

Hospice Shines During the Pandemic, Revealing Expanded Possibilities

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Dame Cecily Saunders, founder of the modern hospice movement, believed in caring for all of a patient's needs, including physical, social, emotional, and spiritual. She encouraged focusing on the whole person and embracing the patient's family and friends as part of their care.

COVID-19 tested the entire medical system. It demonstrated the value and benefit of holistic and home-based care, more social and emotional support, and more care for families and loved ones. Hospice has and continues to model the delivery of these services.

In hospice, a team of interdisciplinary health care professionals bring their expertise, empathy, compassion, and intention to support the whole patient. Additionally, working with the terminally ill, hospice caregiving crosses over into the sacred. Team members know that they are guests in the homes of those served and it is a privilege to be with patients and families to discover and affirm their individual stories. "Home" can be a private residence, long-term care setting, assisted living facility, inpatient facility, or a homeless shelter. The support of hospice is not over when the patient dies. After a patient's death, hospice is still present, supporting families during the grieving process and their transition to living without their loved one.

This sacred time of life is not taken lightly and requires connection and trust. The pandemic has required the use of personal protective equipment, creating a barrier from all physical connection that is traditionally used to create that bond. As seasoned hospice workers know, connection

can come from many places besides touch. Hospice team members rely on listening, eye contact, physical presence, and now out of necessity, the integration of virtual care.

People who work in health care are gritty, self-sacrificing, and passionate about what they do. Yet during the pandemic, even the most committed clinicians experienced fear and guilt, worrying about their own safety and the daily threat of becoming infected or exposing their loved ones at home.

We all saw the media images of family members, hands pressed to the windows, visiting loved ones in nursing homes and personal homes. The inability of families to connect with their loved ones made the role of hospice care even more important. Often, the hospice care team became the surrogate family. As family members could not visit due to facility restrictions or social distancing guidelines, the hospice care team became the bridge.

Throughout the pandemic, hospices found ways to be innovative and supportive of those in need. Virtual caregiver support sessions were provided to facility staff who were coping with COVID-based fatigue and loss. Drive-by parades for facility staff helped bring joy into a dark time. Virtual bereavement groups helped family members coping with COVID losses even when their loved ones were not hospice patients. Hospice interdisciplinary care teams facilitated virtual meetings for patients and family members when travel or gathering was too risky. With virtual reality, a daughter could take her mom on a final beach

trip virtually from her bed. From his hospice inpatient bed, a prisoner was able to “visit” with his children living across the country.

In response to COVID-19, the Centers for Medicare & Medicaid Services (CMS) regulatory waivers created the opportunity for innovative methods of care delivery. Among the flexibilities were the use of telehealth for patient services and certification and the waiver of the requirement for hospices to use volunteers during the pandemic, among many others [1].

The intent of health care regulations is to hold providers accountable and responsible for the care provided. Beyond this noble intent, however, the rules can create unintended barriers and limitations that can have negative outcomes. The pandemic drove outcomes and needs, not protocols, which allowed the focus to be on whatever it took to care for the patient. For example, the use of telemedicine, previously unbillable, was allowed and proved to be extremely effective and successful in connecting with patients when face-to-face encounters were limited or prohibited. Nurses could case-manage with teleconferencing, creating connection with patients and families beyond in-person visits.

We must take innovations like these and allow them to continue to thrive in order to support care. The pandemic also magnified the desire for home-based care and support for those living with a serious or advanced illness. Hospice has been an integral part of home-based care in our communities for decades, and its role can be expanded. A unique competency of all hospice team members is the ability to engage in really difficult but necessary conversations about quality of life, patient choice, and self-determined life closure (e.g., choosing palliative care versus a curative course of treatment). COVID-19 elevated the need for this skill set in all health care settings.

Dedicated and accessible programs are also needed to

support the compounded grief of our health care workers and our communities. Hospices have a depth of experience to help with these complex bereavement needs. Today, community-based grief support is not reimbursed. Additional funding is needed to adequately support the grief and loss needs of our diverse communities.

Whether home-based or facility-based, what has been asked of our health care heroes is unprecedented. We must find ways to nurture and restore our frontline heroes so they can continue their journey to support our most vulnerable patients and families at the end of life. Let us not forget them as life moves on. **NCMJ**

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References

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