


Editorial

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As the number of confirmed COVID-19 cases rise exponentially, the human-centered mandates at the foundation of palliative care philosophy are more important than ever before (Lancet, 2020; Radbruch et al., 2020; Rosa and Davidson, 2020). At the intersection of complex COVID-19 symptoms and a shortage of palliative care specialists and symptom management medications internationally (Knaul et al., 2018), patients who test positive for the virus are at risk for increased suffering and a higher burden of “total pain” (Cassell, 1982; Saunders, 1993; Center to Advance Palliative Care [CAPC], 2020), particularly the seriously ill and those at the end of life. The social gravity of the pandemic, alongside transmission mitigation tactics such as social distancing and quarantine requirements, is already resulting in depersonalized care delivery, greater severity of patient and family caregiver distress, and overstretched resources focused on testing, triage, and viral treatment.

During the current global public health emergency, clinicians may likely struggle to meet the psychological, spiritual, social, and emotional needs of patients and family caregivers. Moreover, the burnout and existential distress experienced by healthcare professionals worldwide prior to COVID-19 will likely increase significantly amid the current pandemic (National Academies of Sciences, Engineering, and Medicine, 2019; Parks, 2020; Pessin et al., 2015). Our purpose is to continue a scholarly dialogue that informs the mitigation of human suffering through safe, high-quality, palliative care in the context of serious illness and in the inevitability of future health crises. While the number of COVID-19 cases will hopefully decline in the near future, the human impact — and suffering — in these initial months of the pandemic will continue to escalate, as communities and individuals face the grief of losing hundreds of thousands of lives worldwide.

Responding to suffering during COVID

COVID-19 is magnifying a collective fear and anxiety about impending destruction, as mortality rates rise steadily and we learn more about healthcare system capacity constraints, the possibilities of resource rationing and blanket do-not-resuscitate orders, and low survival rates linked to advanced stages of COVID-19. The era of social media, constant news streaming, and internet has made this pandemic, and the associated suffering, more visible than any previous public health crisis. Mainstream and alternative media platforms share continuous images of suffering. Loved ones are physically separated and patients die in ways that are in opposition to what many would consider the key principles of palliative care — in intensive care units (ICUs), on ventilators, without family. When considered against the backdrop of serious illness, the daily experience of suffering is magnified, bringing to the surface both an individual and collective existential distress that is detrimental to coping and resilience strategies.

Consider the initial trauma associated with a confirmation of COVID-19. There is likely fear associated with prognosis given the media coverage. There is anxiety related to worsening symptomatology and the possible need for hospitalization. As most visitors are now banned from hospitals, ill individuals experience rapid decompensation characterized by shortness of breath, delirium, and gastrointestinal distress, while family caregivers remain unable to see, hold, or comfort their loved ones. Patients with underlying conditions, such as advanced cancer, depression, anxiety, or chronic pain, may confront worsening of their baseline symptoms. Families watch loved ones taken away by ambulances knowing that may have been their last moment together. Death and dying has increased markedly in hospitals globally, and the grief and bereavement processes of family caregivers have been deeply impacted. Indeed, the existential distress experienced by family caregivers has likely never been higher, as is the potential for post-traumatic stress disorder and prolonged grief disorder in those left behind. The urgent need for medical intervention for patients with COVID-19 is matched by a critical demand to support their loved ones (Kent et al., 2020).

These clinical realities of how the healthcare workforce is “managing” COVID-19 leave much to be desired in how we “tend to” and “alleviate” suffering. While necessary given the physical and human resources of many health systems, the mechanistic, biomedical approach to “flattening the curve” falls short of the relationship-based ethic that underlies palliative and supportive care practice. The scenario described above brings to the forefront many of the tenets of suffering. Ferrell and Coyle (2008) described suffering as a loss of control creating insecurity, associated with loss; intensely personal, accompanied by a range of emotions; involves asking “why?”; associated with separation from the world or loneliness; often coupled with spiritual distress; closely related to pain; occurs when one feels voiceless; and is linked to the deep recognition of one’s own mortality. The clinical progression of COVID-19 for many patients has escalated so quickly there has been little time for patients or family caregivers to discuss the reality of the disease, adjust to the caregiving role, clarify goals of care, or create a legacy as life ends. In some ways, the separation, aloneness, and loss of control associated with COVID-19 have become diagnostic criteria.

Given the unique, high-risk vulnerabilities of seriously ill patients and those at the end of life who are COVID-19 positive, many palliative care organizations are guiding clinicians to employ presence, use deep listening skills, and promote cultures of professionalism and calm in interactions with patients, families, and colleagues (CAPC, www.capc.org; End-of-Life Nursing Educational Consortium, ELNEC, www.aacnursing.org/ELNEC; National Hospice and Palliative Care Organization, NHPCO, www.nhpc.org; VitalTalk.org, www.vitaltalk.org). These recommendations align with Reich’s (1987, 1989) work on suffering. He described three phases of the suffering individual’s journey to find a voice in their search for meaning: mute suffering, expressive suffering, and new identity. Seriously ill patients with a confirmation of COVID-19 may not have the opportunity to find that voice given the acute decompensation associated with the virus. They may experience the circumstantial shock that leads to mute suffering and a subsequent inability to express needs. For many, by the time one is finding language, physical symptoms may have caused significant distress and an inability to lament, tell their story, or interpret their experience. Given poor outcomes for those with underlying conditions, the opportunity to reframe one’s story or embody a new identity on the other side of hardship may be impossible. Indeed, there are countless ill patients in the grips of COVID-19 and wedged in the angst of mute suffering with limited time to experience the healing and care which has become recognized as optimal at the end of life (Berry and Griffie, 2019).

Suffering of clinicians

Burnout, moral distress, and existential anxiety are well documented among palliative care clinicians (Pessin et al., 2015; Harrison et al., 2017; Kamal et al., 2019). However, the sequelae of COVID-19 likely heightens this vulnerability. These providers are impacted by the heightened cumulative loss experienced with increased patient mortality, complex patient–family dynamics, inability to be present physically to support patients at the time of death, moral injury in challenging ethical circumstances, suboptimal symptom management amid medication shortages, and no opportunities to clarify patient/family values or establish trusting relationships. These considerations occur in the setting of greatly increased professional and personal change. Professionally, clinicians may be adapting to telehealth forums

for communication and patient management, new work responsibilities, and a lack of personal protective equipment or medication shortages at the bedside. Personally, they are apt to have fears of transmitting COVID-19 to family members, processing their own family or community losses, and adapting to the collective shock of the pandemic. Frontline palliative care clinicians are likely experiencing heightened transference, questions about their own mortality, and exacerbation of baseline mental health challenges. This pandemic has placed clinicians at personal risk to a degree never previously experienced by most. The thin veil of “we, the healthy clinicians” and “you, the ill patient” has disappeared in the context of COVID-19.

Future direction to respond to suffering

As the global burden of suffering increases in the face of COVID-19, there is an invitation to renew commitment to compassion, whole-person approaches to care, and relationship-based expertise. The worlds of the emergency department and ICU have found new common ground with the specialty of palliative care. The value of communication, family support, symptom management, and spiritual care have become a shared language. Palliative care clinicians have also been transformed with a new understanding of critical care — that intense struggle to help patients survive and the deep and painful recognition of the moment when that goal is not possible.

The legacy of COVID-19 will undoubtedly be one of massive suffering, mortality, grief, and public health and economic crises. But, it will also be remembered for profound compassion, highlighted by images projected by the media of individuals and communities engaged in kind and generous acts. We have witnessed the worst of a crisis, and we have also witnessed the best of humanity responding to the suffering created by this crisis.

For the duration of the COVID-19 pandemic, we, as palliative care advocates, whose aim is to role-model, teach, research, and advance awareness of the human condition in healthcare, must hold fast to our humanistic values through strategic personal and institutional action plans. This is the moment when our art must deliberately and consistently inform the broader science of the healthcare system.

How will we respond?

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