

## Goals of Care in the Dark: Guiding Families of Patients with “COVID-19 Encephalopathy”

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**E**ARLY IN THE COVID-19 PANDEMIC, I got a call from an internal medicine resident for a new palliative care consult. The resident was at a loss; she did not know how to advise the patient’s family about her prognosis. Should she place a feeding tube in this patient who, recovering from COVID-19, now could not wake up?

This previously healthy middle-aged woman admitted due to shortness of breath had been intubated for hypoxic respiratory failure. The patient was ultimately extubated; her oxygen requirement improved, and her laboratories normalized. Yet, she remained largely unresponsive except to noxious stimuli after transfer from the intensive care unit to the general medical floor. She would open her eyes and track around the room, but was otherwise nonverbal. Her computed tomography and magnetic resonance imaging without contrast were unremarkable, and a bedside lumbar puncture had been attempted without success. EEG showed only diffuse slowing without seizure activity.

Although persistent delirium after intensive care unit admissions is not uncommon, we also noticed the same syndrome in other COVID-19 patients with mild respiratory symptoms. It is a syndrome increasingly being described in the literature. What could we expect from “COVID-19 encephalopathy,” as we began to call it, and how should we approach decision making about artificial nutrition with the family? Why was a previously healthy patient, with only a short intensive care unit stay, not waking up and would she ever get back to herself?

As a palliative care fellow, before any goals of care discussion in which I will guide patients and families through complex decisions, I consult the medical literature to learn about outcomes. There is always a degree of uncertainty even after reviewing the literature, and prognostication can be hard. Nevertheless, I usually have enough information to give patients and families a range of possibilities. If a family is deciding about artificial nutrition for a loved one who suffered a cerebrovascular accident, for example, the location and size of the lesion are factors that might help determine chance of recovery. I explain that, with the placement of a feeding tube and after extensive rehabilitation, the best case scenario is that the patient regains the ability to speak in short sentences, the most likely is that she will be able to say a few words, and the worst case is that she cannot communicate at all. After sharing this prognostic information with patients

and families, I guide them in choosing goal-concordant interventions.

With these new consults for “COVID-19 encephalopathy,” I had no prognostic information to share with families. During one particularly challenging meeting, a patient’s son asked me repeatedly, “What is going to happen to my mother?” The medical literature had nothing to say as yet about whether patients with “COVID-19 encephalopathy” recovered. One study reported that ~15% of hospitalized patients in their sample from Wuhan, China, especially those with more severe manifestations of the virus, had “impaired consciousness.”<sup>1</sup> Another study from Strasbourg, France, described a group of patients with “a dysexecutive syndrome consisting of inattention, disorientation, or poorly organized movements in response to command.”<sup>2</sup> These articles were unable to comment on long-term outcomes as most patients were still hospitalized at the time of publication. Prolonged mental status changes associated with the virus were new for all of us, and we were in the dark about disease trajectory.

Although I had experience managing uncertainty as a palliative care fellow, it was never to this extent. And, facing this uncertainty was all the more challenging because COVID-19 pervaded not only my life as a clinician, but also all aspects of my personal life: When would I see my elderly parents again? Did I need to write a will? How could I protect my toddler son from a rare inflammatory syndrome? Maintaining the boundary between these personal, existential concerns and my work was nearly impossible. As I attempted to stay present with families, my mind drifted to whether I might be the next COVID-19 patient admitted to our hospital. Given strict hospital visitor policies that prevented families at the bedside, limited social supports due to physical distancing, and restrictions on funeral services, I had an ethical obligation, now more than ever, to bear witness to my patients’ grief. Even so, I found myself worrying about when I would be the one contacting the overloaded morgue about my family member. I had to consciously reel myself back in.

And, when I did reel myself back in, I saw that I had to directly acknowledge the uncertainty of the situation, confronting my own fears, to guide my patients’ families. Sitting with uncertainty allowed families to do the same, which was a crucial part of making plans for their loved one’s medical care. To guide complex decision making, I emphasized that this conversation was the first of many, rather than the final

one. In the absence of prognostic information, families would have to observe their loved one's degree of recovery and medical care over time, asking themselves whether it was the care that they would have wanted. I still used the skills I had learned during fellowship, sharing best and worst case scenarios and eliciting goals and values, although now I emphasized the idea that every decision would have to be re-evaluated.

Knowing that decisions could be revisited, I explained to families of patients with "COVID-19 encephalopathy" that their loved ones might have full recovery or no recovery: the patient could have a feeding tube placed, go to a rehabilitation facility, improve from the perspective of their mental status, and return home, or the patient might go to rehabilitation and that would turn into long-term care outside of the home without recovery, punctuated by unforeseeable complications and recurrent hospitalizations, maybe even death. I shared with families that time would be short, likely days to weeks of life, without a feeding tube.

I continued to elicit goals and values, asking general questions rather than framing my questions around a particular disease process or expected range of outcomes: Did you ever speak to your family member about a feeding tube? Did she ever discuss with you the use of life-prolonging interventions? How did she feel about spending a short or long period of time in a rehabilitation facility? Was her quality of life before this admission acceptable for her? I used these general questions to understand whether, for a given patient, there was medical care that was not suitable even if the alternative was death. Because of the number of unknowns, for most previously healthy patients with "COVID-19 encephalopathy," I recommended a trial of feeding tube placement as a way to prolong survival and give a chance for recovery.

Looking ahead, ensuring that patients with "COVID-19 encephalopathy" who survive initial hospitalizations receive goal-concordant care will continue to be challenging. It will require access to multiple high-quality conversations about goals and values over time. As patients move between acute care, rehabilitation, and long-term care facilities, providers will change, and lack of continuity will compound this challenge. It will be critical that not only palliative care

specialists, but also other providers caring for these patients remember the circumstances under which goals of care were initially discussed and navigate any relevant changes to those circumstances. Documenting what is most important to patients and families as well as their expectations around recovery will be an essential part of respecting their goals and values. And, documentation of conversations should be proactively shared across care settings.

This pandemic brings uncertainty to the forefront of every aspect of life, including the work of palliative care. And, it has made that work—staying present, supporting patients and families, and bringing out their voices—all the more important. Understanding the longer term neurological outcomes of patients who survive initial COVID-19 hospitalizations will allow us to once again help families interpret prognostic information in the context of their goals and values. Until then, uncertainty will have to be embraced and decisions revisited.

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### References

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