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Ventilators & COVID19 Policy Statement Committee on Public Policy and Advocacy // April 2020

SUBJECT: People with Intellectual and Developmental Disabilities and the Allocation of Ventilators During the COVID-19 Pandemic

In the worst case projections of the COVID-19 virus pandemic, emergency rooms and hospitals will be overwhelmed, intensive care units will experience unprecedented demand, and mechanical ventilators will become a scarce commodity.

Physicians who specialize in the care of patients with Intellectual and Developmental Disabilities (IDD), are painfully aware of the diagnostic overshadowing, discrimination and supervised neglect in the healthcare system that impact our patients routinely, even during times of relative resource abundance.

We are aware that in the face of ventilator scarcity, hospitals will be forced to make difficult decisions regarding who will receive a ventilator and who will not.

We are aware that there are allocation guidelines that suggest that the mere presence of a congenital syndrome, intellectual disability or developmental disability may be reason to deny a person life-saving ventilator support.

We are aware that our physician colleagues may be asked to make predictions of survivability, determinations of life expectancy or quality of remaining life as a means to allocate scarce ventilator resources.

However, we understand that **the spectrum of developmental disabilities and their myriad biomedical causes are too widely varied and too poorly understood by the general medical community to reliably be used as broad evidence-based predictors of life expectancy or the quality of life of an individual.** Moreover, a long history of lack of access to adequate health care for this population may inaccurately skew life expectancy statistics. As such, the historical data related to life expectancy should not be a determining factor when considering the allocation of ventilator support.

“We are resolved... that the presence of an intellectual or developmental disability must not be used as an exclusion criterion for ventilator support or the allocation of other scarce medical resources.”

Therefore, we are resolved and unified in the position that the presence of an intellectual or developmental disability must not be used as a factor for determining life expectancy or quality of life and, furthermore, must not be used as an exclusion criterion for ventilator support or the allocation of other scarce medical resources. The same medical risk factors applied for other patients should be those considered for patients with intellectual and developmental disabilities.

The laws of the United States protect people with disabilities against discrimination. Given that there is no relevant evidence base for physicians to rely upon in this context, we believe that judging a patient to be unworthy of ventilator support purely based on the presence of intellectual or developmental disability could constitute discrimination and a violation of the ethics of the medical profession.

Given the above, the only ethical, legal and professional responsible methodology of allocating ventilator resources is one that is inclusive of people with IDD and utilizes the same criteria applied to people without IDD.



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Ventilators & COVID19 Policy Statement ADDENDUM Committee on Public Policy and Advocacy // May 2020

SUBJECT: People with Intellectual and Developmental Disabilities and the Allocation of Ventilators During the COVID-19 Pandemic

As states and/or hospitals have developed or updated their crisis standards of care for making decisions about medical care in situations where rationing might be necessary, many have included the Sequential Organ Failure Assessment (SOFA) Score as a method to predict short-term mortality for the purpose of allocating ventilators to those most likely to survive. It is, however, the position of the AADMD that the SOFA scoring system has the potential to discriminate against people with intellectual and developmental disabilities (IDD) and, therefore, should not be used in its current form as the sole basis for ventilator allocation.

The SOFA scoring system relies mostly upon objective laboratory data such as blood oxygenation, bilirubin levels, platelet count, arterial pressure and creatinine levels. However, another component of the SOFA score is the Glasgow Coma Scale (GCS). The GCS is typically meant to be used to assess acutely altered mental status. The GCS looks at three parameters: eye response, verbal response and motor response.

Scores on the GCS range from 0 to 15, with 15 reflecting the lowest risk of mortality. The SOFA score works in the opposite manner: the higher the points, the higher the risk of mortality. When translated to a SOFA score, a GCS score of 15 provides no increase in SOFA score. A GCS score of 13 or 14 adds 1 point to the SOFA score. A GCS score of 10-12 adds 2 points to the SOFA score. A GCS score of 6 to 9 adds 3 points to the SOFA score. And, a GCS score of 5 points or less adds 4 points to the SOFA score.

A significant concern arises when the SOFA is calculated for an individual whose preexisting condition is an intellectual or developmental disability. According to neurodevelopmental theory, all intellectual disabilities (and most developmental disabilities) stem from an underlying neurodevelopmental disorder. A neurodevelopmental disorder impacts the development or function of the human brain sometime between conception and adulthood.

“...the AADMD has serious concerns about the current use of the SOFA as fair or objective means by which to allocate scarce medical resources.”

Neurodevelopmental disorders can result in one or more of the following: intellectual disability, seizure disorders, neuromotor dysfunction, psychiatric disturbances, sensory differences and communication difficulty. It is important to note, however, that these characteristics of neurodevelopmental disorders (of which there are over 1000), are not acute in nature and do not reflect a change from a person's baseline functioning. Diagnoses such as cerebral palsy, deafness, autism or Down syndrome do not represent acute brain trauma. In the field of developmental medicine, there are patients who, at their natural baseline of functioning, cannot hear a command, move their limbs or communicate verbally. It is important to note that the ability to hear, move or communicate is not explicitly connected to one's immune response to a viral infection such as COVID-19 and, therefore, should not impact one's ability to survive such an infection.

Given the combination of characteristics inherent in the population of people with IDD, it would be possible to use the “objective” data surrounding the SOFA score to predict a significantly higher mortality risk than is really the case. For example, inability to verbalize words would result in a three point change on the GCS, which is enough to move a patient's predicted mortality from less than 33% to more than 95% in some cases.



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Stated another way, this would have the discriminatory effect of placing somebody with an intellectual or developmental disability who truly has a 67% chance of survival, behind somebody who has a less than 5% chance of survival, in the difficult scenario of a mutually exclusive ventilator allocation.

There are ways the use of the SOFA can be modified to address the inherent deficiencies in the tool that lead to discriminatory treatment of patients with disabilities. Modifications to the SOFA have been developed to address different purposes and populations, such as the pSOFA, qSOFA, and SOFA(RASS). The same could be done to accommodate patients with underlying disabilities, including IDD. Alternatively, items such as verbal and motor response in a person with IDD may be logged as “unscorable” in order to not add points to the SOFA score. However, given the general lack of provider training with respect to patients with IDD, it is doubtful that providers are aware of the potentially discriminatory impact of the SOFA score or how to appropriately modify the tool for patients with IDD.

Because of the known risks of bias, diagnostic overshadowing and lack of experience and training of the medical field in general with respect to patients with IDD, the AADMD has serious concerns about the current use of the SOFA as fair or objective means by which to allocate scarce medical resources. We encourage the medical community and policymakers to identify alternative means of objective assessment that do not have such significant possibility of discrimination, as well as to ensure medical professionals are educated about ways to properly modify the SOFA to avoid discrimination.