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Defining the Difficult to Reach PAH Patient

Dr. Channick:
Hello. Today, we're going to be talking about difficult-to-reach populations. This is a big problem in medicine in general, and certainly, in the field of pulmonary hypertension, is trying to take care of some of our patients that are more difficult to reach. And I'm really delighted to be joining you here today.

My name is Rich Channick. I'm a pulmonary hypertension specialist at UCLA Medical Center, and I'm very happy to be joined by my close colleagues, Dr. Jean Elwing, who's director of the Pulmonary Hypertension Program at the University of Cincinnati and professor of medicine there, Dr. Oksana Schlobin, who is associate professor at University of Virginia and medical director of the Pulmonary Hypertension Program at Inova Fairfax Hospital. And then my close colleague, Dr. Rajan Saggar, who is co-director of the Pulmonary Hypertension and Pulmonary Endarterectomy Program at University of California, Los Angeles. So, it's a real pleasure, everybody, to be here. I think we're going to have a really interesting conversation.

This is a problem I think that we're dealing with more and more. We're all involved in busy practices in pulmonary hypertension. And I think before we get into some of the specific challenges that we're facing with these populations, let's I think try to define what is a difficult to reach patient population, specifically as it relates to pulmonary hypertension practices. And maybe we'll just sort of go around because you each work in fairly different sort of settings. And I'd like to hear your perspective about what are your more difficult to reach patients. So, we'll start with Jean.

Dr. Elwing:
Thank you. And thank you for inviting us to speak about this important topic. As you said, it is increasingly a problem for us. So, I think it is not what everyone thinks. It actually spans many different demographics. And I think we have to ask questions to find out which groups of patients this is. It could be your rural patient that doesn't have transportation or can't get a referral into you, or it could be the patient that may be right next door in the inner city who needs to come to you but has no access and no social support to get to you. So, I think the face of it changes as compared to what we used to think an underserved patient was.

Dr. Channick:
So, in your practice in Cincinnati, give me sort of an example that you face of your biggest challenge with a difficult to reach.

Dr. Elwing:
So, I think our biggest challenge is we're right at the border of two other states. So, we have challenges getting patients that have insurance that don't have access to us, and we have to work with their insurance to allow them to get to us. And then, they may not have the financial support to have transportation to us. So, we have to use this combination of face-to-face visits and telemedicine, which we have to be licensed in those states to be able to provide. And the other patients are the patients that are right next door. The bus system maybe is not as reliable as we'd like it to be. So, I think those are the two biggest groups we have.

Dr. Channick:
Thank you. Oksana, now there's geographical issues related to difficult to reach. But then I think there are also other issues that may make it difficult for our patients to get to see us beyond that from socioeconomic. What has been your experience with some of the other

factors involved?

Dr. Schlobin:
So, we are in Northern Virginia and so, we are located pretty centrally near a big metropolitan area. Having said that, there are definitely areas that are far away from Washington D.C., where patients don't have access to a comprehensive care center. So, West Virginia, some of the areas in Maryland. Some patients don't live too far away but with a lot of traffic, it may take them several hours to drive just 50 miles. So, just as Jean said, geographical factors definitely define some of those patient populations that may be at risk not getting the sort of the care that they need. Other patient populations that come to mind are non-English speakers. So, it can be recent immigrants, for example. So, patients who not only, they do not know sort of how to get care because they don't know the culture, but they also don't speak the language. And that becomes a problem because they really don't know how to navigate the American healthcare system.

Dr. Channick:
So, you have a fairly diverse patient population.

Dr. Schlobin:
Yeah, we do. We do. And with Washington D.C. being an area where there is quite a lot of mobility, we often do get patients who come in who immigrated recently, and they move into the Washington D.C. area. I have a patient right now who doesn't speak any English, has very severe pulmonary hypertension. It's tough. You need to get interpreters. You need to make sure that they understand the disease. It all requires time. But actually, getting them to the providers maybe an issue, because they don't know who to turn to when they even start having symptoms.

Dr. Channick:
So, you face this problem where the patients end up coming later in the course of disease.

Dr. Schlobin:
It absolutely can affect when they're diagnosed. So, the delay to diagnosis, but it also can affect their follow up. So if they do not understand why they need to do the testing and why it's important to come back for a follow up, and I'm sure that all of us have had situations where you're there with an interpreter and you try to break it down and explain the situation. And then there is a translation that takes about a 10th of the time that you just spent. And you're like, did you really just translate what I said? And so, you are just never sure what is being translated and how it's being presented. And so, this bond that I think is formed between a physician or a healthcare provider and a patient is much more difficult to make and maintain if you don't speak the same language.

Dr. Channick:
I'll agree to that. And Raj, we both work in obviously a very large urban area, a big city, in Los Angeles. Certainly, there's issues related to geography, but I think in some cases, my experience has been that even as something as mundane as insurance, to get the patient to the clinic, you would like to think that that wouldn't be a limiting factor, but you've been there a lot longer than me. Have you found that to be a factor that's prevented patients from getting to your clinic?

Dr. Saggar:
I completely agree. Insurance is a big issue. Particularly when you know someone, and you get a phone call for instance from a referring physician or from a provider that you know who happens to know a patient who actually is not doing that well at all. In fact, needs urgent, I would say, more urgent medical attention for their pulmonary hypertension. You get this phone call, so you act swiftly, and you try to get someone in your clinic sooner than later. And then you find out that there's an insurance issue or snafu. Sometimes you can work that out. And a lot of times it gets stuck in the process, so to say. For some of those patients, especially when we know they're that ill will sort of do something out of the box and just contact the patient anyways and sort of go through the motions and put a note into the computer, which of course, we're not necessarily, there's no insurance authorization for that but we try to get something on file and have them present either to the hospital if necessary or locally. So, we try to work something out when the insurance is not coming through, but that can be a big issue. And in addition to the geography and obviously, Los Angeles is very large, and the finances of simply coming to the hospital or coming to the clinic.

So if you take that a step further, and let's say someone actually has got the insurance authorization and can make it, so obviously we're doing a lot of televisits. But what I've had an issue with, and, Rich, you probably can attest to this, is the whole idea of seeing a patient for the first time or let's say in follow up but let's say the first time, and you're sort of scheduled for a video visit but it turns quickly into a telephone visit, because either the video system is not working on our end, or it's not working on their end. And then it turns into a telephone visit. And of course, doing a telephone visit is a whole special, we almost need to be trained on how to do one effectively because you can get through a telephone visit probably in two minutes or you can do one really effectively, you know, it just depends how detailed you want to get. And then when you can't see someone, of course, I think it creates those other impediments there in

terms of, it just compromises the evaluation.

Dr. Channick:
Yeah. I think we'll talk more in a different segment on technology and how we can hopefully use that to try to solve some of this problem. Very briefly, obviously, the COVID pandemic has affected the patient's access to our pulmonary hypertension centers. Jean, maybe you can tell me what you've seen as sort of the arc. We started early 2020 and now we're in early 2022. Has this had a major impact on access to your clinic?

Dr. Elwing:
I believe it has for us. It's impacted patient's ability to see their regular providers. And I'm sure you guys have seen that also. So, they can't get to their primary care because of how busy everyone is. Things are delayed. General care has been delayed. And then that delays them by three to six months getting to us. And so that's been a major problem and resulting in them reaching us later. And then if we run into these access issues, they can't get to us because they can't drive to us or they can't get to us because of insurance reasons. Maybe we'll be pushed back three to four more months working all of those things out. So, it's been a critical problem for us.

Dr. Channick:
Yeah. I mean, I could just add to that. I think part of the problem is just the fear factor. Our patients are literally terrified, rightfully so, of leaving their house. In some cases, especially early on before vaccination etc. I think a lot of that has carried over, especially maybe some of the older patients that are already kind of difficult to reach sometimes. And maybe some of our more socioeconomically disadvantaged people, where there's a real fear of getting anywhere near a hospital. Unfortunately, a lot of that's driven by media and whatnot. I don't know if you've noticed that as well, that fear of just seeing you. Not that we should be fearful of.

Dr. Schlobin:
Yes. I would definitely agree with that. The patients often are scared to come to the hospital because they think there is more COVID there. They are often scared to come to do testing at the hospital because, again, they think that the exposure to COVID will be greater. I think I agree with Jean, it's definitely affected access to care. So, in addition to all of the issues that I think we normally face with some of the hard-to-reach populations, COVID threw in another complicating layer on that. Think another patient population we haven't talked about, we talked about people who have, they are not allowed to see you because of insurance. Then we have uninsured patients who just show up in the emergency room. If they are very sick, they often would come to the hospital, maybe then they can get charity care. You can get them into the system and hopefully catch them at that point, which is probably already too late. But if they just get discharged from the ER, the likelihood is that they're going to come back when they're completely decompensated and maybe so late in their disease that you cannot really do anything to help them at that point.

Dr. Elwing:
I totally agree with that. And the ER has been so busy that they don't have the opportunity and the bandwidth to really tease out these medical conditions. So, they are going home more often. And so, then they have to come back again to be ...

Dr. Channick:
We've had examples of people going to the ER and they get tired of waiting and they just leave, right?

Dr. Elwing:
Yes.

Dr. Saggar:
Absolutely. Yeah, absolutely. And I think the other thing is the COVID testing requirements. So, if you want to do a test, let's say a heart catheterization, or as you know, the ventilation perfusion scan, where even just the perfusion scan piece. But they're often being asked to get tested within X amount of time before the test. So, they have to leave their house twice essentially, and then wait for the test result, before they get the actual test they were trying to get done.

Dr. Elwing:
Yeah, very good point.

Dr. Saggar:
So, I think that's another difficult piece for them.

Dr. Channick:
So yeah, a lot of challenges. We can define difficult-to-reach patients in a lot of different ways. And I think it affect everybody who practices PH, whether it's in a rural or urban setting but it's a huge, huge issue. Some of our other segments we'll discuss potential ways to improve this issue and hopefully get our difficult-to-reach patients more access to our center. So, I'd like to thank you for this sort of

interesting and stimulating discussion and thank you for your attention.