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ReachMD
www.reachmd.com
info@reachmd.com
(866) 423-7849

The Difficult to Reach PAH Patient – Possible Solutions

Dr. Channick:
Hello, welcome to this round table discussion. In this segment, we're going to be talking about our difficult-to-reach patients. Some who are new to the system, some who just have a challenge with technology. And we're going to hopefully discuss maybe some solutions. It's, we believe, a real problem.

So my name is Rich Channick, I'm at UCLA Medical Center where I co-direct the Pulmonary Vascular Disease Program there. I'm joined by my colleague Dr. Rajan Saggar, also at UCLA, co-director of the Pulmonary Vascular Disease Program, professor of medicine at UCLA. Dr. Oksana Shlobin, who's an associate professor of medicine, University of Virginia, and medical director of the pulmonary hypertension program at Inova Fairfax Medical Center. And Dr. Jean Elwing, professor of medicine, University of Cincinnati, who's also director of the pulmonary hypertension program there. So, welcome everybody.

So I think, you know, it's very clear that there are patients out there that need the help of a PH center, and can't get it. And there are a variety of reasons why that is. We know that telemedicine, or reaching patients virtually can be a positive thing, and certainly can allow those difficult-to-reach patients to get to us if you will. But I think the reality is that, you know, they need internet access, broadband, although we'd like to think that in this day and age, everybody has it, there's statistics that that's actually not at all the case, that people have reliable broadband. I mean, Jean, you know, I'm sure you're dealing with that as well, and you know, what would you think, if we're sort of thinking out of the box, you know, could be, how would you deal with that problem? I mean, ideally, we want these patients to get to us, but how can we help them?

Dr. Elwing:
Oh, very good point. And as you said, a lot of people don't have access to very good broadband or any at all. A third of large cities, and then many people in the rural communities don't have access. So, I think if you want to use telemedicine in that patient population who doesn't have it in their homes, and if they have it on their cell phone, they can't afford those minutes to talk to you. We've got to look at other solutions. We've got to find a quiet place that does have WiFi, that they could potentially utilize, like the library, or maybe a friend's home, or their mom or their sister's, and make it a planned visit. It really takes effort. You have to go-

Dr. Channick:
You can't just sort of wing it and do it at the last second.

Dr. Elwing:
Right, like, you can't have them call and get it scheduled five minutes before, you really have to have planning, and maybe a couple days, or it may be the patient's daughter or son have to actually hook the whole thing up for them and be there with them. A lot of my older patients, their grandkids are with them helping them, and truly like, let's turn on the camera, let's turn on the microphone. But with that, they can have a very good visit. And they need different ways to learn how to do it, because it can be overwhelming, very stressful for people who are not technologically savvy. So, we do little information sheets, and we make sure they have all their MyCharts set up before the visit, so everything is as good as it can be. It's not 100%, but it's improved dramatically as compared to where we started. So, I think those are at least ideas.

Dr. Channick:
That's great. Another, Rajan, another problem, is, you know, the patient who, again, has never been diagnosed with PH, never been seen at a center, you know, and goes to a local hospital, they may be in a rural setting, or urban setting, and you know, they're just not, you know, getting to us, either lack of recognition, or for whatever reason. And I think that qualifies as a difficult-to-reach patient, cause we have difficulty getting to them. You know, how would you, and this is a, maybe an unanswerable question, but you know, what are some innovative ways you might start to think about getting more of those patients to us?

Dr. Saggar:
Yeah, I think that this is probably one of the toughest situations for this difficult-to-reach individual, because by definition, this person's showing up to let's say, a local emergency room, and then, which is probably not easy to begin with, because they're difficult to reach to begin with, and actually making that move, and then ending up at a facility where, you know, it's determined that they don't actually need acute medical attention. And so the question is, how do we, if that person indeed has pulmonary hypertension, how would that be figured out at that emergency room visit? And I think obviously in the pandemic, things are very difficult, and obviously, resources are of the essence at this time. So, I mean, turnaround in the emergency room has been a big, you know, obviously, emergency rooms are packed, and you know, so this is particularly a difficult time, but I think even outside of a pandemic, this is probably a longstanding issue, and, you know, preexists the pandemic. In terms of a solution here, obviously, you know, education is the only real way to deal with this.

And, you know, I think for the emergency room staff, it's difficult, because of course, their interest is figuring out if someone needs to be admitted for a problem. And as we all know, pulmonary hypertension patients, you know, can often be dealt with in the outpatient setting. So, the question is, how do we figure out that, how does the emergency room determine that A, that patient may have pulmonary hypertension and B, how do they make sure, ensure that they have follow-up once they leave that emergency room? And I'm not suggesting I know the answer, but I think that's where we need to focus some of our attention in terms of how to make that happen.

Dr. Schlobin:
No, absolutely, yeah, I agree with you, this very, very difficult topic, and that's why it's still a topic, obviously, because people, I think, have been really pondering about it for a long time. And for some of the more common diseases, there are protocols in place, even for the emergency room, that the referrals are made, and hopefully, a patient would follow up. But for more like, orphan diseases that are not as well known, that's where I think we fall short as a system.

Dr. Channick:
Really the, you know, just to jump in here. I mean, these people have often been not to one ER, but multiple ER visits, and there's been many points of care where they could have been directed the right way, and it never happened. We've all looked back at these cases and, I'd say in horror sometimes, you know, visit after visit, and all of you and me have been involved in education for many years, and, but I think as Rajan says, we're falling short somehow.

Dr. Schlobin:
We are, we are, and hindsight is 20/20, because it's easier for us to say, oh my gosh, this person has had, you know, 10 visits to the emergency room for shortness of breath, but the ER or acute care provider at the time may not have even known that. So, if they're going from one system to another, one hospital to another, there is not even a, you know, a trail, you know, that the providers can look at and say, oh my gosh, yeah, they've been, you know, maybe they need more testing of some kind. And maybe technology in the future can help us. So, one of the things that happens is there is integration of different electronic medical records, so EMRs. So now there is, you know, (inaudible) everywhere, which is integrated into Epic. And so hopefully, but again, it takes someone with time to look and say, oh, this person has been in the emergency room here and here, several times, and, you know, that it is a recurring problem. And if they have time on their hand, and they're educated, maybe there is going to be the thought, we need to do some kind of other test, well, let's get an echo.

The other possible technological solution comes from AI. And so, if, for example, they, they get a CT scan, and there are protocols that are wrapped into the radiological studies that, so there is, that recognize signs of pulmonary hypertension on the CAT scans, for example. And I know we talk about it in CTEPH, obviously, but not even, without the CTEPH, just pulmonary hypertension. So, let's say, the right side of the heart is enlarged on a CT scan.

Dr Channick:
Enlarged pulmonary artery.

Dr. Schlobin:
Right, so enlarged pulmonary artery. And so, you would get some kind of suggestion, at least to a radiologist, and then to an internal, to an ER doctor, that would say, you know, one of the possibilities is pulmonary hypertension. But then again, someone will need to act on it. But that may be at least a step in the right direction, because, a piece, a missing piece of the suspicion for the disease, because I

mean, the symptoms are so, so nonspecific, will be there.

Dr. Channick:
Yeah, no, that's a great point about the AI, and you know, I mean, Jean, maybe you can give us, you know, the final answer to how to solve the problem.

Dr. Elwing:
Oh, I wish I could! I would love if we could just educate everyone, and everyone would think of this disease, but it's so hard. Think of your average pulmonary hypertension patient. You know, a middle-aged woman who is fatigued, she has three kids, she's running around, she has a job, maybe she has a second job. And she feels bad, but it can sneak up on us. And so I think what we have to do is keep talking about it, talking about it this way, and just try our best to make sure we keep it on that suspicion, that people think about this disease, so our patients can be triggered to get a full echo and referred to us.

Dr. Channick:
That's exactly right, and I think, you know, we all agree. We have lots, we can offer many advances in our field, but, you know, we have to be able to get to the patients that it helps, and it's a real challenge, and you've identified some, you know, interesting solutions, but obviously, more work to be done. So thank you for this great discussion and thank you everyone for your attention.