with the Pan-American Health Organization, that they can put in place safe evals and ways to appropriately give access to all patients who are in need of opioid medication. I think we have to see an opportunity there to get a balance that we did not have in the past.

Dr. Knaul:

So sometimes chaos and desperation I think it was Churchill who said, "Never miss a good crisis." There's never a crisis or a pandemic that's actually good, but let's not miss the tsunami here and the political opportunity we see to encourage countries to change their policies around access, balanced approaches to opioid medications, working in partnerships with the International Narcotics Control Board.

Lynn McPherson:

Let's hope it is indeed our silver lining. So I'll take that question to Dr. Radbruch. Can you tell me, how has the COVID pandemic increased the need for palliative care? What are you seeing medically as the symptoms patients are presenting with. What kind of a role can palliative care play?

Dr. Radbruch:

First question would be what patients we are talking about because there's different kinds of patients. One is, there are some patients who have moderate intensity COVID disease and do not require Palliative Care, but who have symptoms that have to be alleviated. Then there's patients who may not be eligible for intensive care if you do have an overwhelming number of patients and the intensive care beds have to be triaged and who then have to have an alternative treatment for the symptoms at least. There is quite a lot of, in Germany for example, we had a number of patients who had pre-existing comorbidities and who then choose not to go into intensive care, but said that they'd rather stay where

they are, run the course of the disease and they definitely also need symptom relief. There is palliative care patients with other diseases who may not be able to access hospital beds or hospices or any other places and who now suffer from the symptoms much more than they would otherwise.

Dr. Radbruch:

The symptoms as such are, the physical symptoms, is predominantly breathlessness as you already said. And coughing, which is also quite severe from some patients, but breathlessness is the one thing that has to be alleviated. It's not only the breathlessness as such, but is also the fear of suffocating. So every time the patient doesn't get enough breath, he also has the fear that what happens if this increases that he will terribly suffocate with no relief for that. So anxiety, panic, is always an add on to the breathlessness. Some patients do suffer from confusion and the initial reports that patients would not have pain, but by now we do have more information from all different clinical studies showing that up to one-third or even half of the patients, they have pain. It may be some descriptive pain in some joints or something like that, or it may be the same thing as with very intensive flu that you have aching body all over, and that also requires even analgesic medications.

Dr. Radbruch:

So, patients would require treatment with opioids for their breathlessness and sometimes for their pain. And for the coughing, and they would need benzodiazepines for their anxiety and panic, both unfortunately are controlled medicines that most countries are under strict scheduling and especially the low and middle income countries, are not easily available. So even before Corona, we have always said that many of these countries in Africa and Asia and Latin America, patients would have to be very lucky indeed to find somebody who would give them access to these medications.

Dr. Radbruch:

There's also other issues, which I find as important as the physical symptoms. For example, you do have a lot of things to do with decision making, finding the patient's preferences, deciding on treatment indications and that's actually something where palliative care has a long experience and strong experience how to elicit for example, patient preferences, how to decide if they are ethical dilemma to us and for example, we have offered our experience to the crisis staffs in the hospitals and found that it's very important that when you discuss about triage decisions, about allocation of intensive beds or something like that, that you do have the experience that we have from talking to patients and discussing treatment preferences.

Dr. Radbruch:

As you asked about the need for palliative care, sometimes, in some of these situations, we clearly see a need for involvement of palliative care people and experience, but sometimes it's not shared by the other colleagues. So, sometimes we have to offer our services and support to the intensive care guys and they didn't really want it initially. So we had to convince them. Similarly, with access to opioids for example, we had to really explain that for example, not only the Palliative Care Unit needs enough opioids for that kind of treatment, but that also the general medicine sector, the public health sector, the primary health care sector, really needs access to opioids and adequate amounts. That, especially in low and mid income countries is a real problem right now.

Lynn McPherson:

My impression in the United States is that palliative care has emerged as one of the silver linings of this disaster and I think that people are recognizing what palliative care brings to the table, but it strikes me in these low and middle income countries that with the physical symptoms and the limited availability of the drugs, there's only so much that palliative care can do. So I'm sure they're a little bit hamstrung by that, is that your impression as well?

Dr. Radbruch:

Well it's not only that, but it's also that there is so little palliative care available there. So, in many of these countries you would have palliative care available in some of the urban areas around the capital, but not in the rural areas for the rest of the countries. There are models how you can do that, in some African countries for example, there are some countries that have really stepped up the palliative care capacities in recent years quite significantly, but all in all it's as I said, in many countries of the world you really have to be lucky to find somebody who will be trained to use these medications, who will be able to use them and find a place where they are stocked. Even if they are available in the country, then quite often the local pharmacy, the local physician will just tell you that they're out of stock right now.

Lynn McPherson:

Yes. We have a student in our Masters program who is a missionary in Mozambique and she told me there are only three Oncologists in the whole country and palliative care is really not even a thing. So it is certainly very concerning. Well thank you very much. Let's turn to Dr. Bhadelia. So, Radbruch talked about some of the psycho-social issues that have come up, could you maybe expand on this Dr. Bhadelia? The psycho-social issues that have arisen with the COVID epidemic?

Dr. Bhadelia:

Yes, of course. So the containment measures including lock down that have taken, that have been put in place, have had dramatic impacts on day to day life of billions of people around the world. This is immense consequences in terms of mental and social well being. So in particular, concerns resulting from prolonged isolation and overall the pandemic control measures that have been put in place include loneliness, depression, anxiety. In the context of palliative care we need to mitigate the impact of the social isolation at the end of life and the vast care giver distress that is also resulting.

Dr. Bhadelia:

So there is a lack of information around the dying process for patients, as well as caregivers and family members. Things are happening at a rapid pace. The response to this pandemic has been real time. So measures such as visitors not being allowed at hospitals had a huge impact. Family members, so patients who have severe illness, who have COVID and are dying, cannot have loved ones visit them. So that has, both for the patients themselves at the end of life, the experience that they have, but the families who survive them, that can impact and further result in complicate grief. So, exasperate mourning that can result. The lack of closure at the end of life. So persistent form of intense grief that takes over the life of these family members for a long time. I'm sure my colleagues would have more to add on that, in particular Dr. Radbruch.

Dr. Bhadelia:

I think there's additional challenges also thinking about the stigma that has surrounding this. For example, someone might be ill, healthcare workers when they come back home, the reaction from their families. Sometimes people are facing, of course, understandably, the fear for the disease, but then

there's been racism and physical attacks against Asians and people of Asian descent has spread dramatically with the spread of the pandemic. So one of the things that the, a few weeks ago, the UN Secretary General, Antonio Guterres, said "The pandemic continues to unleash the tsunami of hate, xenophobia, scapegoating and scape-mongering. So we need countries to take decisive action around this."

Dr. Bhadelia:

This is important because Asian-Americans who may have COVID or are experiencing some of these other elements are experiencing an additional layer, additional issues because of the stigma they're facing. Then there's, in terms of survivors, there's a range of issues. We're still learning the issues that they, real time learning what they will face coming forward. I mean, in terms of chronic symptoms that are appearing. I'm not a clinician so I can't comment in detail on that, but the traumatic experience of being in ICUs for such a long time is just one example. There are a vast number of issues that we have to think about, particularly thinking about in the context, as we referenced in our article around, in the context of palliative care and end of life care.

Lynn McPherson:

So, these low and middle income countries, just like Dr. Radbruch talked of, they're not as well equipped to deal with the physical symptoms how are they equipped to deal with the grief that you just described?

Dr. Bhadelia:

You know, I think some lessons were learned by particular countries who have faced, experienced outbreaks such as Ebola. So in West Africa and in DRC and now Uganda has just had more recently its first case of Ebola, though Uganda has not experienced it before. In terms of the Ebola outbreak, one of the major issues that had come up was in terms of how those who have died, how they're buried. Family is not being able to partake in the process, the ritual, the burial rituals that need to take place or culturally appropriate. I think public messaging, working with faith leaders, working with elders in the communities. A lot was done around understanding why this is necessary. That the usual burial practices could not take place. So, I think in those contexts there are lessons. In other places, what's problematic is when you think about a country like India with such high density, it is so much worse, well they haven't faced Ebola, but just in through thinking about how the ability to address just, you're trying to survive.

Dr. Bhadelia:

On top of that, you have to address and manage and deal with loved ones dying and I think there's extreme poverty and we're witnessing mass migration, starvation, mass amounts of food insecurity and so, the basic survival mode is on. People have to basically delay grief and grieving of the loss of loved ones, which is very devastating.

Lynn McPherson:

Oh my goodness. So how about the health care professionals who are working in the field? What are their implications?

Dr. Bhadelia:

Well of course, they're working extended hours and surveying the role of physician, family member, friend at the same time for the patient. They're the ones who are sometimes trying to arrange, if possible, with telemedicine or with the phone's, farewells of the family members. They're the ones who hold the hands of the patient at the end of life. So they're experiencing an immense amount of, immense challenges already physically, but also in terms of psychological impact. So, there will be, we're witnessing this burn out. I think that is going to be an ongoing challenge as the pandemic continues and we see the second wave. So there needs to be, peer counseling for example, regular check-ins with social support networks. Some form of self monitoring and working with teams. These need to be done to impact the exposure to death and dying. I think we have to think of new measures rapidly as a workforce has been pushed, and not even palliative care physicians, but others who don't usually, physicians who don't usually deal with death and dying and so this is a huge impact on health care workers.

Lynn McPherson:

Yes. Yes. I can imagine. I wouldn't want to be a respiratory therapist. I think they're in there pretty hot and heavy. Good grief. Well I think we have to turn the ship here, so Ms. de Lima, there's always room for improvement. As the Executive Director of the association, what thoughts do you have about education and training for both low and middle income countries and the US? What do you got for us?

Dr. de Lima:

Well, first of all thanks for having me in this podcast. And thank also for the interest in issues relevant to lower, middle income countries. That's where most of our work is focused on. Although, we do have a global mission. In regards to education, there's an issue that is really cross-cutting throughout the whole world and includes high income and low income countries as well. That's the lack of education and the limited knowledge and the competencies of health care workers in relation to palliative care. There's a significant need to improve and I think taking on what the previous speakers have said and commented, I think this is an opportunity and how it has become, I think it's now more than ever relevant that palliative care needs to be included in the curricula of health care professionals. Especially in the medical and nursing fields.

Dr. de Lima:

I think the ideal situation certainly will be for every health professional to have some basic training in palliative care so that they can correctly identify patients with palliative care needs and then take the necessary steps to alleviate the suffering that they identify and if needed, refer to a Palliative Care Unit or request a consultation. What we have seen, and certainly there is a lot more education happening now in schools in high income countries, however, in low and middle income countries this is not the case. With very few exceptions, most of the health care professionals are going into the field without having the skills to meet these needs and address the needs, the palliative care needs of patients.

Dr. de Lima:

In many of these cases, we've seen many of the suffering that Afsan mentioned and Lukas mentioned and Felicia as well, have to do with the frustration that they're seeing in their inability or the limited capacity to meet and alleviate some of the suffering. That includes symptom control and that includes communicating with patients and their families and how to deliver bad news and how to alleviate the anxiety and all the other issues that may come up and may present when a patient gets sick. In that regard, there's a lot of work to be done. One of the many issues that we can think of is how can we help

from the academia and the civil society to make this happen? That's one point to work and it's one of the areas of work of the IAHP, certainly to improve and also implement curricula and medical nursing schools and hopefully all health care related careers.

Lynn McPherson:

Wow, I think, I would like to think that all the schools in the US, the pharmacy, nursing, medicine and social work have significantly increased their content in palliative care, but I can't say that with a straight face. I think every professional school ought to have at least primary palliative care skills taught as describe by Dr. [inaudible 00:30:30]. Many of the skills you just described. I will say, I'm very impressed with your search engine you have on the IAHP web page where a person can go on and look for either a particular country or worldwide of by a learning modality or whether they're looking for a graduate certificate or a Masters, or just a course. I think that's a very useful tool. So thank you so much for doing that.

Lynn McPherson:

I know I get a lot of inquiries from international students, but the second question is, can I get a full scholarship? So, it's very difficult for these folks in the low and middle income countries to be able to afford higher education. It's a good first step, I appreciate it. How can the global palliative care organizations support national efforts in the implementation of the recently adopted World Health Assembly resolution on COVID-19 which does include palliative care.

Dr. de Lima:

Well, let me go back just a second on your previous comment in regards to the resources that we have available. First of all, for and as you have seen, this is all free and this is just part of our mission and as a service to the global palliative care community. So for courses [inaudible 00:31:40] and programs that are not leading to formal degrees, we have a global calendar of events that is continuously updated and anybody can put up their core seminar in this calendar of events. We just, we do check that they are legitimate before uploading so it's not real time. It has to go through this filter, but we do check that the organization behind, supporting this event, it's legitimate and then it gets uploaded on the website and that happens with 24 hours. It's not immediate, but it happens quite fast. Then for courses and programs leading to formal degrees such as Masters, Phd, fellowships and Honors, we do have also as well the Comprehensive International Directory of Educational Programs in palliative care.

Dr. de Lima:

So thank you for pointing to those and any listeners to the podcast are welcome to check it out. If they have any programs in their universities that they wish to add, we'll be very happy to add those as well. In regards to the COVID-19, we did build a special website and it's called globalpalliativecare.org. It has the links to resources and includes publications to journals, books and videos. Usually most of those links are also free to the global palliative care community. So, that's, in addition to that the global palliative care and COVID-19 series in alliance with the International Children's Palliative Care Network, the Palliative Care Humanitarian Aid Situations and Emergencies Network called CHASE and the WorldWide Hospice Palliative Care Alliance, WHPCA, and we're doing these series which consist of briefing notes on very relevant topics to palliative care and COVID-19 and then weekly seminars that we do with international speakers. These are also all uploaded on the palliativecare.org website. They're all free.

Dr. de Lima:

Going to your question, how can we help implementation. This resolution, which was adopted, you may be aware. The World Health Assembly is the governing body of the World Health Organization and for the first time in its history, they do have an assembly, it's called WHA or the acronym, and they meet every year in May, however, this past year because of the COVID pandemic, they met for the first time virtually. That was very interesting because it did have more presence than they usually have in terms of the Ministers of Health and Prime Ministers and [inaudible 00:34:36] talking to the assembly.

Dr. de Lima:

That was the first time that they had Presidents and Prime Ministers addressing the assembly. So it was quite an event. The rest of the, during this assembly, the whole assembly voted by consensus to adopt this resolution on COVID-19. Thanks to the work, the IAHPAC Advocacy Officer, Dr. [inaudible 00:35:08] and myself and many others working with palliative care leaders and national associations and countries, were able to work with their own governments so the palliative care now is included in this resolution. That's a very big issue and it helps as an advocacy tool, as a resource, that palliative care workers and national associations should get to hold onto and use to help their own governments to implement programs that integrate palliative care fully and it goes from prevention and all the way to palliative care.

Lynn McPherson:

Very impressive. Strong work. That's great.

Dr. de Lima:

There's another very nice, I think, publication that was recently amended by WHO in the palliative care clinical guidelines on those symptom management and palliative care and they now include a statement and a paragraph about palliative care and how necessary it is to have and ensure the access to opioids and to benzodiazepines that Lukas was mentioning before. So those are very important documents that we have now in the international policy framework that we can certainly help the national associations implement in their own countries.

Lynn McPherson:

That's amazing.

Dr. de Lima:

Yes. Now and the way to do that of course is through good advocacy, building relationships with the government. Establishing advisory committees with the Ministries of Health to see how can the people working in the field of physicians, nurses, pharmacists, social workers, all the health care professionals meet them in the palliative care multidisciplinary team, can help the government implement these recommendations. So those are very good, nice, comprehensive documents that we now have in our hands and as a resource.

Lynn McPherson:

That's great. Are these available on your website?

Dr. de Lima:

They are available on the website. They're also available on the WHO website and they can be downloaded as PDF files and for free.

Lynn McPherson:

Okay, so Ms. de Lima, you and I speak very quickly, but I don't have your adorable accent. Could you very slowly give us your website please.

Dr. de Lima:

So I talked about our website, the IAHPHC website and that's an easy one. It's hospicecare.com or hospicecare.org either one of those will point to the same one. That's the IAHPHC website. The other website that I mentioned is globalpalliativecare.org and that's the one that we've, it's focused on COVID-19.

Lynn McPherson:

Excellent. Thank you. So for all of our speakers, is there any closing thought you would like to share with our listeners? Anything about palliative care, the pandemic, low and middle income countries, anything?

Dr. Knaul:

I just thought, I was thinking there were just a few pieces I thought it might be really worthwhile to highlight.

Lynn McPherson:

Please.

Dr. Knaul:

Thank you. One of our key recommendations is as my colleagues and friends shared, the key recommendations in the Lancet Commission report, is that no health professional or religious or spiritual guide or leader should graduate without at least one course in palliative care. This means it needs to be a requirement for licensing. That's really important in low and middle income countries. It's very different to the US or Canada because our physicians and nurses are trained at the undergraduate level. They start seeing patients, they're usually sent to the field by the time they're 21 or 22, with an undergraduate medical degree. That's how their training happens. They're sent out there with no training in how to manage what they're obviously going to face, which is a normal part of life and death, which is death. So that's one point I think is really an important highlight.

Dr. Knaul:

To say that several of us, myself I'm on the board as well, of the IAHPHC, I don't have that lovely accent, although I wish I did. The IAHPHC, and [inaudible 00:39:49] the Global Civil Society Movement around palliative care and pain relief, it's very unusual, very blessed to have it. We don't have a movement like that for any other disease I think, or any issue, specific issue in the context of universal health coverage. So we're really blessed and that's why so much has been achieved.

Dr. Knaul:

Just finally to share that, my heart goes out to so many who are living through these issues of complex bereavement and separation from their loved ones. Until recently I couldn't quite share it the way I am

now, but my mother is now having palliative care at that stage in Toronto, we haven't been able to get to see her. You have to respect the quarantine and it's just so difficult and it's very different to write about something, to research and study something then to actually live it. My heart goes out to so many people around the world who are and have already lived this kind of bereavement and we just have to do the best we can in solidarity with making our world a safer place.

Lynn McPherson:

Thank you Dr. Knaul. I'm sorry that your mom is ill, that's very difficult and of course you're singing my tune, that's my reason I get up in the morning, is hoping that every professional school would include palliative care education. My argument is, we have pretty good evidence that everybody is going to die, so I'm all about that. I wish that we would do that as well. Anyone else have any closing comments?

Dr. Bhadelia:

I would like to add a little bit on the health inequalities that have been harder due to the pandemic if that's all right. So speaking to the US context, communities of color have been incredibly disproportionately impacted by COVID. So there's structural racism due to which black and minority populations, many of whom have inferior health care access, housing, economic conditions and they're more likely to get COVID. Looking at just the data from New York, the death rates, African-American death rate, among African-Americans the death rate is 92 per 100,000, per Latino individuals it's 74 and for white individuals it's 45. So, that's a huge disparity.

Dr. Bhadelia:

A couple of weeks ago Navajo nation surpassed New York and New Jersey to have the most COVID infections per capita in the US. The American reservations have been quite hardly hit, particularly because residents live in multi-generational homes and so, if the disease spreads within a home, if someone gets sick in a home, it's very difficult to stop the spread. Lack of access to water, major restrictions of basic services. I think that's a really important thing to think about because even particularly in this context of palliative care, end of life care, is that many of these individuals are hard hit in other ways who are experiencing this pandemic. So, the challenges around palliative care, access to palliative care is completely out of the equation. So, we have to target policies, interventions, specifically for these communities.

Dr. Bhadelia:

The second thing I wanted to note was, actually elaborate a little bit very briefly on lessons from [inaudible 00:43:08] because you brought that point up and there's a lot we can learn from countries who have experienced the Ebola outbreak around contact tracing. They have vast experience on how to train a large workforce, health workforce, to conduct contact tracing and I mentioned this because, in this context because those are opportunities to also do assessments of the psycho social suffering for example. Then in terms of other lessons, countries that have had, faced a brunt of the HIV epidemic, in terms of messaging and harm reduction strategies. There's much we can learn in the United States from that.

Dr. Bhadelia:

Lastly, I just wanted to clarify, earlier I mentioned mass migration in India. I just wanted to note further that resulted because of haphazard lockdown that was put into place where an entire country of 1.35 billion people had four hours to get home. Migrant workers had to find ways and rush, they were

trapped walking hundreds of miles. So, wanted to complete that picture on why that was happening and what I imagine suffering experience, [inaudible 00:44:24] experience due to that.

Lynn McPherson:

So disheartening to hear these things, but thank you for sharing that. Dr. Radbruch, anything you want to say as a final note?

Dr. Radbruch:

Yes, maybe the same thing that Afsan hit with the idea that it's a two way road. So on the one hand I think there are things we can learn from this [inaudible 00:44:44] countries, but one thing I was particularly impressed with was after the Ebola epidemic, that they trained survivors as volunteers because they knew that by now the survivors would be immune, that they could care for other patients. Not only the nursing care, but the psychosocial care. We do not know yet whether the COVID-19 does produce immunity, if you survive the infection, but if it does, then it certainly would be an idea to get these people as volunteers for psychosocial support or even for nursing care. So, as Afsan already said, there are experiences in low and middle income countries how to do that in pandemic situations.

Dr. Radbruch:

On the other hand, the other thing that we're, perhaps we have to support low and middle income countries is not only with online training, which they desperately need, but also there may be situations where we even may have to send opioids because by now we know that in many countries there will be stock outs and that will mean that even the few patients who will be able to access a person who is able to prescribe that and has been trained to prescribe that, they may not have any opioids available.

Dr. Radbruch:

Opioid stock outs are becoming an issue even in developed countries. So even in European countries and North American countries, there are first reports that there are not enough opioids around for the intensive care requires lots of opioids and palliative care with increased demands requires also lots of opioids and this will be much more severe in developing countries that have only very little amounts that have ordered only very little for the next year and the INCB has offered little advice on how to emergency import opioids. There are special regulations for that and we urgently advise national governments to use that and stock up their opioids, but also it may just be a humanitarian catastrophe with really huge impact because no opioids are available and that has to be alleviated.

Lynn McPherson:

Yes, when I see the opioids that are left over in a hospice patient's home, the time of death in the US, I know this is pretty naïve of me, but I want to put them in a little brown box and ship them to a lower, middle income country. But apparently I'll go to jail if I do that, which is, maybe you could work on that for me, okay.

Dr. Radbruch:

Yeah.

Lynn McPherson:

Ms. de Lima, thoughts from you?

Dr. de Lima:

Yes, I think probably just an additional thought. I think part of the problem that we're seeing, and this is every sort of maybe some of the lack of or misunderstanding of what palliative care is. We recently published a consensus based definition of palliative care, which is actually focused on the relief of suffering. Still there are many people and I've heard reports from Spain for example, palliative care physicians who had not been allowed to visit patients because they were acute patients and not ready for palliative care. So the definition, this consensus based definition that it's also, it's an open access paper, published on the Journal of Pain and Symptom Management. If the whole content and I think the underlying ethos of the definition is the alleviation of suffering, so it doesn't have to do with the prognosis or the diagnosis of the patient, but is this patient, or his family or her family facing severe health related suffering and if yes, they need palliative care. So, this is I think it's a very useful call for attention that palliative care needs to be incorporated to pull out all the conditions and integrated into the system.

Lynn McPherson:

Wow, absolutely. I think you all inspired me. I'm going to talk to my Dean about trying to get some scholarship money for a palliative care practitioner in a low or middle income country to do our Master's degree. Hopefully we can be little Johnny Appleseed's in that regard. I'm just astounded of what a wonderful podcast this was. I'd like to thank my guests Dr. Radbruch, Dr. Knaul, Ms. de Lima, Dr. Bhadelia. This is Dr. Lynn McPherson and this is presentation is copyrighted 2020, University of Maryland. For more information on our completely online Master of Science and Graduate Certificate Program in Palliative Care or for permission requests regarding this podcast, please visit graduate.umaryland.edu/palliative. Thank you.