Neuropalliative care essentials for the COVID-19 crisis

Benzi M. Kluger, MD, MS, Christina L. Vaughan, MD, MHS, Maisha T. Robinson, MD, Claire Creutzfeldt, MD, Indu Subramanian, MD, and Robert G. Holloway, MD, MPH

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Correspondence

Dr. Kluger
benzi_kluger@
urmc.rochester.edu

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The coronavirus disease 2019 (COVID-19) pandemic is profoundly affecting neurology patients, families, and providers through direct neurologic complications,¹ indirect consequences of COVID-19 on healthcare delivery,² and the consequences of social distancing.³ As frontline providers, neurologists see both the medical consequences of COVID-19 and its toll in heightening personal suffering ranging from interruptions or changes in standard therapies⁴ to patients facing isolation in the hospital and even the prospect of dying without the family being present.⁵ Almost instantly, the calculus of risks and benefits have changed to include concerns of COVID-19 during routine office visits, procedures, and hospital admissions. This affects patients' desire to seek medical care and may explain the dramatic drop in acute hospitalizations and outpatient referrals. Neurologists also face challenges in providing ongoing care for persons with chronic illness, responding to novel clinical situations and hosting an increasing number of difficult conversations, often via telehealth.⁶

Given the morbidity, mortality, psychosocial consequences, and ethical challenges of COVID-19, the palliative care (PC) community responded with strategies for addressing acute needs⁷ and with resources to confront the many PC challenges related to this pandemic.^{8,9} Our goals for this Special Editorial are to identify scenarios where a neuropalliative approach may be beneficial,¹⁰ connect the neurology community to useful COVID-related PC resources, and to address other PC-related concerns voiced by neurology colleagues. We would further like to direct readers to international resources, particularly for neurologists practicing in low or middle-income countries.¹¹

Providing compassionate care at a distance

Public health measures during the COVID-19 pandemic limit face-to-face appointments and challenge healthcare providers to engage in both routine care and challenging conversations (e.g., delivering a diagnosis of brain cancer and discussing goals for a patient with end-stage Alzheimer) remotely. Although most commonly used in neurology for the diagnosis and management of acute stroke, telemedicine has broader applications in neurologic disease and has demonstrated benefits such as reducing caregiver and patient burden and improving access to care.¹² PC approaches to challenging conversations can be applied via telemedicine, and studies in neurologic and nonneurologic patients suggest that remotely establishing rapport, assessing and managing symptoms, and addressing psychological issues is acceptable and feasible with high patient satisfaction.¹³⁻¹⁵

Several PC organizations have made their communication resources freely available during the COVID-19 pandemic (capc.org/toolkits/covid-19-response-resources/; vitaltalk.org/guides/covid-19-communication-skills/; ariadnelabs.org/coronavirus/clinical-resources/covid-conversations/; thewhpc.org/covid-19). The Education on Palliative and End-of-Life Care program now also offers teaching modules targeting neurologists and neurologic illnesses

From the Departments of Neurology and Medicine (B.M.K. and R.G.H.), University of Rochester Medical Center, NY; Departments of Neurology and Medicine (C.L.V.), University of Colorado Anschutz Medical Campus, Aurora; Departments of Neurology and Family Medicine (M.T.R.), Mayo Clinic, Jacksonville, FL; Department of Neurology (C.C.), University of Washington Harborview Medical Center, Seattle; and Department of Neurology (I.S.), Geffen School of Medicine, UCLA, and West LA Veterans Affairs Medical Center, CA.

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Glossary

ACP = advance care plan; COVID-19 = coronavirus disease 2019; PC = palliative care.

(bioethics.northwestern.edu/programs/epec/curricula/neurology-modules.html). Some tips to enhance connection and communication via telemedicine include the following:

- Prepare for a telemedicine visit as you might do for an in-person visit: make sure important people are invited if needed, i.e. family members in person or a friend by phone/video and that the patient is in a quiet place
- Take advantage of the home environment to connect with your patients (e.g., “I love your house. Can you tell me more about that painting?”) and include loved ones for additional information and support.
- Before giving serious news ask what the patients know and what they want to know to ensure that our conversations are appropriately focused in the new and unfamiliar context of a telehealth visit.¹⁶
- When delivering bad news give a clear headline then pause to ensure that the patients understand what you said and to let them process this information.
- The tone of voice, facial expressions, eye contact (looking into camera), and pauses/silence can be used to convey empathy and are even more important when physical proximity or touch are not possible.
- Anticipating and responding to emotions and nonverbal cues is important and can also help build rapport.¹⁷

Addressing COVID-19-related concerns

The VitalTalk resources (vitaltalk.org/guides/covid-19-communication-skills/) provide sample responses to a wide range of COVID-19-related situations from responding to general concerns to what to say in situations requiring triage and allocation of scarce resources and how to assist someone in saying goodbye to a dying relative at a distance. One of the primary messages is that the question is not *if* your patients and families are affected by COVID-19 but *how*. Asking them directly about how their life has been affected by COVID-19 and what they are worried about can help you focus the support you provide. A PC approach may further allow you to respond in a manner that is both compassionate and empowering while acknowledging their concerns. For example, if a patient with an advanced neurologic illness is concerned about getting COVID-19 and dying alone in a hospital, one could use that as an opportunity for them to let you and their family know what their values are (e.g., comfort and being around family) and to create plans that align with those values (e.g., hospice). By contrast, if a patient with a chronic neurologic illness is interested in life-sustaining interventions, it may be prudent to discuss how they can contact your clinic because patients may

overestimate the risks of acquiring COVID-19 in the hospital, underestimate the risks of other health issues, and miss opportunities for early or remote interventions.

Inpatient care challenges

Although COVID-19 has generally decreased the census of inpatient neurology services, it has changed care in other ways. First, the language around limited resources can create a fear among patients of “missing out” on care such as ventilators, especially among patients with chronic or progressive illness. Second, patients are presenting late (or not at all) for common neurologic emergencies such as stroke.¹⁸ This limits options for acute care and increases the need for PC. Third, family members are unable to visit their loved ones in the hospital, which means patients are socially isolated, and at higher risk for depression and delirium.¹⁹ This also places additional stress on family who may have difficulty understanding the medical situation without seeing it. Families may opt for aggressive interventions out of guilt for not being present. Alternatively, some may opt for earlier discharge or hospice specifically to allow for greater social connection and visitors. Last, the hospital environment is challenging to persons with cognitive impairment even in the best of times; the absence of family and presence only of masked persons makes this more disorienting. Clinicians should make extra efforts to connect persons with cognitive impairment to family and include family on rounds to make sure the patient’s voice, values, and baseline status are known.

It is important to designate a point person in the medical team who communicates regularly with a point person for the family regardless of clinical changes and to provide technology, if needed, to facilitate videoconferencing. Finally, because patients and families consider goals of care, the prospect of being discharged to nursing homes with visitation restrictions, or to home with little help for the family, may influence decisions in unprecedented ways. These scenarios all increase the importance of clear communication, eliciting values from patients and families, and proactive screening for depression and psychosocial challenges.

Advance care planning

For those living with neurologic disease, the pandemic presents an opportunity to discuss goals of care and establish advance care plans (ACP), including designating a healthcare surrogate and completing a living will. Patients with advanced neurologic disease may be particularly vulnerable to COVID-19-related morbidity and mortality because of overall frailty and

comorbidities. Even if advance directives are already in place, the pandemic may force new perspectives and shift priorities. Through goals of care conversations, clinicians can elicit patients' values and goals and align recommendations for the care they receive. Careful prognostication and thoughtful, open communication with patients and family members is essential. COVID-19 may also shape these discussions because cardiopulmonary resuscitation may have additional consequences for patients, healthcare providers, and healthcare resources during the COVID-19 crisis.²⁰ The online resources mentioned above can guide these conversations, and The Conversation Project (theconversationproject.org/covid19/) and Prepare for You Care (prepareforyourcare.org/covid-19) have patient-facing resources.

The pandemic presents unique challenges to having goals of care and ACP discussions. With the tragic experience in Italy during this pandemic,^{21,22} the inability to supply needed resources such as ventilators is of great concern.²³ Many patients are worried that a preexisting disability, such as a neurologic disease, may exclude them from lifesaving treatments. As patients with terminal or life-limiting illnesses, they present ethical challenges for centers that may need to prioritize access to ventilator care because of insufficient critical care capacity⁴ or public health policies that prioritize doing the greatest good for the greatest number of patients.²⁴ With restrictions on visitors in hospitals and other facilities, it is imperative that patients with poor chances of survival are given the chance to make an informed decision about remaining at home.²³ The National Hospice and Palliative Care Organization has created COVID-19-related tools to assist in shared decision-making with patients and families (nhpco.org/wp-content/uploads/COVID-19-Shared-Decision-Making-Tool.pdf) and for healthcare decisions to frame ethical policies (nhpco.org/wp-content/uploads/COVID-19-Ethical-Framework-Decision-Making.pdf).

Symptom management

Several strategies for optimizing patient care during the pandemic include the following: (1) Provide “if, then” scenarios to help guide patients and caregivers if symptoms occur or worsen; (2) Ensure that risks and benefits of medication are understood and prescription refills are available; (3) Consider bridge therapy needs for patients who have procedures or treatments that have been postponed such as botox, epilepsy surgery, or intravenous immunomodulatory therapy; (4) Recommend daily routines such as exercise and mindfulness to reduce exacerbations in underlying symptoms or conditions due to stress, lack of sleep, or change in diet^{25–27}; (5) Anticipate and screen for new psychologic or psychiatric symptoms due to the stress and social isolation; (6) Develop a plan for touch points with patients who are high utilizers of the healthcare system; (7) Proactively communicate changes in the neurologic practice to patients and caregivers in an effort to reduce anxiety about missed or upcoming appointments and

encourage remote allied health visits; and (8) Refer patients to specialists who can provide additional symptom management remotely such as psychiatry, psychology, PC, physical therapy, occupational therapy, and speech therapy.

Psychosocial and spiritual support

Uncertainty, resource shortages, isolation, fear of or self-blame related to infection, fear of death, and financial insecurity are among the major stressors that contribute to emotional distress associated with COVID-19.^{28,29} Neurologists can provide frontline emotional support. When discussing loss or other difficult emotions, it is best to approach these topics directly and not avoid or minimize the underlying concerns.³⁰ Naming, validating, and exploring difficult emotions can provide some comfort and may indicate whether more formal counseling is needed.^{17,29–31} Some organizations have specifically established hotlines and virtual support groups including the Alzheimer's Association alz.org/. The American Academy of Neurology's patient and caregiver magazine *Brain and Life* has blogs on relevant COVID-19-related information for patients with neurologic disease brainandlife.org/. When available, chaplains, psychologists, or social workers can be helpful, particularly in addressing severe psychosocial distress.

Shelter at home measures present entirely new and stressful situations for caregivers.³² Suggestions for how best to support family caregivers during COVID-19 include consider family caregivers in all discussions of personal protective equipment, implement simple risk assessment questions or checklists to assess caregiver needs and well-being, include caregivers in goals of care discussions, show gratitude for all they are doing, and encourage them to leverage their social networks in whatever way that is helpful and safe.³² Regional and national online support groups (e.g., pmdalliance.org/events/) can provide additional information, support, and connection.

Palliative care referrals and end-of-life palliative care (hospice)

Although the practice of primary PC skills are important for neurologists,¹⁰ it is also important to know when patient or family concerns may exceed one's skill set. When available, specialists in the emerging field of neuropalliative care may be consulted for both educational and clinical needs.³³ Because there is still a very limited number of neuropalliative care providers, we would encourage neurologists to consider consultations with palliative medicine colleagues when complex goals of care discussions, symptom management, and psychosocial support needs are present.

End-of-life PC (hospice) should be considered for patients whose goals are primarily comfort and have either end-stage neurologic disease or who have advanced neurologic disease

and are seriously ill with COVID-19. In the United States, hospice enrollment guidelines include a prognosis of 6 months or less and comfort as the primary goal of care ([medicare.gov/Pubs/pdf/02154-Medicare-Hospice-Benefits.PDF](https://www.medicare.gov/Pubs/pdf/02154-Medicare-Hospice-Benefits.PDF)). Referrals to hospice are facilitated by physicians, including neurologists, and shared decision-making tools regarding the appropriateness of hospice care in COVID-19-positive patients can be useful nhpco.org/wp-content/uploads/COVID-19-Shared-Decision-Making-Tool.pdf.

Conversations about transitioning to hospice care should not be delayed during the COVID-19 pandemic because patients near the end of life and their families can benefit from the interdisciplinary support of the hospice team. One of the most important benefits of hospice is providing 24/7 access to the hospice team, which provides an alternative to 911 calls and may allow them to stay out of the hospital. Hospice teams consist of physicians, nurses, chaplains, social workers, aides, and volunteers, all of whom work together to assess and manage physical and psychologic symptoms, provide anticipatory guidance, support caregivers, and maximize quality of life. Hospice provides durable medical equipment and is paid for by both Medicare and Medicaid as well as most insurers. Hospice organizations remain open and functional during this time, although the delivery methods of particular services may be modified. For families concerned about increasing exposures in the home, they can be assured that hospices are taking precautions including the use of telemedicine to meet the needs of patients and caregivers while reducing potential exposure to patients and spread by and amongst hospice staff.

Self-care for patients, families, and clinicians

Healthcare providers are often trained to put aside their own feelings and emotions to put patient well-being and care first, and during a time of a crisis, this focus can be intensified; the idea of self-care may feel counterintuitive.²⁹ Caregivers may similarly feel guilty about attending to self-care needs. These natural and noble impulses unfortunately may contribute to higher rates of burnout and undermine not only well-being but the ability to care for others. Thus, during this crisis, everyone should be encouraged to establish self-care routines including healthy food, sleep, social connections, and limiting news media ([who.int/docs/default-source/coronaviruse/mental-health-considerations.pdf](https://www.who.int/docs/default-source/coronaviruse/mental-health-considerations.pdf)).

Ongoing ethical care for patients and families requires dealing with the personal thoughts and emotions that arise during care.³⁴ PC has long recognized the importance of self-care to all healthcare professionals as is evident through a suite of quality standards, core competencies, and practice standards in which self-care practice is mandated.³⁵ In addition to individual practices, departments and institutions can work to ensure that ongoing and emerging self-care needs are met for their faculty and staff.³⁶

Personal resilience is a construct associated with the ability to adapt and even thrive when challenged by stressors or adversities.^{37,38} We can build resilience, even in the midst of a crisis by focusing on our strengths, what we can control, flexibility, who we want to be when the crisis is over and making time to connect with meaning, hope, joy, and people we love.^{39–41} We can similarly encourage resilience and hope in our patients and families by reminding them of their strengths, empowering them to focus on things they can control, and encouraging them to pursue activities they find meaningful or joyful.

Neuropalliative care opportunities and the post-COVID-19 era

Although the field of neuropalliative care is young, the COVID-19 pandemic has accelerated and brought its primary goals into focus—to relieve suffering and find opportunities for joy, hope, and meaning for patients and families with neurologic disease. This growth and maturity will be accomplished by applying our expertise of neurologic disease and following the basics of practicing good medicine and PC: building trusting relationships, practicing shared decision-making, reducing symptom burden, mindful cultural awareness, and exploring opportunities for growth even as health declines and death approaches. This pandemic also affords us all a once in a lifetime opportunity to reimagine how to best bring care to patients, on their terms, as opposed to our terms of bringing patients to care. This may be the bellwether event to motivate new care designs, delivery strategies, and communication approaches that gets us closer to the ideals of truly person-centered care.

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Appendix Authors

Name	Location	Contribution
Benzi M. Kluger, MD, MS	Departments of Neurology and Medicine, University of Rochester Medical Center, Rochester, NY	Design and conceptualization of the manuscript and drafting and revising the manuscript for intellectual content.

Continued

Appendix (continued)

Name	Location	Contribution
Christina L. Vaughan, MD, MHS	Departments of Neurology and Medicine, University of Colorado Anschutz Medical Campus, Aurora, Colorado, USA	Drafting and revising the manuscript for intellectual content.
Maisha T. Robinson, MD	Departments of Neurology and Family Medicine, Mayo Clinic, Jacksonville, FL	Drafting and revising the manuscript for intellectual content.
Claire Creutzfeldt, MD	Department of Neurology, University of Washington Harborview Medical Center, Seattle, WA	Drafting and revising the manuscript for intellectual content.
Indu Subramanian, MD	Department of Neurology, Geffen School of Medicine, UCLA, and West LA Veterans Affairs Medical Center, Los Angeles, CA	Drafting and revising the manuscript for intellectual content.
Robert G. Holloway, MD, MPH	Departments of Neurology and Medicine, University of Rochester Medical Center, Rochester, NY	Drafting and revising the manuscript for intellectual content.

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