Telemedicine Explored for People with ALS in Rural Areas

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Host: ALS Association Chief Scientist Lucie Bruijn, Ph.D.
Guest Speaker: Ed Kasarskis, M.D., Ph. D.

By Richard Robinson

The best ALS care comes from the multidisciplinary team at an ALS specialty clinic, but these clinics are typically found in urban areas, associated with large research universities. Travel can be a burden for many people with ALS. “How do you connect ALS patients in rural environments to multidisciplinary centers for optimal care?” asked Ed Kasarskis, M.D., Ph.D., in a recent webinar sponsored by The ALS Association. Dr. Kasarskis is the Medical Director of the ALS Center at the University of Kentucky in Lexington.

Dr. Kasarskis is currently studying the potential of telemedicine to improve clinical management of people with ALS, a project funded by The ALS Association. In addition, he has led the effort to establish a national registry of veterans with ALS.

Care in a multidisciplinary center is recommended by the American Academy of Neurology, based on a review of the medical literature showing improved survival. A likely benefit contributing to the increased survival is that “therapists are anticipating problems before they occur,” said Dr. Kasarskis.

The goal of telemedicine is to bring high-quality care closer to the person who needs it. Telemedicine is in use in several medical specialty areas, including acute stroke diagnosis; however, the chronic, multi-skilled care needed by a person with ALS presents a challenge.

Several care delivery models have been tried. Having the neurologist from the clinic travel to a rural hospital “is not a good option,” Dr. Kasarskis said, since he or she will not be familiar with the local resources needed to make good use of the facility, such as therapists and equipment.

An alternative is for the clinic team to “visit” the person with ALS at the local hospital, without involving the local care team, using video teleconferencing. “The jury is still out on whether this approach can work,” he said. Directly communicating with the person with ALS at their home is also not practical, except perhaps to check in or to respond to a crisis. “But this would not be sustainable for effective care.”

The model his team is testing is to establish satellite ALS centers in rural locations with an on-site neurologist and care team, which communicates with the expert team via video teleconferencing while the ALS patient is in the room. Local therapists also attend training sessions at the multidisciplinary clinic.
“The key to success is the regional therapists,” whether in speech, nutrition, respiratory therapy, or physical therapy. “Developing their expertise is the key.” As time has gone on, they have required less input from the expert team. The success of the program has meant hundreds of fewer miles driven and many hours saved by people with the disease, since they are visiting a center much closer to their home.

“There are many models for delivering care to remote locations, and I don’t think we are going to find one model for every circumstance,” Dr. Kasarskis said. “Our success has been due to having an enthusiastic partner in the local clinic.” Operating in the same state has also been important, for issues of licensing and insurance. Whether this model can be sustained financially is still being tested.

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