

Center-based Care

As guest editor of this issue, Dr Chakinala organized a group of individuals who each had different perspectives and relationships to Pulmonary Hypertension Care Centers. In conversation among the physicians, nurse, social worker, and patient, they touch on the evolution of care of pulmonary hypertension patients over the past 20 years and the complexity of care that new medications and their side effects create. They discuss the advantages that centers of care can bring to the patients and to the field as a whole from access to experts to multidisciplinary care and clinical research during their lively conversation.

Dr Chakinala: This issue of the journal focuses on center-based care, with a spotlight on the Pulmonary Hypertension Care Centers (PHCC) and the Pulmonary Hypertension Association Registry, known as the PHAR. I've put together some broad topics that I want to cover and will delve right in with our diverse panel. First, let's quickly introduce ourselves and our roles at our respective centers. Dave, you want to start us off?

Dr Badesch: Sure, David Badesch, the Director of the Pulmonary Hypertension program at the University of Colorado. And we've been participating in the PHA registry and related activities. It's a delight to be here with you, Murali.

Dr Awdish: I'm the Director of the Pulmonary Hypertension program at Henry Ford Hospital in Detroit and also the Medical Director of Care Experience for the system.

Ms Stewart: I'm Traci Stewart from the University of Iowa, pulmonary hypertension nurse coordinator.

Ms Bathon: Rebecca Bathon, social worker at Barnes-Jewish Hospital and Washington University, working with Dr Chakinala.

Dr Chakinala: And last, but certainly not least, Colleen?

Ms Connor: I am Colleen Connor. I'm a PH patient, now 10 years in.

Dr Chakinala: Great to have all of you join today. My first question for the group: how do you think the care of pulmonary arterial hypertension (PAH)

patients has evolved over the last 15 years? We have all these therapies and you're certainly welcome to speak to that. But I would ask you to expand on the overall approach to care of the pulmonary hypertension (PH) patient now versus the past.

Dr Badesch: I think the Centers of Care program has helped to encourage referrals to centers of excellence. And I think that's a good thing for patients, as well as for clinical research. It's still not a common disease and I think that having experience with the disease and being able to offer clinical trials and participation in registries and things is important. So, I'm a strong advocate of center-based care and multidisciplinary care. I think that the Pulmonary Hypertension Association's Centers of Comprehensive Care program has helped to encourage that and formalize it in very good ways. And the addition of the PHA registry has been a very positive development, as well.

Dr Chakinala: Not to pick on you Dave, but you are the most senior member on our panel and you taught me what I know about pulmonary hypertension. What about the individual patients that come to see you now: how are they different than when you first started doing pulmonary hypertension?

Dr Badesch: So, it's interesting, Murali. I think that the patient population has expanded substantially. Twenty years ago, we were seeing predominantly patients with Group 1 PAH, largely idiopathic PAH (IPAH) or connective tissue disease-associated pulmonary hypertension. And now we see a broader group of diagnoses in patients. And it's important to understand the evaluation that's

necessary to properly identify folks. And then to understand that our therapies might not be applicable in all forms of pulmonary hypertension or actually, they certainly are not. So, it's important that patients go through a proper evaluation and that therapies are used with some discretion. I do think—I'm sure this is probably the case at Washington University, too, Murali—but we see a fair number of folks that are referred a little bit later, having already been initiated on therapy in the community. And sometimes that's appropriate, but sometimes it's not. And so encouraging referral to centers of specialized care, I think, is a very important and worthy effort.

Dr Chakinala: Traci, could you reflect on your early days at your center and specifically how our treatment approach and maybe how "goals of care" have evolved?

Ms Stewart: Sure. So, these patients are just—they're really complicated. And like Dr Badesch said, I think the diagnostic evaluation has improved. However, I still see a lot of people that are referred late or misdiagnosed. And so, I think from my perspective, really when I first started doing this, we had one med to choose from and that was epoprostenol. And some people were just absolutely not great candidates for IV or parenteral therapy. So, I think what makes them more complicated now is that we have a lot more options. A lot of education is required to talk to the patients about what their therapy options are and having that conversation about what their goals are ... and trying to match the best medicine and the best treatment plan with the outcome that they want. All those conversations take

a lot of time and getting to know each other. And I think a lot of times when patients are referred to a big center, sometimes it takes a little while to build up that trust. So, I think having multidisciplinary care from a PH center, which includes a physician, nurse, pharmacist, and a social worker, and all those aspects, really has changed since I first started doing this, where it was more just a model of a physician and a nurse.

I think the medications are really a challenge—to get them through the insurance hoops and prior authorizations, and the medications have a lot of side effects. So, we need to have a lot of conversation about managing heart failure and medication side effects, so that patients have good quality of life.

Dr Chakinala: Thanks Traci, those are great comments and they're going to be a great segue to the next section of the discussion. To summarize what the two of you are saying: our care and workload have evolved because we're taking care of more complex patients. We also have more complex therapeutic regimens. Thankfully, people are living longer. And there's a lot more chronic management we have to do, instead of just starting the infusion and hoping folks survive, like in the past. Appreciate getting us started.

So now, I'd like to shift to the actual PHCC. Maybe we could start with some general comments to expand on what was already said: what is the benefit of going through the accreditation process and getting that label of being a PHCC, especially for the staff at the center? Rana, you could start us off?

Dr Awdish: So for us at Henry Ford Hospital, becoming accredited as a PH Center of Comprehensive Care was important for a number of reasons. One, it helps us to stay current with best practices across the country. It also helps our organization really understand the support structure that's necessary to have a very high-functioning PH program. As health care resources are often scarce, having a unified standard in terms of what the team looks like helps us to make a case for a dedicated social worker, a coordinator-to-patient ratio

that's truly safe, and enables more direct provider contact with patients. Having our pharmacist embedded in the team, so that there is a smooth integration of inpatient and outpatient care, too. And having a prior authorization specialist to help us with insurance approvals. All of those features of care were part of the standing of a PHCC. Also, having access to how other centers are positioning their safety protocols in the intensive care unit (ICU) and on the floors, having access to the registry—those are all of tremendous benefit. And my hope is that those things will continue to grow over time. And that insurance companies will look at centers and perhaps be a little more generous in their judgment and acceptance of what we believe patients should be treated with. And we'll learn from the patients who are enrolled in the registry.

Dr Chakinala: A lot of great points that you made. I'd like to shift the spotlight onto the patient's perspective. So, Colleen, what do you think are patients' expectations when they come to a center? And do you think they've changed over time?

Ms Connor: Well, I do think that the expectation has changed if, in fact, people have been able to identify and become educated that PH Care Centers exist. Unfortunately, I still find too much today, even in our current day, that not all patients are aware. And so, for example, I met a patient in the last few months who is being treated with PH medicines. However, the person has never had a right heart catheterization. And I imagine that that step is critical to confirm the diagnosis and determine which medications should be leveraged. And so, I think that the expectation for people who are aware is terrific. I think as a patient, I'm absolutely thrilled that the best and brightest come together and share their best practices. And that they're willing to incorporate new centers into that process, to help them elevate their game. So, I am thrilled that everyone is on the same page today in care centers, as it relates to diagnostic tools, treatment protocols, and continually re-evaluating best practices to

improve patient outcomes. But I don't think that we're there yet.

Dr Chakinala: I completely agree. And we always say that the PHCC is a work in progress. If I can just stay with you for one more minute, as a layperson, what does it mean to you when you hear a program or a center is "accredited"? Does that resonate with patients?

Ms Connor: For me, it does. I believe that it means people have gone through some kind of a review process to ensure that they meet a minimum threshold of care or quality. And so, I would think that the word accreditation does resonate with most patients.

Dr Chakinala: Rebecca, one of the issues that not infrequently comes up is that even though we built this network and promote PHCCs, some patients still can't get to the centers for various reasons. They have issues with access to care. Knowing that you have a lot of experience as social worker in the transplant and cystic fibrosis arenas, could you comment? And how have you tried to help patients who are unable to get to a center because of financial issues?

Ms Bathon: I want to kind of tag team that with what Traci and Colleen have said. I think the beauty of having care teams and developing that sense of expertise, when you introduce those to new patients, you start to build rapport and a continuous relationship. And that continuity really helps us think about what problem areas could be. Too many times, I think social workers in an institution or large hospital setting are called in when there's a crisis or when there's a problem. But in care centers like this, it's really nice to be able to have a relationship with a family or a patient before those problems come about. So, having longevity and knowing resources and anticipating that this might be an issue, like transportation or being able to just find childcare to come for an appointment, is something that those teams can work out. Through discussion between the physician, nurse coordinator, and the social worker, we can anticipate issues and apply what

resources are available in our area in a more proactive way.

Dr Chakinala: What about for that patient who hasn't yet even been to the center, and can't get there because perhaps their insurance won't allow them to go there? What are some ways patients might be able to overcome that "access to care" hurdle?

Ms Bathon: I think touching base with the social worker before they even come in the door is always good. Just to kind of anticipate what they think is going to happen. There are many, many times that I'm reaching out to all types of patients that come from many miles from our institution to talk logistics. And I think too many times, patients don't want to raise those issues with nurses and physicians because they feel that maybe it's something that might jeopardize them being seen by that particular physician. And if I'm offering assistance or talking about finances, I like to let families know that that can be very separate from care. If I need to assess their income to see if they might be eligible for a particular program, that's information that's really just between the patient and me. It isn't something that the team needs to know, specifically what their dollar amount household income is. But if I know it, I can figure out what programs they might be eligible for.

Dr Chakinala: Great, thank you. I'd like to shift gears a little bit and discuss some of the other key players at the PHCCs. We often remark that taking care of PH patients really "takes a village." Dave and Rana, could you comment about the other integral folks who you recruited to help address your patients' needs? I ask this from the standpoint of enlightening our patients, who may not realize all that's happening behind the scenes and also for aspiring centers.

Dr Badesch: So, I think that the most important component of the team by far actually is the nurses. We have a wonderful cadre of clinical nurses. We typically have between three and four clinical nurses. We also have two

nurse practitioners, who are critically important. Other essential members of the team include five clinical research coordinators, an administrative assistant, and a volunteer with the program. So those are the people that are immediately involved in the program.

What I think you were getting at, Murali, though, is that multidisciplinary team approach. We're a pulmonary-based program. Some programs are based in pulmonary medicine and others in cardiology. But we have very strong interactions with our cardiology colleagues, especially the cardiologists that work in the cath lab and those that run the congenital heart disease program. We also work closely with our interventional radiology team, in terms of intravenous access, as well as respiratory therapy, the pulmonary function lab, the lung transplant team, the liver transplant team, social work, pharmacy, and then case management. There are a variety of folks that play into this multidisciplinary team approach and that's extremely important. And I think the care centers program emphasizes the importance of that and actually requires it.

Dr Awdish: I'll just add a bit to that wonderful summary. We are also a pulmonary-based PH program, although we've become multidisciplinary in the sense that one of us is a heart failure-trained cardiologist who also did a critical care fellowship. So, she is in a way serving as our strongest link to the cardiac program. And I think what is implicit in everything you described is that having true allies in each of those departments, who understand the unique aspects of pulmonary hypertension, whether it's in the echo lab, in the cath lab, or whether it's the anesthesiologist who is called to intubate a PH patient, knowing how specific drugs affect our patients from a pharmacologic perspective. You need allies in every group. And having all of those pieces brings such better coordination of care for our PH patients, but so much of it can often be behind the scenes for patients, that they may not even realize it.

Dr Chakinala: I really like the term "allies," and maybe we can expand on it

a little more. I think what you're both hinting at is that we have a laundry list of things that we need to do in order to take care of PH patients, for example doing a VQ scan or a heart catheterization, etc. But we know, it's so much more than just a checklist of things. You have to interpret these diagnostic studies and manage situations in an informed way that is mindful of the PH diagnosis. So you may have excellent cardiologists and radiologists at your institution, but do they have really expertise in pulmonary hypertension?

Dr Awdish: Absolutely. I think there's so much that's a subtext of care that's hard to articulate. But just taking one example of a right heart cath, which is seemingly straightforward, you need the physician performing the procedure to be responding in real time, understanding the effects of volume on the RV, how nitric oxide testing is interpreted, who understands what the implications are if our patient comes in hypertensive or hypoxic, who understands how that will affect the results and how to mitigate that. We're only as good as the data that we get in. And our interpretation really relies so much on many of our consulting teams that they really have to become part of our core team and have PH as their mission, as well, or we can't make the right decisions for our patients.

Dr Chakinala: Very true. Now turning to, in my opinion, the most important person on the team. Not to sound sexist, but who I call the "Mom" of the team, and that's the coordinator. You can't have a well-functioning or successful PH center without that outstanding coordinator. Traci, could you talk a little bit about your role at your center? Dave already touched on a lot of things, but maybe you could expand?

Ms Stewart: Sure. I think the role of the coordinator is kind of the glue that holds everything together and makes sure that things don't fall through the cracks. I think patients are somewhat overwhelmed with all the different people, testing, and appointments, whether it's in the community or with specialists

in the PH center; sometimes patients just get lost and need some guidance. So, I feel like the nurse coordinator is the person that makes sure that whatever gets ordered at the provider level actually gets done and gets back to us and reviewed. We're always out looking for information from the community to pull back into the patient's chart, to help make sure that we have real, live, up-to-date clinical reports on what else is going on in the community, because patients have a lot of comorbid conditions that are also getting dealt with by other providers.

A lot of what I do from day to day is kind of balanced between *heart failure management* (such as taking phone calls from patients either dealing with fluid retention, worsening symptoms, and needing their medications titrated) and *managing medication side effects* by working with the provider and the patient to manage those things as an outpatient.

Another big portion of what I do is PH medication authorization. I know some centers have specific people that help with prior authorizations. But at our center, we haven't been as fortunate to have somebody take that on for us. So, a lot of time is spent filling out paperwork to get medications, get the prior authorizations in place, and then helping patients identify ways to access the medications if they have copay assistance issues. And many times, patients are on multiple PH medications. So, we are seeking renewals to avoid gaps in treatment while we assess adherence and barriers to taking PH medications, because we all know that's such an important piece of long-term survival.

Dr Chakinala: You brought up a sensitive and contemporary topic. And that is the challenges that we, as a community, face in acquiring and maintaining therapies because of financial hurdles and the challenges of health economics. I know my coordinators do a lot of what you just said, too. And in my opinion, that's one of the greatest benefits of receiving your care at a center, where there are dedicated and knowledgeable people working towards securing medication authorizations in a timely fashion. Traci or Rebecca, do you have any thoughts on that vital role

and some of the ways that you've really tried to help people, secure their meds?

Ms Stewart: Well, Rebecca, I can kind of speak to it from my perspective—and you can chime in. I think it changes day to day. And so being involved and having the ability to network through either Pulmonary Hypertension Association correspondence or through the Pulmonary Hypertension Professional Network is really a benefit to help patients. So I definitely would encourage nurses or any allied health professionals to be a part of those resources. I think just being accessible to our patients is a great relief for them. I often hear from my patients, who are dealing with other practices, that they will call the office and just not get an answer. So we really need to be accessible to our patients, to be able to guide them because sometimes resources can change daily and we can help them navigate the system. We get calls often from patients who don't have a computer or don't understand how to get through a phone tree to get the resources that they need. We can help patients identify programs that are available, and I think is a huge part of access to medicine.

Ms Bathon: I totally agree with you. And I'm working with the Pulmonary Hypertension Association on a project, just to make sure that we always constantly refine those resources. Making sure Web addresses are correct, making sure phone numbers are working, ensuring the health care providers are available—one day HealthWell may be open, the next day it may be closed. And we have to keep up on that and make sure that it's working for our patients. We also have to fully utilize health care options for each patient. Are they eligible for Medicare or Medicaid and do they have access to resources to help them decide? I think it's also using our critical thinking skills, to think about what might work or how we can be creative about some things or what have we not thought about. And networking with other care centers and other disciplines is useful.

Dr Chakinala: Great points from both of you. It is a scary time for our patients

and the centers are the lifeline for patients. And I think they find great solace in knowing there is somebody who's advocating for them.

So before we leave the various roles that key personnel play at centers, Rebecca, could you talk about the evolving role of palliative care? And I preface this by saying that mental health and mood disorders have been underappreciated in our community but are starting to get attention. Dave and his colleagues at University of Colorado have been leaders in helping us to appreciate this better.

Ms Bathon: Sure. We formally started palliative care at our institution about 10 years ago. And just as a consult service in our hospital, the services they provide have evolved significantly, even the growth of their team. I think, initially, many people associated palliative care with hospice, death, and dying. But now, in a lot of other disease populations, palliative care is involved early in the diagnosis and throughout someone's course. And the reason is to also have a focus on symptom management. Not just saying we're going to stop treating a disease and manage your pain or your discomfort, but we're going to do that, in addition to prescribing medications that can help stabilize where you are in the spectrum. I like to talk to patients and approach that as a consult service, such as we would have a renal service see them or we would have a gynecology service see them. We're not talking necessarily about stopping your care or putting you into hospice.

Regarding mental health, I think that's something that still has a significant stigma in our society and is a very difficult pathway to negotiate. And, we also struggle so much to find psychiatrists and to find people that can provide mental health services that 1) take patients' insurance, but 2) really have developed an expertise in chronic illness such as pulmonary hypertension or cystic fibrosis or whatever we're addressing. And I always tell patients that finding a good therapist is like finding the right pair of jeans. You may have to try on a few before you find what works. That seems a little odd in a method of

approach in health care, but it really is true. And sometimes when we find really good providers in our community, it's continuing to educate them and teach them about the disease that we're talking about, so they can be up to speed and up to par with their own knowledge and in their work with any patients that we're referring to them.

Dr Chakinala: And to harken back to what we said earlier about having an expert cath person or radiologist, I think we would serve our patients best if we forge relationships with one or two mental health experts that we can really call upon on a consistent basis, because our patients have some unique challenges.

We've talked about all the benefits of being an accredited center, and there are many, but to be balanced, I want to ask the panel about the challenges to being an accredited center and having that label of being a PHCC?

Dr Awdish: I'm happy to start. I think one of the challenges was just the time investment in the initial process. Inevitably that takes time away from other clinical obligations and research commitments and you try to work it around patient care. I would advise people who are considering going down this road to really look carefully at how to delegate tasks in terms of what's required for the process. And really take a good, close look at the requirements for accreditation to understand where your blind spots may be. I think that was a learning process for us: the way that we'd set up our database of patients just wasn't as functional as it needed to be for the process and we had to redo that. So, to lessen the challenges, consider reaching out to people who've been through it, and learn from their experiences, so that you can streamline it for yourselves.

Dr Chakinala: So in our last few minutes, I want to turn our focus on the future. How do you think the PHCC program can benefit new and up-and-coming programs? And what would you say to convince them to pursue accreditation?

Dr Awdish: So I think there's tremendous value in pursuing accreditation, in the sense that it really does hold you accountable to ensure that all of the components of a really well-rounded program are in place. It's an opportunity to network with your colleagues and find out how directors at other centers are navigating safety protocols in the hospital; how they're succeeding with insurance authorizations. We didn't realize how unique we were in having a prior authorization specialist. They handle all of that and I think that was something that the PHA got to take back and look at whether that was a resource that could be centralized. So, it comes down to, I think, sharing of resources, in illuminating what's possible, and really improving the standard for everybody.

Dr Badesch: I would agree. I think it's a learning experience and an opportunity to learn best practices and how things are done across the country. And so, participating in the accreditation program was I think a highly favorable experience for a site. Really helps you to get organized, think about how you're doing things, formalize some of the collaborations that you have, and supporting relationships with supporting services and whatnot. There are many positive things about going through the review process and participating.

Dr Chakinala: Traci, anything you want to add, especially for those young coordinators that are just getting started?

Ms Stewart: Well, I agree with what's been said already. It does, it takes a lot of time, but it is so important to help identify resources and get organized. I think that was one of the things that I had been here a long time and I had different supporting documents in different folders, in different departments. Just pulling all that together into one area so that it was much more accessible when needed.

I also think it's a great opportunity for "asks"; it helps identify places where you may be short on resources and to be able to have that feedback in writing from the review committee that, for example, maybe you could benefit from more

clerical support or nursing, is concrete documentation you can provide to administrators. It's a great opportunity to kind of re-evaluate where your strengths and weaknesses are and how to network with other people that are really in the same boat.

Dr Chakinala: Colleen, if you were meeting a patient, someone who was diagnosed with PH but hadn't been to a center and doesn't really understand why they should go to a center, what would be your reasoning or rationale for going to a center?

Ms Connor: Sure. I do always encourage patients to seek out PH care centers. Because I share with them that those people have done a kind of a peer-to-peer review. And that they're going to be the most competent and capable people in making sure that they have an accurate diagnosis. Also, they are going to be very knowledgeable and licensed to initiate even the most invasive therapies, if required. I encourage them to work with people who are truly interested in striving for excellence and stress that it's going to help them have a better outcome. I give them the example of a friend who has yet to go through the proper diagnostic testing and could be on the wrong medicine. Unfortunately, I've had another friend who passed as I was trying to convince him to go to a care center. His doctor had convinced him that they knew enough. But they did share with him that they were employing the "phone-a-friend" methodology of determining a treatment plan. And my friend passed away before he ever had access to the most advanced therapies. That broke my heart, so I'm very passionate about making sure that all patients know about the existence of care centers and they understand what the value is.

Dr Chakinala: And I think patients are our greatest ambassadors because who would you trust more than another patient who's gone through the same ordeal? So we appreciate efforts like yours and certainly that includes PHA support group leaders around the country, who promote center-based care.

My last question is addressed to the entire panel: what are your hopes for the PHCC and the PHAR in the future?

Dr Badesch: Sure. I think a network of people truly focused on providing the very best diagnostic and therapeutic care available. And a resource for research, I think, perhaps networking about clinical trials. So, helping to contribute to the development of new therapies. An educational network to sort of share best practices across centers. I think there's a huge opportunity for quality improvement projects, based on the PHAR registry. I think those are probably the areas that I see for kind of future development of growth with the care centers.

Dr Awdish: I think to be completely aspirational, what we all hope for is a cure. And honestly, with the registry and with the aggregation of clinical trials at these sites, that's not something that's out of reach. And certainly, refining our treatment in the meantime is a very valuable goal. I think also we have to be policy-minded and present a united front, in terms of lobbying against some of the changes that are happening in health care that are detrimental to our patients who have chronic diseases and the barriers that insurance can provide sometimes. And finally, by having a network of support for not only the clinicians, but for the patients, that everyone will find the resources that they need and we will elevate best practices.

Ms Bathon: I completely agree with that. I think it also creates a sense of empowerment when you start networking and learning from your colleagues.

Even myself as a social worker, being able to talk to other social workers who do the same work that I do and sharing resources and then knowing that some of the issues or the problems are across the board and how can we collectively have a voice and have more power than just me, isolated in a small city, reaching out to people that change policy or create health care policy.

Dr Chakinala: Really strengthening the community at multiple levels. Traci?

Ms Stewart: I would go back to what Colleen said, when you asked her about patients' really knowing more about this being an opportunity for them. I really feel like maybe because I live in a rural area that's predominantly elderly people, I think we have a lot of opportunity to increase awareness in the PH community and for patients to really know that there are experts in this area and that this is a challenging disease state. Sometimes travel is difficult to get to centers, but as more centers become available, hopefully patients will have better access to guideline-driven care.

Dr Chakinala: And lastly, Colleen.

Ms Connor: My hope for the future is that patients all become aware of these two incredible initiatives. Also that the community physicians who are treating PH who are not yet fully equipped determine that they need to come on board and meet minimum requirements of knowledge to be treating these patients and commit to upscaling themselves, so that they can promote best outcomes.

As a patient, I just want to quickly say, too, that I am so inspired by the willingness and the dedication of you all and the PH experts across the United States who continually strive for excellence. I think that all of you who open yourselves up to knowledge sharing and enable yourselves to be somewhat vulnerable in letting people review your processes, programs, etc. You have a deep inner wisdom and humility, and we're just so indebted that you voluntarily participate and do what you can to increase PH patients' chances of survival.

Dr Awdish: Colleen, thanks for those kind words.

Ms Stewart: Yes, thank you. That is a great way to wrap it up.

Dr Chakinala: Collen, as indebted as you are to us, we'd be remiss if we did not say how indebted we are to our patients. All of us went into medicine and health care to help others and to intellectually stimulate our minds. But when we can devote our time and interest to a worthy cause like PH and see our patients battle their disease and succeed towards meeting their individual goals, it makes our profession and our day-to-day responsibilities so much more worthwhile and rewarding. We are truly grateful and honored for the trust that our patients bestow in us.

I was really thrilled by all the perspectives that were shared today. Even though we had a diverse and unique panel, we still heard many recurring themes and an overarching singular focus that our community thrives upon. Thanks again for a lively discussion!