

The Burden of Deciding for Others: Caring for Unrepresented Patients with COVID-19

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“Is there anyone — family or friends — who would help make medical decisions for you in case you could not?” I asked, sounding muffled through my constrictive N95 mask and face shield. My patient, an 82 year-old-woman with dementia who was admitted with severe COVID-19 pneumonia, slowly shook her head no. My patient was unrepresented – meaning she lacked the capacity to make her own medical decisions, had not previously expressed wishes about treatment, and did not have a decision-making surrogate.¹ The COVID-19 pandemic has highlighted the impact of structural inequities and social determinants on health outcomes.² These disparities become especially significant among unrepresented patients, who are more likely to be people of color, homeless, socially isolated elderly, or those afflicted with mental illness.³ As a result, unrepresented patients are particularly vulnerable which raises numerous ethical considerations for clinicians and healthcare systems. Although nearly 50 percent of hospitalists or intensivists report seeing at least one unrepresented patient per month, the challenges of caring for these COVID-19 patients has not been sufficiently explored.⁴

In the context of the coronavirus pandemic, collaborating with patients to make medical decisions has presented challenges. Only one third of adults have documented advance directives, meaning that many COVID-19 patients were likely unprepared to even think about advance care planning.⁵ Additionally, nearly one third of hospitalized COVID-19 patients have demonstrated confusion due to brain disease at the time of admission.⁶ Many others did not have family members present due to strict visitation policies.

There has not been much data on healthcare outcomes of unrepresented patients during the pandemic, but, given the demographics of this group, they would likely be disproportionately affected by COVID-19. For instance, people of color are three times more likely to be infected with COVID-19 and six times more likely to die from it.⁷ The mortality rate for homeless people with COVID-19 in New York City is estimated to be nearly 80 percent greater than the rate for domiciled New Yorkers.⁸ With these statistics, it is no surprise that the

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unrepresented are more likely to require intensive care unit (ICU) care. One study estimated the number of unrepresented patients in the ICU may be as high as 16 percent of all critically ill patients.⁹ To make matters worse, the number of unrepresented patients is expected to increase by 2030.¹⁰ As their wishes are unknown, these unrepresented patients are at risk for both undertreatment and overtreatment.¹¹ Unrepresented patients are also less likely to be enrolled in hospice, even when curative options are exhausted.¹² Though the best interest standard has determined the basis for decision making for patients in this group, the “best” treatment strategy for severe COVID-19 infection remains difficult to elucidate.¹³

During the COVID-19 pandemic, physicians face challenges to make a myriad of important medical decisions for their patients based on limited medical evidence and a rapidly expanding body of research, some of which has been unreliable or inaccurate.¹⁴ Making these decisions for unrepresented patients heightens these challenges, especially when considering treatments with limited supporting data or facing patients’ deaths without any proven treatments to offer. In spring 2019, when the pandemic began, clinicians struggled to decide if medications such as corticosteroids or hydroxychloroquine, seemingly innocuous but without much supporting data, would do more harm than good. Though there are now nearly 200 phase III trials, unrepresented patients belong to marginalized groups that are regularly excluded from clinical trials.¹⁵ Since many investigational COVID-19 therapies have undetermined benefits, physicians may struggle with the moral dilemma of either excluding unrepresented patients from potentially beneficial therapies or exposing them to greater harm. Also, some studies do not allow the enrollment of incapacitated patients without surrogates, which further limits the patients’ access to emergency treatment options that are readily available to patients with surrogates.¹⁶

I was recently involved in the care of an elderly COVID-19 patient who I learned was a Holocaust survivor. Like the estimated 3 percent of older adults in nursing homes, this patient was incapacitated and had no surrogate or appointed guardian.¹⁷ He presented to the emergency room with respiratory failure and was immediately intubated. Several hours later, a decade-old Medical Order for Life-Sustaining Treatment (MOLST) was discovered. The MOLST indicated the patient would have wanted a critical care trial without permanently relying on machines to sustain his life. The medical team struggled to discern what a duty to provide a trial of care means for someone who is expected to die regardless. A few days later, the patient died while still on a ventilator.

In addition to medical uncertainty, the isolation of hospitalized patients has been a well-recognized source of moral distress for clinicians, which is amplified in the care of unrepresented patients.¹⁸ In some ways, COVID-19 has made the hospital experience equally isolating for all patients. The majority of hospitalized elderly patients with COVID-19 died without family present and, due to acute illness, they were unable to express their wishes in their last days.¹⁹ Amid such isolation, we have been buoyed by the many moving stories of togetherness and connection. I have seen elderly couples with COVID-19 sharing the same hospital room, and I have been moved by patients’ sentimental FaceTime calls to family. However, it is far more distressing to see patients without any such connections enduring these challenges alone. For hospitalized and unrepresented patients, healthcare workers are the ones offering human connection.

As physicians, to be worthy of our patients’ trust, we have pledged to make the most medically and ethically sound decisions for our patients. We also feel a deep sense of connection to our patients’ suffering, as moments of clinical or moral uncertainty can leave indelible marks on our minds.²⁰ While medical decisions should be objective, the human dimension in deciding for and with patients cannot be underestimated. Many clinical decisions also become personal ones. This personal element to decision-making – the part that relies

on a patient's values, hopes, and relationships – is inaccessible to unrepresented patients. As clinicians, we can be left wondering if we are genuinely doing what is best for our most vulnerable patients. We wonder whether we are doing too much or too little. Even after the pandemic is over, part of the emotional burden healthcare professionals will carry will be the psychological impact of making difficult decisions for others, especially for those who could not advocate for themselves and had no one to advocate on their behalf. In a world where having someone to love is exalted, we will remember that those who are alone are not any less worthy of our care.

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