

Keeping the Patient at the Forefront

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The Institute of Medicine (IOM) monograph titled, *Crossing the Quality Chasm: A New Health System for the 21st Century*, recognized the importance of communication in health care. The report identified patient-centered care, described as “care that is respectful of and responsive to individual patient preferences, needs, values, and ensuring that patient’s values guide all clinical decisions,” as one of the 6 dimensions that define quality in health care.¹ Through active listening, empathy, and negotiating the health care provider contributes to patient-centered care.

Patient-centered care is essential to providing excellent treatment to patients diagnosed with pulmonary arterial hypertension (PAH). When initiating a new therapy or transitioning from one therapy to another, PAH patients often experience a spectrum of emotions (ranging from fear to excitement) and develop specific expectations about how the therapy will improve their quality of life. Given the number of new therapies recently available, it is essential that health care providers are aware of patient expectations. Both new and established patients have been anxiously awaiting the approval of the new therapies, namely oral treprostinil, riociguat, and macitentan. For many patients there is a hope that one of these drugs will be the

“magic bullet,” perhaps allowing them to transition from a continuous pump therapy to an oral formulation. When conducting conversations with patients regarding initiation of a therapy or a transition, the health care provider should incorporate patient-centered care through establishment of collaborative decision making. To accomplish that, providers are encouraged to do the following:

- Ask the patient open-ended questions related to expectations.
 - For example: “Can you tell me about the hopes you have about starting this medication?” “What are your expectations related to this therapy?” “What goals do you have related to treatment for your PAH?”
- Tailor the conversation to include the expectations.
- Establish a clear functional baseline before initiating a therapy or transitioning from one therapy to another.
 - For example: “Can you tell me how long you can walk without having to take a break to catch your breath?”
- Communicate with the patient frequently as the transition is occurring.
- Establish a protocol with a specialty

pharmacy in terms of the practices expected during transition.

▪ *Specialty pharmacy providers are exposed to many different approaches to treatment. It is essential to have a conversation with your specialty pharmacy provider to make sure that your approach to drug initiation and titration is followed.*

- Communicate with the patient regarding the possibility that if their function deteriorates, he/she may have to return to the prior therapy.
- Discuss expected side effects as well as potential adverse reactions.
- Communicate the importance of required monitoring.
- Discuss when the patient should expect to experience a response to the medication.

Incorporation of these elements during conversations with PAH patients will help to ensure an emphasis on patient-centered care, as well as a better understanding of patients’ goals, fears, and expectations. With this knowledge, health care providers will have the ability to create a collaborative approach to patient care.

Reference

1. Institute of Medicine (IOM). *Crossing the Quality Chasm: A New Health System for the 21st Century*. Washington, DC: National Academy Press; 2001.

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