

Protecting the most vulnerable among us: Access to care and resources for persons with disability from spinal cord injury during the COVID-19 pandemic

Donna Huang MD^{1,2}  | Sameer A. Siddiqui MD³ | Hilary N. Touchett PhD⁴ | Felicia Skelton MD, MS^{1,2,4}

¹Spinal Cord Injury Care Line, Michael E. DeBakey VA Medical Center, Houston, Texas

²H. Ben Taub Department of Physical Medicine and Rehabilitation, Baylor College of Medicine, Houston, Texas

³Spinal Cord Injury Division, VA Boston Healthcare System, West Roxbury, Massachusetts

⁴Center for Innovations in Quality, Effectiveness and Safety, Michael E. DeBakey VA Medical Center, Houston, Texas

Correspondence

Donna Huang, Michael E. DeBakey VA Medical Center, 2002 Holcombe Blvd, SCICL 128, Houston, TX 77030, USA.
Email: donna.huang@va.gov

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INTRODUCTION

In 2019, the severe acute respiratory syndrome coronavirus 2 (SARS-CoV2) virus emerged, leading to the coronavirus disease 19 (COVID-19) pandemic. Individuals with spinal cord injuries and disorders (SCI/D) are affected directly and indirectly by the COVID-19 pandemic, as they are vulnerable to pulmonary infections and social distancing may limit their access to caregivers, supplies, and equipment. In an international survey of healthcare providers caring for individuals with SCI/D, participants described patient-reported concerns regarding the risk of severe infection, fragility of the caregiver network, inability to access routine supplies, and inability to access appropriate testing.¹

Caregivers for individuals with SCI/D are often family members who take on these roles without compensation. With healthcare systems often being fragmented and difficult to navigate, caregivers are faced with difficult choices with limited resources. An increasing proportion of caregivers reported difficulty coordinating care across multiple providers, and about a quarter reported difficulty accessing affordable services in their care recipient's geographical location.²

In addition to concerns of tenuous caregiver support, allocation of critical resources such as ventilators is a concern for individuals with SCI/D. From

the outset of the pandemic, disability advocates have raised concerns regarding the widening of existing healthcare disparities among the disabled population during COVID-19.³ Outside of the Veterans' Health Administration (VHA), there are no national criteria for the allocation of scarce resources such as intensive care unit (ICU) beds and ventilators during a pandemic. As such, individual institutions and local governments have formulated their own policies, some of which may have an adverse impact on persons living with disabilities.⁴

The COVID-19 pandemic has strained an already overburdened system. Here we present three vignettes from an SCI/D center in a Veterans' Affairs (VA) hospital. With these vignettes, we highlight some of the specific challenges our patients have faced maintaining steady caregiver support as well as concerns about resource rationing, while offering considerations for those caring for this vulnerable population.

Vignette 1

Veteran A is a 68-year-old man with T10 ASIA Impairment Scale (AIS) A SCI who allows only a sole caregiver to perform bowel care. As a part of the SCI center's COVID-19 response, the SCI home care team

has been reaching out to veterans to facilitate contingency planning. Veteran A stated that the only way he would allow someone else to perform his bowel care was if his caregiver was admitted to the hospital. The veteran was encouraged to continue to consider backup plans should his caregiver become unable to provide care. Ongoing support from the SCI home care team was offered.

Vignette 2

Veteran B is a 45-year-old man with C1 AIS B SCI who requires mechanical ventilation via tracheostomy. He resided in rural Maryland but decided to relocate to a city closer to his support system in April 2020. During an inter-VA facility conference call, the urgency of a cross-country move was questioned given the ongoing pandemic. Veteran B cited concerns of the scarcity and reliability of caregivers in his area because of the pandemic and the desire to be closer to his caregiver/significant other as the reasons “the move has to happen now!” Using video visits, a “warm” handoff was provided from his original care team to the receiving team, including ensuring his new residence was accessible. He completed the move successfully, including resumption of home health and skilled nursing services upon arrival.

Vignette 3

Veteran C is a 68-year-old man with C4 AIS B SCI and severe anoxic brain injury complicated by ventilator-dependent chronic respiratory failure. During the COVID-19 pandemic, his family member expressed concern to the patient’s SCI physician that his ventilator would be withdrawn if the hospital’s resources became overburdened by a surge of COVID-19 cases.

DISCUSSION

These vignettes highlight challenges to access to caregiver support and allocation of life-sustaining resources under crisis conditions for individuals with SCI/D. In Veteran A’s case, the family could not identify an alternative plan for bowel management if the primary caregiver were to become ill, highlighting that for many veterans, in-home care is largely dependent on a single family member. Meanwhile, Veteran B felt compelled to undertake a cross-country move, with its risks in the midst of a pandemic, because of concern for a shortage of caregivers in his location. Veteran C’s family member expressed concerns that the veteran’s ventilator would be withdrawn if the supply of ventilators became constrained because of the pandemic.

Challenges in access to caregivers and caregiver support

During the COVID-19 pandemic, assessment of capacity for serious illness care in the home should be implemented.⁵ Veteran A’s case is an example of this assessment. The SCI home care team in this center has been performing standardized needs assessments, including identifying potential vulnerabilities in caregiver supply and addressing them before any shortfall occurs. Identifying vulnerable patients and formulating disaster-preparedness protocols has been well established in this center, as it is located in a hurricane-prone area. This existing infrastructure serves as a foundation for tailoring COVID-19-specific risk assessment for individuals with SCI/D.

There has been a growing reliance on a lay workforce of family caregivers as the population ages and complex care has progressively transitioned to the home.² In a commentary on the effects of the COVID-19 pandemic on caregivers for palliative care patients, Kent et al highlight three major challenges that the pandemic has imposed that are relevant to the SCI population.⁵ First, social distancing can exacerbate isolation, loneliness, and associated adverse health outcomes already experienced by caregivers and those they care for.⁶ Second, caregivers may face increased financial stressors because of COVID-19. Third, caregivers face an unprecedented decision-making landscape.

With regard to the first challenge, caregivers may be reluctant to seek help during the pandemic because of fears of having outsiders who could transmit the virus come into their homes. As for the second, approximately 61% of caregivers in the United States already experience some level of economic strain due to employment loss and out-of-pocket medical expenses.⁷ The pandemic intensifies this burden as many family caregivers do not have jobs amenable to remote work. Additionally, caregivers may need to take on childcare and home-schooling responsibilities because of school closures, while continuing to fulfill work and caregiving responsibilities. Regarding the third challenge, access to routine health care, including primary care, disease surveillance, and home health, has been restricted during the pandemic. The need for visits may be questioned on the grounds of safety and goals of care. With the impact of stress on caregiver mental and physical health already posing an urgent public health issue,⁸ the COVID-19 pandemic may intensify caregiver distress about whether they are making the right decisions for their care recipients.

Priorities for caregiver support

When considering priorities for supporting caregivers, caregiver access to personal protective equipment

(PPE) should be maintained.⁹ Individuals with SCI/D frequently require hands-on assistance for personal care that requires PPE, most often gloves. Caregivers for people with SCI/D are providing care to individuals at risk for severe pulmonary infections and are often doing so without direct supervision or formal training on COVID-19-specific precautions. Caregivers providing support to older individuals often tend to be elderly themselves² and are susceptible to higher mortality risk from COVID-19. Healthcare systems can support caregivers by providing guidance on appropriate PPE use.⁵ Ensuring adequate PPE supply for community-dwelling SCI/D individuals is of tantamount importance not only for mitigating the risk of spread of COVID-19 but also for preventing secondary complications of SCI that could precipitate emergency department presentations and hospital admissions, increasing the risk of exposure to COVID-19. Recognizing the importance of adequate PPE in the SCI/D population, the VHA issued a memorandum indicating that individuals with SCI/D and their caregivers were required to have continued access to appropriate PPE, including gloves, masks, gowns, and hand sanitizer, during the COVID-19 pandemic.¹⁰

During a pandemic with rapidly changing guidelines, updating caregivers on the latest recommendations is of utmost importance. Healthcare providers can support caregivers by providing access to current guidance from public health agencies as well as COVID-19 resources from reputable caregiving organizations. The VA has clinical COVID-19 guidance and caregiver-specific resources through its Caregiver Support Program,¹¹ and there are several non-VA based organizations that are compiling COVID-19 resources.

Challenges to allocation of life-sustaining resources

During crisis conditions that cause a scarcity of life-sustaining resources, the prevailing ethical mandate in medicine shifts from maintaining patient autonomy to providing the greatest good to the greatest number of individuals while balancing respect for human dignity and fairness.¹² Disability advocates have raised concerns similar to those of Veteran C's family member regarding potentially discriminatory rationing policies in the face of shortages caused by COVID-19. In response to these concerns, the U.S. Department of Health and Human Services Office for Civil Rights (HHS OCR) published a bulletin on 28 March 2020 clarifying that entities funded by HHS cannot deny those with disabilities medical care "on the basis of stereotypes, assessments of quality of life, or judgments about a person's relative 'worth' based on the presence or absence of disabilities."¹³

Ethical frameworks for scarce resource allocation

VHA COVID-19 resource allocation protocols are outlined in *Meeting the Challenge of Pandemic Influenza: Ethical Guidance for Leaders and Health Care Professionals in VHA*.¹⁴ According to these guidelines, Veteran C is not at risk for losing his ventilator under pandemic triage protocols. This document explicitly states patients residing in community settings who require life-saving resources for daily maintenance are not subject to pandemic triage protocols. These standards of care apply nationally, though the thresholds for implementing them are made at a local level after attempts to acquire resources to meet needs are exhausted.

The VHA guidance mandates interdisciplinary teams appointed by facility leadership to make decisions regarding which patients receive scarce resources such as mechanical ventilation. The overarching criterion in the VA's approach to allocating scarce resources is based on clinical expectations of survivability as determined by Sequential Organ Failure Assessment (SOFA) scores.¹⁵ Patients are triaged based on clinical exclusion criteria and illness severity into priority categories for receiving scarce resources. Within each category, resources are allocated on a first-come, first-served or lottery basis. Clear guidelines for reassessment are described as are recommendations for review, appeals, and communication regarding triage decisions.¹⁴ This guidance provides a detailed description of the ethical framework under which resource allocation criteria are evaluated based on whether they supported VHA goals to stop or limit the spread of disease, reduce suffering and death, and/or sustain operations. Resource allocation criteria in the VHA guidance were also evaluated as to whether they were ethical, legal, politically feasible, and practical to implement.

Another ethical framework for allocating scarce medical resources that has garnered attention during the pandemic has been the multiprinciple approach of Douglas White and colleagues, originally published in the *Annals of Internal Medicine* in 2009.¹² This framework relies on three guiding principles: maximizing survival to hospital discharge, maximizing the number of life-years saved, and maximizing individuals' chances to live through life's various stages (also known as the fair innings principle). When considering maximizing survival to hospital discharge, similar to the VHA guidance, the White framework advocates the use of objective, transparent mortality prediction models, such as the SOFA score, that are uniformly applied to all patients.^{12,15} This approach avoids ethically irrelevant considerations such as race, socioeconomic status, or disability status and balances the principle of efficiency with the egalitarian principle that all lives have value. A drawback is that models of short-term survival cannot

be extrapolated beyond conditions for which they were validated. There is no evidence that any given mortality prediction model is more accurate than another; however, the SOFA score has the benefits of being easy to implement and requires relatively few laboratory tests.

The utilitarian principle that all else equal, it is better to save more years of life than fewer underpins the second guiding principle of maximizing life-years saved. This principle balances the patient's medical need (ie, prognosis without treatment) with the expected duration of survival after treatment. This principle can be applied to all patients, not just those with extremely limited life expectancies, therefore promoting consistency and fairness.¹²

With the fair innings principle, the goal is to give each individual an equal opportunity to live through the various phases of life. Though on its surface this may seem to disadvantage the elderly, White et al have argued that it is inherently egalitarian in that it seeks to give all individuals the opportunity to live a normal life span. Furthermore, this approach applies the principle of equality to an individual's entire lifetime rather than the current conditions.¹²

White et al's model combines its three guiding principles in a weighted score that triages individuals to priority levels. Although a multiprinciple allocation strategy is more complex, it attempts to more comprehensively reflect diverse moral considerations relevant to difficult decisions. As in the case of the VHA guidance, use of a multiprinciple approach avoids the need to categorically deny treatment to certain groups. Regardless of the specific approach used, ethical guidance for resource allocation benefits from input from multiple stakeholders, transparency with regard to guiding principles and circumstances under which rationing frameworks are implemented, and equitable application to all individuals.

CONCLUSIONS

The challenges faced by Veterans A and B and their families in the vignettes demonstrate some of the ways in which the COVID-19 pandemic has strained a fragile caregiver network that is vital to the well-being and independence of individuals with SCI/D, and Veteran C's vignette revealed how COVID-19 threatened the availability of life-sustaining resources. The VA SCI/D system provides a more robust safety net than what is often available to nonveterans given it is an interconnected healthcare system that has a precedent of providing comprehensive, longitudinal care to those with SCI/D. Nonetheless, the pandemic has revealed vulnerabilities. Ongoing efforts to address these challenges should emphasize preventing unanticipated medical illnesses including COVID-19 exposure, providing risk assessment, contingency planning, and

caregiver support as well as adopting robust and equitable frameworks for resource allocation that avoid categorical discrimination against specific patient groups, with the aim of empowering and protecting individuals with SCI/D and their caregivers during times of crisis.

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ORCID

Donna Huang  <https://orcid.org/0000-0001-8620-639X>

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