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The PERSIST Study: A Phase IV Qualitative Research Analysis Evaluating Practices Associated With High PAH Medication Persistence Rates

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Background: Inadequate adherence and lack of persistence to prescribed medication regimens for various diseases result in increased risk of morbidity and mortality, as well as increased healthcare costs. The World Health Organization (WHO) report on compliance with long-term therapies reports 50% adherence to drugs prescribed for chronic diseases. Currently, there is limited data evaluating PAH medication persistence and adherence in the United States from both the clinician and patient perspectives. Prospective registry data of pulmonary arterial hypertension patients shows a 23.4% overall discontinuation rate for macitentan and a 14.4% discontinuation rate for selexipag due to adverse events.

Methods: PERSIST (Practices Effecting Opsumit and Uptravi patient persistence Rates utilizing the PH clinical Site and patIent perSpecTives) is an ongoing, two-part, Phase IV qualitative analysis of data obtained from PH clinical sites (Part A) and patients with PAH (Part B) using Institutional Review Board-approved survey assessment tools. Part A includes PH clinical sites (N=40) with high and low specialty pharmacy shipment persistence rates with ≥20 patients receiving macitentan or selexipag. Persistence is defined as currently receiving macitentan for ≥3 months or currently on a maintenance dose of selexipag for ≥1 month. High- and low-persistence sites are defined as those with ≥80% and ≤40% persistence, respectively, at 12 months. Both PHA accredited and non-accredited sites are eligible. Survey interviews (one for each treatment) are completed by the healthcare professional who discusses medication education and adherence/persistence with patients at each site. In Part B, patients with PAH (N=200) are eligible if they have been persistent with or discontinued macitentan and/or selexipag therapy within the previous two years. Participating patients will be invited to complete an electronic or mailed survey. For Part A, qualitative thematic and content analysis will be performed to identify practices associated mainly with high-persistence sites. For Part B, patient-cited reasons for continuing/discontinuing medication will be evaluated. Responses from Parts A and B will also be compared to identify any disconnect between clinical site and patient perspectives.

Results: Survey response collection is scheduled to complete in August 2019.

Conclusions: The identification and implementation of optimal patient education, clinic availability, and patient–clinician communication strategies may improve rates of adherence and persistence for PAH-specific treatments macitentan and selexipag.

Figure 1

Macitentan Survey			Selexipag Survey		
Part A					
PH Clinical Sites n=20	High persistence	n=5	PH Clinical Site n=20	High Persistence	n=5
	Low Persistence	n=5		Low Persistence	n=5
	PHA Accredited	n=5		PHA Accredited	n=5
	Non-Accredited	n=5		Non-Accredited	n=5
Part B					
Patients with PAH n=100	Persistent	n=50	Patients with PAH n=100	Persistent	n=50
	Discontinued	n=50		Discontinued	n=50

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