

MONTHLY Feature

Innovations for Home Assisted Ventilation



Thanks to advances in clinical care and technology, many patients with neuromuscular disease who need respiratory support can avoid tracheostomy and live at home. Jason T. Ackrivo, MD, MSCE, a pulmonary and critical care physician and associate director of the Randy and Jay Fishman Program for Home Assisted Ventilation in the Perelman School of Medicine at the University of Pennsylvania, oversees an initiative to track respiratory output and other important data for these patients via telemonitoring. This is just one of the initiatives at Penn's home assisted ventilation program, which is at the forefront of innovating ways to improve care for these patients.

Key data

Many people with neuromuscular disease who use respiratory support at home depend on their ventilators for quality of life or for sustaining life. According to Dr. Ackrivo, monitoring ventilator data is an important part of managing their pulmonary care.

Telemonitoring for ventilators only became possible within the last decade, as home ventilator technology became more advanced. Some machines began capturing data on small hard drives or SD cards. "When they come in for a clinic visit, you can pull the card or plug in a USB device and download the last three months of data that way," Dr. Ackrivo says. "You can imagine that's

problematic, because you don't have the data until they actually come in."

Some ventilators now have the capability to capture data — settings, time used, and dynamic parameters, such as respiratory rate — one or more times a day and send that data to a cloud-based server, where Dr. Ackrivo and his team can access it.

"I can view a patient's ventilator data from as recently as the last 24 hours to as long ago as I want, and I can get averages and percentages," he says. "If a patient calls me, and they're having issues, it allows me to troubleshoot what's actually going on."

With telemonitoring, Dr. Ackrivo sees key information that helps him care for his patients in near real time. One of the most common issues he catches is leak (air escaping into the room) due to a mask that does not fit properly.

"That's something that we can easily identify from the data," he says. But patients often don't know why their ventilator doesn't seem to be working. "You can imagine a patient may call up and say, 'I'm not comfortable,' and you play with the ventilator settings — but it's not the ventilator that's the problem; it's actually the mask. You would have no idea until they showed up for their visit."

Ventilator data also can help Dr. Ackrivo and his team see if ventilator settings need to be adjusted. In some cases, they might notice a patient isn't using their ventilator as often as expected. "Then we would call them and maybe start troubleshooting rather than waiting for their appointment four months from now," he says. "Telemonitoring has allowed us to proactively address issues."

A new standard

Telemonitoring for ventilators currently is not a common practice in the United States. Dr. Ackrivo, along with John Hansen-Flaschen, MD, director of the home assisted ventilation program at Penn, is helping to spread the word. Recently, they were invited to write a

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focused review on their experience with telemonitoring for ventilators for the Annals of the American Thoracic Society.

Barriers to implementing ventilator telemonitoring include devices or durable medical equipment companies that don't support sharing data with a cloud-based server and patients who don't have reliable WiFi or mobile internet service to allow data transmission. In addition, the various ventilator manufacturers that do support data sharing each have their own proprietary programs, requiring physicians and staff members to learn how to access data through multiple systems.

Despite the challenges, Dr. Ackrivo believes ventilator telemonitoring, which has been studied and put into practice more widely in Europe, will become common across the country. "For us it's the standard, and it should eventually be the standard," he says.

Other areas of interest

In addition to providing clinical care, Dr. Ackrivo studies respiratory failure and ALS with the goal of improving respiratory care for patients who need home assisted ventilation. Currently, he is developing a longitudinal ALS cohort study involving three centers in Philadelphia: Penn, Temple University, and Thomas Jefferson. He hopes to validate a prediction model that has been published, as well as to continue to identify respiratory phenotypes and collect data, including subjective data from interviews with patients throughout the course of their disease about their respiratory care.

In addition, Dr. Ackrivo is collaborating with the Children's Hospital of Philadelphia (CHOP) Technology Dependence Center/Home Ventilation Program on transitioning patients who need respiratory support from pediatric care to an adult program. "It's been a lot of studying the behind-the-scenes work that goes into the transition," Dr. Ackrivo says. Dr. Ackrivo and his collaborators at CHOP involve social workers and various other subspecialties to help get the patient and family ready, and they've found ways to smooth out the process. "We've now transitioned 45 patients," he says.