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How Do Patient Experiences and PAH Perspectives Vary Across Regions and Cultures Worldwide?

Announcer:

Welcome to CME on ReachMD. This activity is provided by Total CME, LLC. This episode is part of our MinuteCE curriculum.

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Dr. Ford:

This is CME on ReachMD, and I'm Dr. Jimmy Ford. I'd like to talk about how patients' experiences with pulmonary arterial hypertension care can vary considerably across the world. This includes significant differential access to proper diagnostic tools, medications, and expert PAH providers, particularly in the context of an accredited pulmonary hypertension care center.

The 7th World Symposium on Pulmonary Hypertension task force on patient perspectives surveyed providers and patients throughout the world and found that access to right heart catheterization is effectively absent in many regions of the world. As you might imagine, this precludes even the ability to diagnose the disease in the first place and properly characterize it clinically.

Similarly, access to medications for PAH is very limited in certain regions. Providers with expertise in pulmonary hypertension may be located many hours or miles away from patients in certain areas, with some patients reporting travel times of 4 to 5 hours one way to reach a PAH center.

A large survey of pulmonary hypertension patients and providers and their proxies—called the Pulmonary Hypertension Global Survey—was recently completed. In this survey, over 3,000 patients or proxies from 88 unique countries reported on their experiences of care, diagnosis, and treatment for pulmonary hypertension. Some of the more striking findings include very low rates of the utilization of genetic testing, participation in clinical trials or even access to clinical trials, and also the number of patients having filled out a patient-reported outcome measure, or PROM, tool—only approximately 20% of patients for each of these queries.

The way healthcare delivery is structured and funded in different regions of the world will also lead to variations in how different social determinants of health—such as poverty, education level, and the built environment—affect outcomes for PAH patients.

These social determinants of health can be differential and impact not only in regions that are challenged in terms of financial and healthcare access. Even within more developed regions of the world, disparities continue to exist, both in rural and urban areas. Race and ethnicity have also been noted to play a role in disparities in PAH disease course. The effects of pollution and climate change also differ throughout the world and have negative effects on patients with cardiopulmonary diseases like PAH.

In addition, the culture of healthcare delivery in some countries may hamper the robust use of a shared decision-making approach, wherein the patient is simply prescribed treatments without input in their selection. Global health access disparities are a big problem for common diseases, so it is easy to see how the problems are even more pronounced for a rare disease like PAH.

Looking toward solutions to improve underserved areas, some initiatives that have been carried out on a small scale on the African continent include on-site training and tools for right heart catheterization from centers in the US, Asia, and South Africa to clinics in

Uganda and Zambia. Continued development of such collaborations will be key in working to improve access to diagnosis and medications across the world.

Continued efforts must be made to improve access to PAH diagnosis—particularly the right heart catheterization—medications, and access to expert providers. Multiple stakeholders will be important in this endeavor, but collaboration between countries, governmental and nongovernmental organizations, and the healthcare industry is critical.

Thank you for tuning in today, and I hope you found this information insightful.

Announcer:

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