Monitoring and Peer Support to Improve Treatment Adherence and Outcomes in Patients with Overlap Chronic Obstructive Pulmonary Disease and Sleep Apnea via a Large PCORnet Collaboration (O2VERLAP)

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Project Aims

O2VERLAP study specific aims:

- Aim 1... Focus groups were conducted to determine barriers to O2 and CPAP use in the overlap syndrome (OS) patient population. This information has been used to guide the patient centeredness of the overall project; it helped the study team refine the studies primary aim to focus on CPAP adherence alone. Additionally, participants provided feedback on how we might improve the patient-centeredness of the study intervention (i.e. curriculum topics etc.).

- Aim 2... The study will compare the effectiveness of a proactive care intervention (web-based, peer-support and education) to reactive care, on improving continuous positive airway pressure (CPAP) adherence, in individuals living with OS.

- Aim 3... Contribute educational resources to the PCORnet commons, including: emerging research methodologies, educational webinars and methods for dissemination.

How does your project benefit from using PCORnet infrastructure and resources?

The study leverages the PCORnet common data model, as well as resources that have helped in the guidance of the projects evaluation and engagement.

How does your project benefit the further development of PCORnet?

- Documenting best practices for governance structures for a multi-network collaboration in research; including multiple Patient-Powered Research Networks (PPRNs) and one Clinical Data Research Network (CDRN)

- Creating and operationalizing methods of study promotion within PCORnet

- Providing a model for a dyadic, peer-based, behavioral intervention

- Engaging and training patients in the research process

- Developing models for patient engagement through robust social media networks

- Engaging DMEs and other providers PAP and other medical services

- Creating and operationalizing methods for study dissemination within PCORnet

Methods

How is PCORnet being utilized to advance this project?

The study is leveraging its PCORnet collaborators to aid in study promotion, patient engagement and ultimately dissemination.

How does your project reflect research done differently?

Patient advocates and the overlap syndrome community have significantly guided both the study design and intervention itself.

How does your project reflect research done differently (continued)?

The O2VERLAP projects, dyadic, peer-based intervention has been shaped by information collected by engaging the overlap syndrome community in focus groups as well as online, via social media. Information gathered helped better inform the primary outcome for our study, helped better incorporate psychosocial outcomes measurements and confirmed that the eligibility criteria would allow representation of a significant portion of the current overlap syndrome community.

PCORnet Collaborators...
PRIDEnet PPRN, COPD PPRN, ABOUT PPRN, Health eHeart PPRN, PI connect PPRN and pSCANNER CDRN.

Objectives

Why is this project important?
The overlap syndrome (OS) patient population is poorly studied. This study hopes to provide an effective, patient-informed, peer-based intervention, focused on improving patient-centered outcomes in this community. If successful, the study will provide a method for improving OS patient CPAP adherence, which is shown to significantly reduce morbidity and mortality in this population.

Why is this project important (continued)?

Most importantly, the study hopes to provide an effective patient-informed model for creating an online, peer-based intervention, focused on improving patient-centered outcomes in a chronic illness.

How is it "people-centered"?

The study is people-centered by including diverse patient representation on both the study executive committee and stakeholder advisory board. Additionally, the studies primary aim, overall design, outcomes and educational content have been significantly guided by overlap syndrome community engagement and feedback.

Describe the role patients play in forming the research question/objectives.

The research question and objectives were determined by engaging the overlap syndrome community in a series of focus groups and online surveys via social media.

Progress

What is your progress so far?

The study will begin recruitment in November of 2017.

What do you expect to find?

Hypothesis 1: CPAP adherence in 6 weeks will be improved in the proactive care group compared to the reactive care group.

Hypothesis 2: The improvement in the sleep quality, symptoms and patient-centered outcomes at 6 weeks and 12 weeks will be greater in the proactive care group compared to the reactive group.

DISCLOSURES
There are no disclosures to be named at this time.

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