

Opinion & Special Articles: Shared Decision-Making During the COVID-19 Pandemic

Three Bullets in 3 Hemispheres

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Patients with traumatic brain injury may be dependent on the decision-making of their families. Restrictive visitation policies implemented during the coronavirus disease 2019 (COVID-19) pandemic disproportionately affect these patients and their families. This narrative aims to illustrate this phenomenon and catalyze discussions regarding the need for careful evaluation of restrictive family visitation policies and exceptions that may be required for patients with brain injuries.

“GSW [gunshot wound] to the head on the right. GCS [Glasgow Coma Scale] 7 on arrival. Not moving left side of body.” As the neurosurgery resident on call Sunday night, I felt my adrenaline begin to crescendo. My immediate call back consisted of one request—hold sedation until I could obtain a neurologic examination. It took me 3 minutes to get to the trauma bay. I mentally rehearsed acute intracranial pressure (ICP) management and ordered the decisions I would make if this patient had a survivable injury.

Endotracheal tube. Intraparenchymal ICP monitor. Decompressive hemicraniectomy.

For patients with severe traumatic brain injury, these life-saving decisions are made in real-time and rarely with family input.

Goals of care. Tracheostomy. Gastrostomy tube.

This stands in stark relief to the following days and weeks, when acutely brain-injured patients are reliant upon their loved ones for decisions that are fundamentally foreign to most families. Coronavirus disease 2019 (COVID-19) era restrictions on in-person family visitation have taken these families’ incomprehensibly difficult choices in the wake of acute brain injury and made these decisions profoundly harder.

My patient required an emergent decompressive hemicraniectomy that Sunday night, as did my GCS 8 patient, with an isolated right parietal gunshot wound resulting in a large subdural hematoma, on Monday night.

Beyond an initial 2-hour visitor allowance for trauma patients, the families of these critically ill, brain-injured patients were not permitted to be at bedside. This policy was in keeping with Centers for Disease Control and Prevention guidelines at the time.¹ Since the early months of the pandemic, many hospitals allowed one support person for women in labor and one parent or guardian for pediatric patients. As regional pandemic dynamics evolved, case-by-case exceptions have been granted for end-of-life care and patients with certain disabilities.

“I’m so sorry, but it’s the policy right now.” I hated how coarse these words felt leaving my mouth as the patient’s daughter asked when she could come see her father in the neurocritical

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Glossary

COVID-19 = coronavirus disease 2019; GCS = Glasgow Coma Scale; GSW = gunshot wound; ICP = intracranial pressure; ICU = intensive care unit.

care unit. My explanation felt inadequate, lacking, hollow—how could a hospital policy substantiate my refusal to let her see her loved one?

For 2 nights in a row, the adrenaline of an emergent hemispherectomy faded and I called these patients' families to explain these surgeries and the events precipitating them. For 2 nights in a row, I was struck by how much we were able to do for these patients acutely and how little we could do for their families in the aftermath.

"GSW to back of head. Intubated. No movement." It was Wednesday night and my patient was GCS 3 on arrival. The bullet that entered through an isolated occipital wound had shredded the confluence of his dural venous sinuses. Without any brainstem reflexes or motor response, minimal midline shift on imaging, and evident dural venous sinus injury, he would not benefit from neurosurgical intervention. He was admitted to the surgical intensive care unit (ICU). The trauma surgery attending, surgical intensivist, and I were in agreement—the best care we could offer was to find his family and provide them physical space, at his bedside, where they could begin to seek closure. Visitation was granted for this family under an established exception for end-of-life care.

Three patients in 4 nights sustained isolated gunshot wounds to the head. Only one family was able to spend more than 2 hours at their loved one's bedside.

As a junior neurosurgery resident, the greatest effect of the COVID-19 pandemic has not been the ubiquity of facial masks or the necessary restrictions on public life. Rather, it has been the indelible absence of families in the hospital. While I learned to make rapid decisions in acute situations, the absence of family members at the bedside of my neurologically injured patients has proven to be more challenging.

"No right bone flap!" This sign is printed plainly in 96-point font and taped in multiple places in these patients' rooms. If the ventilator, ICP monitor, central venous catheter, and infusions of hypertonic saline, propofol, and fentanyl were not enough, this paper sign starkly reminds the entrant to the room of the severity of this patient's trauma. The lived experience of being at the bedside of an acutely brain-injured patient is heavy.

No number of video calls can convey this weight. Caring for these brain-injured patients during the COVID-19 pandemic, I witnessed the difficulty families experienced in making decisions to limit care when unable to be at their loved one's bedside. I believe that some families felt that the only way they

would be allowed into the hospital was if they agreed to transition their family member to comfort measures. Pleading family members called daily and I felt powerless. My promise to submit another exception request felt inexcusably small.

Charge nurses are willing to advocate for visitor exceptions, neurointensivist colleagues are committed to providing frequent family updates, and ICU nurses are dedicated to organizing video calls between families and their brain-injured loved ones. However, I remain concerned that COVID-19 era policies regarding family visitation are negatively affecting our ability to partner with families in navigating complex decisions after brain injury.

Goals of care conversations are an integral part of postinjury care for severely brain-injured patients. They are also uniquely challenging. Clinicians may disagree on prognostication^{2,3} and all decisions are made by family members or surrogates, as severely neurologically injured patients are often unable to participate in their care decisions. With families unable to be at the patient's bedside and to speak with clinicians in person, these conversations are fundamentally more difficult. We are asking so much of families—to make life-altering decisions about their loved one—while giving them so little. Already, there is evidence that race and socioeconomic factors affect end-of-life decision-making for patients with traumatic brain injury, with Black patients less likely to have withdrawal of life-supporting treatment than White patients.⁴ These observations undoubtedly reflect the complex interplay of racial identity, trust in the medical establishment, and intimately personal preferences regarding quantity and quality of life.^{5,6} Broaching these topics via telephone or across a video screen, when the family members have not been able to spend time at the patient's bedside, strikes me as a uniquely cruel injustice of the COVID-19 pandemic.

Shared decision-making, a key tenet of patient-centered care, is a process that integrates the medical expertise of the patient's care team with patient and family preferences and values.⁷ For brain-injured patients, this process is both more challenging and more important, as the patient may be unable to participate. Before the COVID-19 pandemic, shared decision-making was facilitated by regular, in-person family meetings. Families could visit the patient and then work with the clinical team to understand the severity of the patient's injury. Regular family meetings facilitated trust. These longstanding practices were upended by the pandemic. Remote digital alternatives have emerged, but fail to capture the all-encompassing heaviness experienced at a severely brain-injured patient's bedside. The small acts that build trust,

placing a comforting hand on the shoulder of an overcome family member, cannot be digitally replicated. Those of us caring for these patients must recognize these limitations and dedicate additional time to family updates, recognizing families will likely need more time to make decisions when unable to meet their loved ones and the care team in person.

Moreover, visitor policies must be more flexible. Well-intentioned infection control measures implemented in the uncertain early days of the pandemic are now having unintended negative consequences on brain-injured patients. If local COVID-19 infection rates prevent modification of visitation policies, early involvement of social work and palliative care teams, combined with a greater emphasis on shared decision-making, is necessary to deliver family-centered care during the ongoing pandemic.^{8,9} Given evolving COVID-19 dynamics, decisions about family visitation must be considered on a hospital-by-hospital basis and require regular reassessment.

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References

1. Centers for Disease Control and Prevention. Interim Infection Prevention and Control Recommendations for Healthcare Personnel during the Coronavirus Disease 2019 (COVID-19) Pandemic [online]. Available at: [cdc.gov/coronavirus/2019-ncov/hcp/infection-control-recommendations.html](https://www.cdc.gov/coronavirus/2019-ncov/hcp/infection-control-recommendations.html). Accessed September 17, 2020.
2. Williamson T, Ryser MD, Abdelgadir J, et al. Surgical decision making in the setting of severe traumatic brain injury: a survey of neurosurgeons. *PLoS One* 2020;15:e0228947.
3. Turgeon AF, Lauzier F, Burns KE, et al. Determination of neurologic prognosis and clinical decision making in adult patients with severe traumatic brain injury: a survey of Canadian intensivists, neurosurgeons, and neurologists. *Crit Care Med* 2013;41:1086–1093.
4. Williamson T, Ryser MD, Ubel PA, et al. Withdrawal of life-supporting treatment in severe traumatic brain injury. *JAMA Surg* 2020;155:723–731.
5. Steinhauser KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA. Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA* 2000;284:2476–2482.
6. Bone AE, Evans CJ, Higginson IJ. The future of end-of-life care. *Lancet* 2018;392:915–916.
7. Muehlschlegel S, Shutter L, Col N, Goldberg R. Decision aids and shared decision-making in neurocritical care: an unmet need in our NeuroICUs. *Neurocrit Care* 2015;23:127–130.
8. Abbott J, Johnson D, Wynia M. Ensuring adequate palliative and hospice care during COVID-19 surges. *JAMA* 2020;324:1393–1394.
9. Hart JL, Turnbull AE, Oppenheim IM, Courtright KR. Family-centered care during the COVID-19 era. *J Pain Symptom Manage* 2020;60:e93–e97.

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