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Patient-Reported Outcome Measures (PROMs): Valuable Insights Into the Lived Experience of PAH

Announcer:

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Dr. DuBrock:

Good morning. This is CME on ReachMD and I'm Dr. Hilary DuBrock. Today, we are going to discuss patient-reported outcome measures, or PROMs, in pulmonary arterial hypertension.

Pulmonary hypertension is associated with significant symptoms like shortness of breath, fatigue, edema, and syncope, and these symptoms contribute to impairment in health-related quality of life or overall well-being. In fact, studies have shown that pulmonary arterial hypertension negatively impacts physical, social, and emotional aspects of quality of life. And beyond that, impaired health-related quality of life in pulmonary arterial hypertension is associated with things like increased hospitalizations and worse survival.

So hopefully I've convinced you that health-related quality of life is important, but how do we measure it? Well, we can measure quality of life using PROMs. A PROM is any measurement of a patient's health status that's directly elicited from the patient. It's often a questionnaire that includes questions related to symptoms and the impact of a disease. PROMs may be associated with outcomes like functional class and 6-minute walk distance, but it can't be extrapolated from a test result. You need to actually ask the patient.

Fortunately, there are several generic as well as disease-specific PROMS in pulmonary hypertension that we can use in the setting of PAH and that have been well studied and validated. We'll talk about those in more detail in Episode 6.

As a testament to the value of the patient's perspective in pulmonary hypertension, the 6th and the 7th World Symposium on Pulmonary Hypertension had an entire task force dedicated to the patient perspective. The task force included both clinicians, as well as patients with pulmonary hypertension, and suggested routine use of these PROMs in clinical practice in order to facilitate communication and to guide shared decision-making.

PROMs allow us to capture the patient perspective directly from the patient in a systematic way. One of our goals of pulmonary hypertension therapy is to improve a patient's quality of life, but we can't know if we're achieving that goal unless we ask the patient and we assess PROs at our clinic visit. Notably, our PAH therapies are very effective in improving hemodynamics and functional class and 6-minute walk distance and clinical worsening, but they can also be associated with significant side effects that might negatively impact a patient's quality of life.

So our medications only target the tip of the iceberg and often don't address things like the cognitive and the emotional aspects of the disease, such as depression, anxiety, worry, or frustration, or multidimensional aspects of pulmonary hypertension related to things like employment or finances and the impact of that on both patients and their caregivers. There's so much beneath the surface that we don't know about unless we ask.

I think we need to shift the paradigm in pulmonary hypertension from a disease-centered care that defines patients by their disease classification and their hemodynamic phenotypes and sort them into rigid kind of one-size-fits-all treatment pathways to more patient-centered personalized care approaches that treats patients as individuals and really relies on a strong clinician-patient relationship built on trust, as well as shared decision-making. In order to do that, we need to give patients a voice in their treatment and their management. And we know from studies that assessing PROMs in clinical practice, that it's both feasible and valuable and can provide prognostic value beyond traditional risk stratification.

Speaking from experience, assessing PROMs in clinical practice can also be very eye-opening, so we looked at incorporating PAH-SYMPACT, one of the PAH disease-specific problems, into our clinic visits and found that it was fairly easy to do and provided really important information for our management of patients. And patients also expressed support for incorporating PROMs into clinical practice, really recognizing it as validation of the importance placed on their quality of life.

So what are some barriers to us using PROMs in clinical practice? I think the major challenge with incorporating PROMs is the time required to complete them. The integration of PROMs into the electronic health record and automation of PROMs as electronic surveys can help to overcome some of these barriers. Aligned with this, the 7th World Symposium task force recommended capturing PROMs at least once a year for patients and also suggested that electronic PROMs could improve convenience of data collection.

So why is it important to use PROMs in clinical practice? Well, some disease as well as treatment effects are only known to the patients, the person who's living with the disease day in and day out. And systematic assessment of the patient perspective using PROMs provides valuable information. Use of PROMs can also improve communication in shared decision-making to facilitate more personalized patient-centered care.

Thank you for your attention. I hope this information will be useful in your clinical practice.

Announcer:
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