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

Delays in PAH Patient Referral: How Do We Overcome Them?

Dr. Elwing:
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.