

VIEWPOINT

Ensuring Adequate Palliative and Hospice Care During COVID-19 Surges

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Relieving physical and emotional distress and supporting patients and families through illness, even when cure is not possible, is foundational to medicine. Yet, while states and health systems have devoted much work to the fair allocation of scarce critical care resources, novel therapeutics, and potential vaccines during the coronavirus disease 2019 (COVID-19) pandemic, many triage protocols assume all patients who need palliative and hospice care will have access to these services.¹ But even under usual conditions, shortages in these services are common.² As the United States surpasses the grim milestone of 200 000 excess deaths due to COVID-19,³ surges in demand for end-of-life care have exposed and exacerbated underlying gaps in access to specialty-trained physicians and teams, palliative care medications, and bereavement support for patients and families.² These gaps jeopardize the quality of care for seriously ill and at-risk patients, including those whose prognosis is uncertain and those with diseases other than COVID-19.

Beyond surging demand in addition to preexisting resource limitations, the pandemic has also brought novel challenges to ensuring quality end-of-life care. Most important and always, good care involves having a clear

ing comfort-focused support in hospitals have encountered insufficient access to staffing, bed space, and medications for symptom relief.⁵ Patients preferring in-home hospice care have experienced delays or lack of access due to COVID-19 restrictions and overwhelming demand for community-based hospice services.⁶ Shortages of personal protective equipment have compromised services from professional personnel in institutions and hindered caregiver and family support at home.⁷ Many patients have died of COVID-19 in isolation while disconnected from family and friends, and their loved ones have also experienced forced separation and an inability to share important feelings, provide comfort, and find closure.⁵⁻⁷

With proactive planning and lessons from earlier experiences, these consequences should be preventable, even as demand surges. In Colorado, for example, clinicians and the state recognized the need for a focused plan and developed crisis standards of care for palliative care and hospice services.⁸ The plan identified 3 action pillars to strengthen palliative care response to future surges in demand (Table). First are actions to improve communication and documentation of patients' goals of care and preferences for treatment prior to and during a COVID-19 surge.^{2,4} Second are plans to ensure alternative care processes and spaces for patients receiving comfort-focused care to accommodate expected surge overflow from hospitals, nursing homes, and other care facilities.⁹ Third are plans to create a virtual hotline for round-the-clock specialty-level advice and support to extend palliative care expertise during

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understanding of patients' goals, values, and preferences for treatment. But goals-of-care conversations have often been limited for patients during the pandemic due to overburdened health systems, restrictions on face-to-face clinical interactions, and sometimes rapid physiologic decline among patients with COVID-19. Moreover, family members and caregivers are often important contributors to these conversations, but restrictive visitation rules have altered and reduced their interactions with clinical teams. Absent or ineffective goals-of-care conversations can create subsequent problems for health systems as well as individual patients. For instance, during a surge simultaneous with scarce intensive care unit (ICU) capacity, preference uncertainty weakens the ability to achieve the goal of fair allocation of scarce ICU resources, and these skilled conversations can help identify patients who would have preferred comfort-focused therapies.⁴

Multiple examples of inadequate palliative care during COVID-19 surges have been reported.⁵ Persons need-

ing a surge.^{4,5} Absent a second overwhelming wave of COVID-19 in Colorado, whether this bundle of changes will improve palliative care services remains unknown.

Providing adequate end-of-life care under surge conditions will require innovative actions across the 3 pillars, including changes that might be contentious or even unacceptable under usual conditions. Even so, such changes might inform eventual permanent improvements. For instance, in a surge environment, patient verbal requests for designation of health care agents and e-signatures for just-in-time advance directives should be recognized as legally equivalent to traditional written advance directive documents. Opioids and other drugs necessary for palliation should be equitably available across all settings and communities where people are in pain and dying, which could entail diverting supplies from acute care settings to those offering comfort-focused care and to historically disenfranchised communities. Expanding the palliative care workforce in

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Table. Colorado's Priorities for COVID-19 Palliative and Hospice Care Surge Planning^a

Pillar	Goal	Presurge and surge actions
ACP	Ramp up ACP conversations and documentation of treatment preferences for a COVID-19 surge	Encourage virtual and in-person ACP conversations across all settings and for all patients regardless of underlying risk of severe COVID-19 illness Adjust ACP forms to encourage documentation of treatment preferences specific to the possibility of severe COVID-19 infection Work with local leaders to deploy ACP initiatives in communities that are most affected by COVID-19 Create training materials and other resources to increase clinician comfort with ACP conversations related to a COVID-19 surge Address policy barriers to timely ACP decisions during a surge, including allowing verbal designations of decision makers and e-signatures of ACP forms
Alternate care sites	Plan for rapid deployment of alternative care sites for patients needing palliative and hospice care	Locate options for alternate care sites with sufficient beds, resources, and visitation policies to provide adequate end-of-life care during a surge Address policy barriers to site operations, including relaxed licensure and staffing standards under specified surge conditions Set aside adequate personal protective equipment, essential medications, and testing supplies to ensure that all patients, whether COVID-19-infected or not, experience high-quality end-of-life care
Consultation services	Implement a statewide consultation hotline	Build infrastructure and partner agreements to establish access to telehealth specialists via statewide or regional call centers Partner with health care organizations, hospitals, long-term care facilities, and hospices to strengthen access to consultation and support

Abbreviations: ACP, advance care planning; COVID-19, coronavirus disease 2019.

^a Adapted from Colorado Contingency and Crisis Standards of Care—Palliative Care and Hospice Services.⁸

a surge might mean on-demand training as well as relaxation of staffing and licensure standards; under extreme conditions, this might entail allowing family members (especially those who have already been infected) to provide care usually reserved for licensed professionals.^{2,10} Hospitals, nursing homes, and other facilities must reduce the risk of patients dying alone in isolation by loosening overly restrictive visitation policies for dying patients, providing adequate personal protective equipment for their visitors, and ensuring tools for virtual visitation.⁷ Hospitals are not prisons, and patients and families should be allowed to undertake reasonable risks of visitation with dying loved ones, with the understanding that this exposure could result in potential illness among visitors or may entail subsequent quarantine.

Lessons learned from providing end-of-life care during the COVID-19 pandemic should also inform future medical training. Some clinicians are comfortable with eliciting goals of care and providing care focused on palliation, but these skills are not emphasized in traditional medical training and do not come naturally for many clinicians focused on

curing illness. Further, comprehensive palliative care often requires the expertise of interdisciplinary teams, and only in recent years has teamwork become a focus of medical training and practice.

An ethical approach to pandemic surge planning requires recognizing and addressing threats of scarcity throughout the community, including for patients whose primary goals are symptom relief and comfort at the end of life. Failure to plan for adequate palliative and hospice care when a substantial increase in disease and death is expected is unconscionable, and it risks undermining patient-family trust, long-term emotional health, and the core values of society. This has been recognized at least since the 2012 report on Crisis Standards of Care from the Institute of Medicine, which declared that “provision of palliative care in the context of a disaster with scarce resources can be considered a moral imperative of a humane society.”¹⁰ That call to action was largely ignored in the first wave of this pandemic, but it is more real now than ever during ongoing threats of overwhelming local and regional surges in demand for palliative and hospice care.

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1. Antommarría AHM, Gibb TS, McGuire AL, et al. Ventilator triage policies during the COVID-19 pandemic at US hospitals associated with members of the association of bioethics program directors. *Ann Intern Med.* 2020;173(3):188-194. doi:10.7326/M20-1738
2. Bowman BA, Back AL, Esch AE, Marshall N. Crisis symptom management and patient communication protocols are important tools for all clinicians responding to COVID-19. *J Pain Symptom Manage.* 2020;60(2):e98-e100. doi:10.1016/j.jpainsymman.2020.03.028
3. Centers for Disease Control and Prevention. Excess deaths associated with COVID-19. Accessed August 16, 2020. https://www.cdc.gov/nchs/nvss/vsrr/covid19/excess_deaths.htm
4. Lee J, Abrukin L, Flores S, et al. Early intervention of palliative care in the emergency department during the COVID-19 pandemic. *JAMA Intern Med.* 2020;e202713. doi:10.1001/jamainternmed.2020.2713
5. Powell T, Chuang E. COVID in NYC: what we could do better. *Am J Bioeth.* 2020;20(7):62-66. doi:10.1080/15265161.2020.1764146
6. Birnstengel G. Next Avenue, Twin Cities PBS website. Hospice: demanded but threatened by COVID-19. Published April 10, 2020. Accessed August 2, 2020. <https://www.nextavenue.org/hospice-covid-19/>
7. Lynn J. Playing the cards we are dealt: COVID-19 and nursing homes. *J Am Geriatr Soc.* 2020;68(8):1629-1630. doi:10.1111/jgs.16658
8. Colorado Department of Public Health and Environment website. Colorado Contingency and Crisis Standards of Care—Palliative Care and Hospice Services. Accessed July 26, 2020. <https://www.colorado.gov/pacific/cdphe/colorado-crisis-standards-care>
9. University of Nebraska Medical Center; Global Center for Health Security. Comfort-only care unit. Cohorting COVID-19 and non-COVID-19 patients in a comfort-only care unit. Published May 6, 2020. Accessed September 14, 2020. <https://www.unmc.edu/healthsecurity/ethics/consultation-reports/Comfort-Only-Care-Unit.html>
10. Committee on Guidance for Establishing Crisis Standards of Care for Use in Disaster Situations; Institute of Medicine. *Crisis Standards of Care: A Systems Framework for Catastrophic Disaster Response.* National Academies Press; 2012. doi:10.17226/13351