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ReachMD

Underserved PAH Populations: Why Don't We Connect?

Announcer:

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Dr. Elwing:

Welcome. Thank you so much for joining me. My name is Dr. Jean Elwing, and I'm a Professor of Medicine and the Director of the Pulmonary Hypertension Program at the University of Cincinnati. We are going to be talking today about underserved PAH populations and how do we improve our connections. So, our learning objectives today are really to define this population, examine the use of remote monitoring in following these patients, discuss potential solutions to maintain access to these patients, and really hone in on the barriers and how to overcome them.

So, let's start with defining the problem. How do we define our underserved patient population? So, really, it's threefold. We have social barriers to care, medical barriers to care, and economic barriers to care. In those social barriers, we have physical remote populations, we have immigrant populations, non-English speakers, minority populations, innate prejudices, patient trepidations, and disbelief in medicine and science, which holds people back. We have the economic barriers to care: insurance issues, drug costs, care costs, lack of transportation, and lack of patient access to the tools for telemedicine. Then we have these very important medical barriers. And they may come in multiple forms: telemedicine and access issues, delays in referrals, physician awareness, patient disabilities, and access to primary cares.

Let's talk about social barriers to care. Native Hawaiians and other Pacific Islanders suffer a number of poor health outcomes such as high rate of overweight status, obesity, hypertension, and high rates of asthma and cancer mortality. This was actually recently looked at using Behavioral Risk Factor Surveillance System data, and they found that when all factors were taken into account, these patients were still 66% more likely to experience fair or poor health as compared to their Asian counterparts. Insured Native Hawaiians and other Pacific Islanders were more likely to experience a cost barrier than insured Asians, although there was no difference between the groups in regard to having a personal healthcare provider. If they were uninsured, they were less likely to receive an annual routine checkup as compared to uninsured Asians. So you see here, there are subgroups of the patient population that are not receiving the same level of care because of background and other issues.

So let's talk about the gorilla in the room. There are prejudicial attitudes that affect patient access, and we need to talk about these things so we're aware of them and we can adjust and adapt, so all patient populations are receiving similar levels of care. Racial discrimination is an emerging risk factor for disease and a contributor to racial disparities in health. According to a study from the Commonwealth Fund, about a quarter of Latinx and Black older adults reported facing racial discrimination at the doctor's office, making it harder for them to receive the care they needed. Patients of color 60 years or older were more likely to say they were treated unfairly or had health concerns dismissed by medical professionals. One in four Black or Latino older adults reported racial or ethnic discrimination when seeking healthcare, while fewer White older patients reported this. More than a quarter of US older adults who

experienced discrimination based on their race or ethnicity felt they did not get the care they needed. So this is going hand in hand. They feel discriminated, and with that, they're not receiving the care they would like to receive from their care providers.

So what is also important about this? The older patients experienced discrimination also had more healthcare needs. The older patients experiencing this discrimination, they felt when they went into healthcare, are more likely to have feelings of social isolation and report material hardships and feel dissatisfied with their care than older adults who did not feel this discrimination. So not only did they not have access, they felt more isolated that was in a negative experience in this setting.

Are there ways to address some of these issues and how is it affecting our PAH patients? So some of the things we can do is to improve literacy and low health literacy, especially, identify cost effective resources, expand care offerings, enhance the patient-provider relationship, and cultivate a culture of teamwork and customer service. Helping patients find the least expensive options for transportation, insurance, and medication was the most compelling patient-centered strategy that was reported. Appointment reminders and confirmation of patient plans for transportation to appointments also can reduce no-show rates, and this is extremely important in this vulnerable patient population.

Some other solutions. We need to promote transparency and accountability by identifying instances of discrimination and publicly reporting discrimination data. We need to develop medical school curricula to educate students about how the US healthcare system has interacted with patients of color and other historically marginalized communities. We need to reform policies that enable discrimination and address the lack of diversity in the US healthcare workforce. And very importantly, we need to provide culturally and contextually appropriate care to address patients' communication needs and their preferences.

So, let's talk about reducing economic burden to improve that access and overcome those economic barriers for PAH treatment as a means to increase access to care. Annual cost of PAH medications can be a demotivator for patients to seek and maintain their management of the disease. Socioeconomic reasons result in delays of care in PAH centers. A major concern impacting access to care is the cost of our medications. The mean retail 30-day cost of PAH therapies is more than $5,000. And you look here in this table, the cost is extraordinary. And, of course, people will have insurance coverage and they may be eligible for assistance, but still these numbers are daunting. So, cost includes several things. You could pay for your insurance and then have co-payments, and you also have other costs like oxygen and transportation, and other non-PAH medications. And as I said, there is help, but still, this is a very daunting thing for our patients.

Transportation is also an issue, and this is another economic barrier to care. This is a major obstacle for low-income patients that live at distance from a PAH center. They need to arrange transportation. They need gas money, maybe a hotel stay, and meals during that time. So, a trip to the doctor may not just be that 120 miles. It could include all of those things and may also include hiring somebody to take you to your appointment if you're not able to drive or don't have your own transportation. Specialist outreach is an option but requires that the PAH specialist leave a busy practice to see one or two patients at a distant location. This problem can be avoided if the specialist has a focus clinic for PAH, where enough patients access that it makes it worth the time to take a day to go serve those patients while leaving other patients behind. So we have to look at this and try to really work with patients in a remote area and the physicians to develop a relationship, where we can see a number of patients at that remote clinic.

So shared care is a way to improve access. We need to be able to extend our reach through our partners in the community. Shared care between the primary provider and the PAH specialist is another option to increase access across physical barriers of time and distance. Patients can be seen locally with the input of their PAH specialist. This reduces the number of trips to the PAH center and provides for educational opportunities between the PAH specialist and the referring physician. There are barriers. Many community clinics and hospitals are not equipped to care for patients on parenteral prostanoid therapy. They lack the knowledge and exposure to this to provide safe care. But we can impact and reduce that risk by education, by educating our healthcare providers and EMS in those communities, to be able to see, assess, and then determine what the best management strategy is for patients on parental therapy and communicating with the PAH specialist to transfer patients when necessary.

So let's look at this model. We have two major groups of people. We have the physicians in the community and then the PAH center. Those physicians in the community are seeing the at-risk patient population. They're providing their day-to-day care. They are the ones that are going to identify the at-risk patients and screen them and then refer them to the PAH center, where the patients will have access to the PAH specialty-trained physician, advanced diagnostics, medications, and clinical trials, lung transplants, support groups, and advanced teaching. So this is a relationship that needs to be bidirectional because one group cannot do it without the other.

It's not just primary care physicians we need in this group. We need the patient's primary pulmonologist, their primary cardiologist, their rheumatologist, and their primary care physician to all interact in a positive way to allow the patient to have the best outcome.

So let's talk about some medical barriers to care. Let's talk about delays in PAH referral and how we can overcome them. Slow referrals,

misdiagnosis, incorrect prescriptions all limit patients access to effective care. So where do we start? We start with ground zero. The doctors in the community caring for our patient's day to day. And we really need to improve the awareness of this condition. We also have to be mindful that there could be influences from outside, commercial influences and different things resulting in earlier prescribing practices that may not be consistent with what the center would recommend. And in a recent study, more than 60% of the patients referred to a PAH center were advanced, they had functional class three and four symptoms. 33% of those patients had been misdiagnosed. 30% had already been prescribed PAH medications prior to referral. And nearly 60% of those referrals had prescriptions on board that were contrary to current guidelines. So it's very important we open these lines of communication, and let people know. Send your patient you're worried about. Send your patient you think could have pulmonary hypertension, and we'll evaluate and treat based on our current guidelines.

So there's an education grant gap, obviously. We can see that from our previous slide. We're failing to recognize and refer PAH patients when they enter medicine at the primary care level and at their primary cardiologist and pulmonologist level. Despite ongoing efforts to PAH education in the community, physician education on the topic of PAH remains problematic. Due to work hour restrictions, internal medicine and pediatric residency programs have insufficient time to educate trainees about PAH. While the ACGME mandates PAH education, many pulmonary medicine fellows receive little or no exposure to echo, right heart catheterization, or advanced PAH therapy information. In contrast, while cardiology fellows who train it programs with large PAH referral practices, they may be more likely to be exposed to patients with PAH. The majority of training institutions do not have enough PAH presence to offer fellows really significant exposure to allow them to go out and be able to identify and practice medicine for these patients with PAH.

So there are some ideas of how to overcome this, in a more of a stepwise fashion. We need to be able to educate at multiple levels. Education of the primary care physician is critical. As PAH patients often first presented these individuals, vague complaints of shortness of breath, chest pain, syncope, fatigue are often the initial presenting symptoms. And they're oftentimes mistaken for many other common conditions which we oftentimes think of first. So a three-tiered model of generalist physicians, general specialists, like cardiologist and pulmonologist, and PAH specialists have been proposed as a framework to improve education worldwide. To start with that generalist, and the general specialist and the PAH specialist all working together in this educational effort.

There are some other resources we have to be aware of. These are just a few. This is not all inclusive, but we can learn about pulmonary arterial hypertension, and other forms of pulmonary hypertension through the Pulmonary Hypertension Association, American College of Chest Physicians, and American Thoracic Society all have education for the provider, as well as the patients.

So now we know a little bit more about how to educate, how can we reduce the diagnostic delays? How do we go the next level? We need to screen people who are at risk, and we need to identify those patients at early stage disease. Educational efforts through primary care physicians and public awareness campaigns are in play. And they help, but we need more. We've been working on this for a long time, and we need to go the next level. Artificial intelligence may play a role. It could identify possible causes based on healthcare utilization in these large databases like our electronic medical records, and especially PAH centers can minimize barriers to referral and develop pathways to expedite evaluation and access to testing by really solid communication with our community providers.

So what should be the trigger to send someone to a PAH specialist? Patients are at risk for pulmonary hypertension and they present with these nonspecific symptoms. Dyspnea/change in exercise tolerance. But we've got to be aware that certain patient populations. When they say these words, we need to go on and look for pulmonary hypertension. That is like your HIV patient or your scleroderma patient. Any signs of worsening dyspnea, worsening exercise tolerance, echo signs of right ventricular dysfunction, elevated pulmonary pressures, right atrial and right ventricular changes need to prompt referral. And we need to be really clear about that. And open to seeing these patients. We're going to be seeing some patients in the PAH centers that don't have pulmonary hypertension, but we need to be able to see all of them to catch the patients really early and allow follow up and treatment early to delay that time to worsening. Ongoing dyspnea after pulmonary embolism should be something that would prompt someone to send a patient to a PAH center. Dyspnea with an elevated BNP that is not left heart related, think PH. And a PFT with markedly reduced DLco and no other significant abnormalities, think pulmonary vascular disease. So I think we need to think outside the box of an elevated pulmonary pressure and refer for these reasons.

Mobile health care can help, but there's limitations. Smartphone apps offer enormous opportunities for our patients for dealing with future challenges in public health. Mobile devices are widely available and have a lot of medical content. But unfortunately, only a small fraction of our patients are using these devices. Orthopedic and trauma apps have been used but tend to be used by younger patients, possibly excluding many of the patients we talked about earlier that are on the fringe and have less access to care. Can we adapt what we are using in mobile health and attract older adults to be able to use this more easily? This is something we need to really think about when developing these educational apps. Make it as user friendly and the least daunting we can so everyone will access these educational tools. So let's look at potential for mobile health and telemedicine and see how this can positively affect our patient experience.

Now let's talk about telemedicine. Bringing medicine to the people, the rise of telemedicine in PAH management. How can it work? And how can we use it to its fullest potential? The pandemic has forced us a rethinking of how PAH patients are managed. COVID-19 has adversely influenced PAH care, clearly, especially during the early pandemic. There were periods that there was clearly stay-at-home policies that decreased patients confidence coming to the hospital and coming to the office. PAH expert centers adopted telemedicine tools to evaluate potential complex patients. And telehealth was used broadly, and really encompassed any technology-enabled healthcare management tool we could find to deliver care at that time.

There's been a fundamental change in how we interact with patients, and it now includes telemedicine. That's what I believe at least. However, we lack data. There's no studies that yet have demonstrated the effectiveness of the use of telehealth to improve outcomes, specifically in PAH patients. PAH patients rely on this aggressive multimodal, regular evaluation of their risk assessment to see if they're worsening. And this can be subtle. Current guidelines for management of patients with PAH require ongoing objective risk assessment based on multiple factors: functional capacity, walk distance, exercise testing, BNP and NT-proBNP, as well as echocardiographic and hemodynamic findings. So, these are a lot of pieces of the puzzle we look at when we're seeing a PAH patient to decide how they're doing.

COVID-19 lockdowns reduced in-office visits and PAH treatment initiation. During the COVID-19 lockdown, there was close to a 50% decline in new patient appointments for PAH, with a similar reduction in the initiation of PAH-specific therapies. This is huge. That was a great number of patients who had a delay in their care. The US study looking at 77 centers found that fewer clinic visits were occurring, and a higher level of telemedicine visits were occurring in PAH patients during the early pandemic. The incidence of COVID-19 in PAH and CTEPH patients was found early in the pandemic to be about three per thousand and of these 30% more hospitalized and 12% died. This was worse than the general population. Making us aware that we had to protect our patients and offer them options to see us outside the clinic. Delayed referrals and assessments clearly have potential to harm patients and we needed to think of ways to overcome this.

So, let's look at this study a little closer. So, we can see that pre-and post-pandemic there was significant reduction. And you'll see here, typical number of outpatients weekly from 30 to down to a number less than 15 after COVID-19. Use of telemedicine increased from 7% to 83%. So we did our best to replace some of those visits with telemedicine. But at the same time, we reduced our exposure of our patients to testing. And you'll see here, there are fewer echos, fewer right heart catheterizations, fewer VQ scans and fewer initiations of medical therapy for our PAH patients. So we did our best to try to offer telemedicine, but we were not able to offer the full package early in the pandemic.

So let's look at this. Early in the pandemic, 2020 to 2021, telemedicine expanded exponentially. Initially, there was a use of telemedicine, both audio and visual, as well as phone calls. And the phone visits fell off and the bimodal telemedicine, with audio and visual, went up over that period, from 3/11 to 4/4/2020. We adapted quickly. So in this instance, we found in a study at NYU that 80% of in-person visits decreased, and there was an increase of more than 650% of telemedicine during that time.

So, if telemedicine for routine assessments of PAH patients is the new deal, are we getting the most out of it? And I think that's an important question we have to ask. Good enough is not good enough. We have to make it as productive and effective as we can. But now let's talk about how we can do that.

As you know, risk assessment in pulmonary hypertension is multimodal. We have to look at biochemical markers, so people need to get labs. We need to do clinical assessments, so we need to talk to patients. We have to have enough face time that we're able to look at functional class, symptoms, right heart failure, changes. And we need to do some sort of exercise assessment. We need to look at echocardiographic features and we occasionally need to look at hemodynamics. And we have to put that all together to be able to appropriately risk assess our patients.

How can we do this? Can we really do this in the setting of telemedicine? Progress in PAH has focused strategies for combination therapy and escalation of treatments. In 2018, revised treatment strategies were based on severity of the newly diagnosed PAH patients by those multiparametric risk stratification models. In risk stratification, clinical, exercise tolerance, RV function, hemodynamic parameters were all looked at to define patients as low, intermediate, or high risk based on their one-year mortality. The 2018 treatment algorithm defines initial treatment strategies based on those risks. And with those risks, we would determine, do you need monotherapy, dual therapy, or triple therapy? So we cannot do this without proper risk assessment. And we need to be able to reevaluate to drive patients to low-risk status.

Let's take a look at some of our risk tools. We have here the Swedish registry, the French, and COMPERA. And all have one thing in common. If we are able to get patients to low risk and maintain low risk, patients do well. If you can see here in the Swedish registry, the low-risk patients or those who improved to low risk had an 89% or better survival at five years. The same in the French registry. And

COMPERA also showed, the lower your risk, the better your survival.

How can we adapt with telemedicine? Risk assessment protocols like REVEAL Lite 2 make maximum out of these noninvasive parameters. And we could use this for our telemedicine approach to PAH care. REVEAL Lite 2 was developed using the same data as REVEAL 2.0. It was based on REVEAL 2.0 but uses only six noninvasive and modifiable parameters. We look at functional class, blood pressure, heart rate, walk distance, BNP, and renal function. And with that, patients are then divided into low-, intermediate-, and high-risk groups, just like in REVEAL 2.0.

What are the main issues using telemedicine for risk assessment and monitoring PAH patients? How can we make this happen? So currently we have telemedicine, which is able to reach many patients. But we are not able to reach everyone. Currently, telemedicine can be used to gather information about functional capacity, maybe do some walk assessment to look at six-minute walk test, and we'll talk about that. We can look at labs and we can look at echoes if patients can get out to get a test done. But there are challenges. Not everyone has access to broadband. Not everyone is technically savvy. Some people lack the appropriate equipment, and some providers lack the skills to be able to really interact with patients on this virtual level.

So now let's talk about physician-perceived barriers to effective telemedicine. The perceived barriers include the lack of comprehensive medical assessment, technical challenges, public resistance, cost, reimbursement, and some providers feel that they're providing a lower standard of care. The groups that were most concerned about telemedicine were those in the US and Europe. And the other groups in Australia, Middle East, Africa, and India were less concerned about these barriers. But important to be aware of and important that we look to address them so more physicians can provide care they feel very comfortable is effective and optimal.

So what are the patient-perceived barriers? They also have to be comfortable with telemedicine. Patients with older age and lower level of education perceived barriers to telemedicine. Also very importantly, patients who had bandwidth issues with internet or lack of telephones were very concerned about use of telemedicine for their healthcare. So things that we need to be aware of and we need to ask these questions when we offer telemedicine to patients. If you don't have broadband access, you can't do virtual visits. You could do a telephone call, but you can't have that full experience where you are able to have audio and visual interaction with your patients. This is particularly a problem in rural communities where we don't have the greatest internet connectivity. The availability of high-speed internet or mobile data networks may be insufficient in those regions. Some individuals cannot afford or maintain their own connectivity or camera-enabled devices and some patients just don't feel comfortable with the video devices and setting it up in a timely fashion for a visit and they become very anxious about this. They may even fear the potential embarrassment because they don't understand how to use these devices. So we need to be sensitive to these issues and be able to adapt, see patients in person, or via telephone in patient situations where they're not comfortable or able to connect.

Let's talk about the gravity of this situation. It's probably bigger than you think. 19 million Americans lack broadband service. Telemedicine solutions come in two forms. You could just do an audio-only, where you just talk on the telephone. But that's not always as productive as we'd like. We're not able to do a virtual examination and we're not able to get a full experience for the patient. And then of course we have the synchronous, two-way audio/video conferencing, which allows us to do more in our visit. Successful transition to telemedicine requires three parts. We need to have access to broadband, we need to have internet-capable devices, and we need to have sufficient technology literacy to take advantage of those. Just to have a little bit of sense of the problem in the inner city, I have 31% of the patients in New York City without broadband and lack of broadband disproportionately affects Blacks and Latinx Americans. So we now have a patient population that has difficulty accessing, and we put another factor on top of it that limits the care that group of patients receives. So something we really need to wrap our heads around before we find telemedicine to be the solution for everyone.

What about remote monitoring technologies? And how are they utilized for our patients? This is something that's being developed and really a lot of work is going into better understanding how we can use these technologies to care for our patients.

So, in the COVID-19 era, telehealth visits were used more and more frequently than they'd ever been before. And wearable devices were looked at to see if they could play a role in our evaluation. Many wearable devices for monitoring patient activity and vital science have not been fully vetted by the Scientific Literature, but patients are using them, and we are interested in them. One of the most significant challenges in the evaluation of a PAH patient during a telemedicine visit is to figure out how they're actually doing functionally and how they're doing in terms of the right heart failure. We need to look at vital signs, blood pressure, and exercise capacity, and that's sort of challenging when you're talking to someone when they're sitting at their computer or on their cell phone. We could use technology to help us understand their average daily step count, we could look at their weights with a scale that is a smart scale, we could look at heart rate and blood pressure with tracking devices, and we could see once those things are going in the wrong direction, we're getting closer to the patient having a worsening event or nearing risk for hospitalization. So, what patient information could we routinely obtain via remote monitoring to use in these reassessment visits? What data can we really use? Well, we can look at a patient, like we're looking at each other, we can observe physical signs, we can look at general appearance, behavior of the patient, we can look

at their skin, we can look at wounds, catheter sites, devices, swelling, rashes, breathing patterns, and physical movement. So, we can learn a lot about how the patient looks and maybe a little bit about how they're feeling by their expressions, and that's why the video portion is so very important for these interactions. We can talk to them about daily physical activity, we might be using accelerometer, or we can do step counting with their watch or their smartphone, we can look at a Pulse Ox. We can look at blood pressure and heart rate and we can at times see JVD. We can do remote monitoring devices to measure parameters, but remember, these are not validated in our PAH patient population, we can get a gestalt about how they're doing through these means.

So, let's talk about these parameters and what is available, okay. So, we have things we want to know; we want to know heart rate, we want to know blood pressure, we want to know step count, some of these can be done through a regular blood pressure cuff and patient uploading them, or we can have a link device that can upload to their smartphone and then they could share that device with us through their MyChart or whatever means that we communicate in our clinics. We could use step counts with smartwatches. We can use a Pulse Ox that could be recorded through their smart device or patient could manually upload. And we could use an Apple Watch or something of that sort to look at heart rhythm. So, we can learn a lot, but this is not going to give us all of our information that we would normally see in clinic. And remember, this is patient-reported data through a device that's not validated.

So, all of the things we talked about are great but one missing link is our six-minute walk distance. We don't have a validated tool to check six-minute walk distance. Currently, we're able to count steps, we're able to look at exercise capacity, we are able to look at things through accelerometry like ActiLife and ActiGraph to see how far patients are walking, but we don't have a tool to definitively look at our six-minute walk distance. A recent study Salvi et al supported the six-minute walk test as a feasible in-home environment using a device-based application but such tools have not yet undergone validation among individuals with PAH.

So can we create a six-minute walk test that can be performed remotely? Activity assessment in patients who are spending most of their time at home can be challenging. Increased time at home for most individuals has led to substantial cardiopulmonary decondition. Six-minute walk testing is a common clinical instrument we're using in clinic but has not been developed for home use in a validated way. Primary measurement of the test is total distance walked. Secondary measurements are fatigue, dyspnea, pulse ox and recovery. The advent of affordable digital device and mobile phones, it may become possible in the future for the patient to complete this in their home or near their home with sensors like accelerometers or global positioning systems, GPS, to estimate distance walked.

Is step counting the answer for functional capacity assessment? Well, maybe. Smartphones are able to regularly and easily obtain objective measures of physical activity. The Apple iPhone includes a health app that summarize step estimates derived from accelerometric embedded sensors and generated movements as the device went carried and the Android has the same similar kind of offerings. And some people opt for using things like Fitbit or Garmin to do the kind of things that they would do with their smartphone otherwise. And there's even some novel accessories like earphones, necklaces, hats, rings, shirts, to look at this information, but this is variable and again, has not yet been validated for our patients.

So how do patients react to telemedicine? How do they fell about telemedicine? Well, I think we first have to understand what patients want out of their visits. They want to know how to improve their physical function, improve their quality of life, look at their financial, social, emotional status, and they want treatment and visit convenience. Whereas we as the providers want to look at their exercise capacity, their hemodynamics, their biochemicals, their walk distance, their peak V02, and sometimes these don't marry well. So we need to understand what the patients are looking for and try to help them understand why we're looking for the things we're looking for, because our improvements, most of the time, will result in what they're looking at and their goals of care. So we need to marry those in a better way.

We as physicians are looking at symptoms, exercise capacity, biomarkers, hemodynamics, and survival, but that's only the tip of the iceberg in terms of what we're trying to achieve with our patient interactions. Our patients are looking to us to change their quality of life, improve their stability, improve their interaction with other people and patients, reduce their frustration, their worry, and the stress of this disease, and also, they're looking to us for help with the cost of their care, but we do encounter barriers. We encounter fear, anxiety, self-doubt, and apprehension about communication and testing. So, we need to be aware of these things so we can optimally communicate and allow patients to be able to express these things to us.

So again, looking at the patient's perspective, that's what it's all about, right, isn't it? We want the patient to improve, and in doing so, have the best experience they can have with this illness, pulmonary arterial hypertension. Patients experience living with pulmonary hypertension and the impact on him, her and the caregivers around them is extremely important. It includes their symptoms, their intellectual interactions, psychosocial aspects, spiritual aspects, and goal-oriented dimensions of disease and treatment. We need to be able to understand these and communicate at multiple levels with the patient and other healthcare providers about these important issues. Others involved in patient's experience may include those healthcare providers that are their primary care physicians but also could include mental health workers, spiritual counselors, family, their social network, and other healthcare influencers, which we may

not think about, their insurers, the medical industry, government issues where they have to apply for assistance and things of that nature. So they're all affecting the patient's experience, and they really impact their perspective.

So how can we bridge what we usually think about when we care for a patient and what the patient is looking for from their experience? Well, we need to understand it, and we've talked a little bit about that. As I said, most of the time we're on the tip of the iceberg of what is important to the patient. The patient's experience is influenced over time by this relationship we build and by us being open to them expressing their concerns. The traditional approach of looking at symptoms, testing, and treatment recommendations, probably not adequate. Understanding the burden of illness and impact of patient's quality of life really requires this bidirectional exchange of opinions and a discussion between all of us. Patient-centered collaborative care includes decision-making by all of the people involved, and it empowers us and the patients on their treatment course. So extremely valuable, extremely important, and the only way patients will successfully improve because so much of the work that is done in pulmonary hypertension is done by the patient in their homes, trying to be active, taking their medications every day, and we need to understand everything we can to be able to improve that.

So how satisfied are patients with this telemedicine approach to care? Online survey-based study of cardiology patients probed the limitations of telemedicine accessibility, patient satisfaction with telemedicine relative to in-person visits, and the perceived advantages and disadvantages of telehealth. No-show rates for telehealth in this study was about 17%, which was the same as their face-to-face visits, so no different. Both in-person visits and telehealth visits were viewed favorably, but in-person visits were rated higher across all domains of patient satisfaction. So, patients were a little bit more satisfied when they saw us face to face. The only significantly lower mean score for telehealth was in clinical competence domain. So, we need to be aware of that. We need to make sure we express ourselves adequately so they're confident in our clinical recommendations. Reduced travel time, lower visit wait time, cost savings were also seen as significant advantages. Poor internet connectivity was rated at least somewhat as a factor of an influence of how they tolerated and felt about telemedicine in about 1/3 of respondents. So, this was impactful. They were aware that they could have internet connectivity problems and that could influence their telemedicine experience.

Let's sum this up. Let's talk about finding pathways to ease PAH patients access to care. There's been a change in the landscape for our PAH patients. Recent world events with COVID 19 have made it more difficult for our PAH patients to receive the quality of care and disease management they require. The COVID pandemic and economic challenges have added burdens to the PAH patients seeking specialty care. Socioeconomic factors, lack of affordable transportation, prejudices against modern science and medicine, as well as challenges faced by minorities in the healthcare system, all contribute to difficulties of the PAH patient finding and continuing their care. Collaboration between community physicians and PAH specialists can obviate the problem of the undiscovered or underserved PAH patient population but we have to work together to resolve this.

There are solutions, but they take work. A rethinking of the physician's education and to build increased awareness of PAH is important. This is a rare disease, but it can be treated, and followed, and outcomes can be improved. Disease networks can be built for patient education and referrals to make patients easier to access and for patients to find PAH centers. Patients and physician education around PAH can help pave the way for more patients to obtain specialty diagnosis and disease management. The COVID 19 pandemic inspired a rise in telemedicine and remote patient monitoring, we just need to take it to the next level. Cooperative arrangements between community physicians and PAH specialists can improve this access to our PAH diagnosis and treatment if we open lines of communication, we improve communication in terms of education and patient follow up and working together to care for patients.

So, I'd like to end with some final thoughts. While patients generally hold favorable views of telemedicine, there are numerous areas which require development or refinement, and they include minimizing technological burdens for patients and secondarily for the healthcare providers. We've made great successes and great improvements here but we have more to come. Continued development of peer-reviewed and accredited tools for remote PAH patient risk assessment like a validated six-minute walk distance is needed and we are working on this. Validation of modernized risk assessment protocols for the telemedicine-based patient environment is important. An improvement of physician skills in using telemedicine to effectively and efficiently perform remote PAH risk assessment is key and we need to continue to advance this. Creating better educational interfaces for patients and healthcare providers to understand the appropriate identification and treatment of PAH is important and we need to continue our efforts on this area. So, with this, I'd like to say thank you so much for joining me, and I hope you enjoyed this presentation.

Announcer:
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