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## Letter to the Editor

## Modification of non-invasive ventilation for the advanced amyotrophic lateral sclerosis patient during the COVID-19 pandemic - do it now



## ARTICLE INFO

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The ALS patient with respiratory insufficiency who is on home non-invasive ventilation is at high risk for COVID-19 complications. It is the ALS neurologist's task to alert patients and families about this risk and potential adaptations for patient and caregiver safety.

The current knowledgebase includes 1) a detailed advisory from the American College of Chest Physicians (ACCP), on managing patients with neuromuscular disease who are suspected to have or have already been diagnosed with COVID-19 [1] and 2) the Muscular Dystrophy Association guidelines for breathing support written by experts in the field of ALS Neurology and Respiratory Medicine [2].

An ALS patient's infection with COVID-19 may not appear in symptoms associated with recent diagnostic algorithms. Current algorithms include clinical signs and symptoms providing evidence for COVID-19 infection. A recently published case series of 214 hospitalized coronavirus patients in Wuhan, China, identified more than a third of patients had non-specific symptoms including headache, dizziness, anorexia and diarrhea, and neurological symptoms such as loss of taste, hearing, and vision; confusion or a decreased level of consciousness; or a new seizure or cerebrovascular accident [3]. Such information further reduces the threshold for suspecting COVID-19 infection and raises safety concerns for the ALS patient – caregiver dyad.

Among patients who test positive for COVID-19 based on real-time Polymerase Chain Reaction (RT-PCR) assay from nasopharyngeal swabs, the rate of transmission of COVID-19 to household contacts, specifically spouses, was found to be 27.8% [4]. When treating ALS patients in the home environment, the potential for generating infectious aerosols should be a primary concern. Viral particles from an ALS patient may be dispersed when using airway clearance devices during respiratory treatment, nebulization, suctioning, and use of cough assist. When using non-invasive ventilation, the spread of viral particles occurs due to wearing vented masks or poorly fitting full-face masks. Particles are also spread through CO<sub>2</sub> exhalation ports [1]. For the advanced ALS patient dependent on a home non-invasive ventilator, equipment modifications may reduce virus transmission and the infection of caregivers.

The non-invasive ventilator modifications recommended by the ACCP convert the tubing and mask circuitry to a closed system by using both a double lumen tube with a viral/bacterial filter and a non-vented full-face mask to restrict viral spread [1,5]. This conversion is

performed in three steps and is overseen by the ALS Neurologist or the ALS Pulmonologist. First, a respiratory therapist must set-up a new ventilator or revise an existing one. Second, the respiratory therapist titrates equipment settings to the patient's comfort. Finally, the respiratory therapist instructs the patient and family in the use of the new or modified equipment, including providing instruction in sterile precautions. Please note that these modifications during a pandemic, when medical resources become low, may not be easily feasible due to a lack of personnel or medical and protective equipment. Ventilator equipment adapters may be in short supply. Furthermore, patients that do not tolerate a non-vented mask will require sealing the vent ports on their existing mask. Caution must be taken when modifying/sealing existing vented masks as they contain an anti-asphyxia valve that MUST be removed or disabled or risk asphyxia in the event of a machine malfunction.[6]. A further limit to feasibility may occur when patients or the patient's family may bar medical personnel from the home out of concern for increasing their risk of exposure to infection.

Despite all precautionary measures to prevent infection, an ALS patient may succumb to COVID-19. Due to severe underlying illness, hospitalization may be recommended. The need for an advocate to assist an ALS patient requiring hospital admission is indicated by state of quadriplegia, loss of speaking abilities and cognitive impairment. These medical needs must be anticipated well in advance and require equipment preparation prior to hospitalization.

Another factor merits attention and may increase the desire of the ALS patient to choose home rather than hospital care. Some healthcare systems provide Virtual Hospital management that employs active home telemonitoring devices to treat COVID-19 patients [7]. For the advanced ALS patient that may require hospitalization, a no-visitor hospital policy may affect the patient's decision to ensure that end-of-life care happens at home surrounded by family. In such a situation it is important to have input from palliative or hospice care to provide the appropriate end-of-life treatment options.

To minimize the potential for increased COVID-19 infection and spread in the ALS patient using non-invasive ventilation - caregiver dyad, we endorse the ACCP / MDA recommendations and recommend immediate modification of non-invasive ventilators well in advance of the anticipated COVID-19 surge. The current estimates predict a drawn-out lower than anticipated, but higher than expected, continued

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exposure to community-acquired COVID-19 infection.

This strategy may not be immediately feasible. Equipment resources may be low or unavailable, as acute care hospitals require the same ventilators modified for prevention of aerosol generation to prevent exposure of healthcare workers. As equipment becomes more easily available, the recommended modifications may be fully implemented. The ALS ambulatory care COVID-19 pandemic model is one that minimizes the risk of aerosol infection of caregivers and healthcare workers Ventilator equipment modification should be pursued in all ALS patients supported by non-invasive ventilation. Successful implementation is essential in resuming in-person care and will shape the face-to-face ALS clinics of the future.

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### References

- [1] M. Cao, S. Katz, L. Wolfe, Care Recommendations for the Home-Based Ventilation Patient Undergoing Therapy for Known or Suspected Respiratory Viral Infection with COVID-19, CHEST Home-Based Mechanical Ventilation and Neuromuscular Disease NetWork, American College of Chest Physicians, 2020, <https://www.chestnet.org/Guidelines-and-Resources/Resources/CHEST-Novel-Coronavirus-Resources> (web archive link, 02 May 2020) accessed 05/02/2020 <https://foundation.chestnet.org/patient-education-resources/> (accessed 05/02/2020).
- [2] M. Cao, S. Katz, E.S. Greene, E.M. Davis, A. Verma, J.W. Day, L. Wolfe, Pulmonary Support for Neuromuscular Disease Patients During COVID19 Pandemic, Muscular Dystrophy Association, 2020, <https://www.mda.org/sites/default/files/2020/03/MDA-Guidelines-for-Healthcare-Pros-Pulmonary-Support-Neuromuscular-Disease-Patients-COVID-19.pdf> (accessed 05/02/2020).
- [3] L. Mao, H. Jin, M. Wang, et al., Neurologic Manifestations of Hospitalized Patients With Coronavirus Disease 2019 in Wuhan, China, published online ahead of print, 2020 Apr 10 *JAMA Neurol*, <https://doi.org/10.1001/jamaneurol.2020.1127>, (2020).
- [4] W. Li, B. Zhang, J. Lu, et al., The characteristics of household transmission of COVID-19, published online ahead of print, 2020 Apr 17, *Clin Infect Dis*. (2020) ciaa450, <https://doi.org/10.1093/cid/ciaa450> (accessed 05/02/2020).
- [5] M.V. Flores, M. Cohen, Preventing airborne disease transmission: implications for patients during mechanical ventilation, in: A. Esquinas (Ed.), *Noninvasive Ventilation in High-Risk Infections and Mass Casualty Events*, Springer, Vienna, 2014, <https://link.springer.com/content/pdf/10.1007%2F978-3-7091-1496-4.pdf> (accessed 05/02/2020).
- [6] AM Esquinas, S Egbert Pravinkumar, R Scala, et al., Noninvasive mechanical ventilation in high-risk pulmonary infections: a clinical review, *Eur Respir Rev* 23 (134) (2014) 427–438, <https://doi.org/10.1183/09059180.00009413> (accessed 05/22/2020).
- [7] Atrium Health News, Atrium Health Uses Telemedicine to Treat Eligible COVID-19 Patients at Home, <https://atriumhealth.org/about-us/newsroom/news/2020/03/atrium-health-uses-telemedicine-to-treat-eligible-covid19-patients-at-home>, (2020) (accessed 05/02/2020).

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