Hospice Care Continues — Without the Human Touch

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Melissa Moody, a nurse with Heart of Hospice, runs a pop-up hospice for COVID-19 patients that opened in the New Orleans area in April. A photo pinned to her gown shows her patients an image of her smiling face without a mask and face shield.

Courtesy of Heart of Hospice

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As Melissa Moody leaned over the bed of her patient, a dying old woman with COVID-19 and dementia, she was surprised when the woman raised a wavering hand and gently caressed the shield that covered the hospice nurse's face.

"She wanted to stroke my cheek, but instead stroked my face shield," said Moody, who runs an in-patient, COVID-only, pop-up hospice unit near New Orleans.

"It struck me that she needed to feel human touch at the end of her life."

Shortly after, the woman took her last breath.

If anyone in the health care industry might have been expected to be prepared to face the grim toll from COVID-19, it was hospice care providers whose purpose even in normal times is to usher the dying to peaceful, pain-free endings.

Yet even hospice care workers have found their professional lives altered in unimagined ways. The pandemic introduces fear and risk into their daily routines while limiting the arsenal of customary tools they wield to bring comfort to the dying and bereaved.

Touch is just one of those techniques. “Hugs used to be a big part of my job,” said Luan Biggs, a certified nursing assistant with the southern Wisconsin hospice and palliative care provider Agrace. Skin-on-skin contact — so prevalent, if not essential, in hospice work — is off limits now.

Hospice care, which addresses the physical, psychological and spiritual needs of patients and their families, is particularly intimate. Patients develop bonds with hospice caregivers, who include physicians, nurses and nurse assistants, social workers, bereavement counselors and often spiritual care coordinators as well.

Unlike elsewhere in health care, hospice workers tend to spend prolonged time with patients and their families. Care is often holding a hand or offering an empathetic smile. A premium is placed on physical and emotional presence.

Story continues after map

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Dallas-based hospice care provider Intrepid USA, which serves homes and long-term care facilities in 17 states.

Most hospices also must console or offer complicated care details to family members by phone rather than in person.

And many hospices report instances of staff falling ill with the virus.

“We struggle knowing that this isn’t the ideal model we always held up for ourselves and our communities,” said Bill Finn, Western Reserve’s CEO. “Our staff has expressed pain in their soul that they can’t provide care as they’re used to.”

Even when hospice care workers are there in person, they offer care from behind masks, face shields, gloves, head-to-toe gowns and booties. “Most patients from nursing homes have a degree of dementia,” said Moody, who works for South Carolina-based Heart of Hospice. “When they see us, it can be frightening, and that has been hard for us.”

Moody, like hospice workers elsewhere, has begun pinning a laminated photo of her unobscured, warmly smiling face to her gown. It’s not much, she said, but she hopes it transmits the concern that her mask now obscures.

Another disturbing difference Moody has noticed between her pre- and post-pandemic professional life: “The amount of people who have whole families that are ill and are having multiple losses. We’ve had two different patients whose spouses died shortly before or after they did.”

Because of nursing home restrictions or relatives’ fears about visiting, hospice workers sometimes find themselves substituting for family members. Sigrid Larson, an Agrace hospice nurse, regularly meets the daughter of a patient in a Target parking lot.

The mother yearns for the home-cooked meals she and her daughter until recently could share together, so the daughter delivers the meals to Larson, who takes prepared dishes to the mother at the nursing home, where the daughter, as a family member, is barred.

Some workers have been the only ones present when their patients died.

Perhaps counterintuitively when the virus has sickened 1.2 million and killed more than 76,000 Americans, some hospices are reporting less rather than more demand for their services, at least so far.

Many hospital patients with COVID-19 deteriorate and die so quickly, Finn said, that there is no time for hospice. Many other patients ill with other conditions, he said, are avoiding hospitals out of fear, which is eliminating many of the referrals hospices would normally expect. In addition, many nursing homes are closing their doors to outsiders, including hospice workers.

Finn said occupancy at Western Reserve is down by about 60%.

But those dips aren’t everywhere. Some hospices say they are getting more home patients as family members pull loved ones out of nursing homes for fear that visitor restrictions at those facilities would keep them out at the time of death.

The coronavirus is forcing other changes as well. Wendy Miano, a home hospice nurse for Western Reserve, tends to a 44-year-old hospital patient with advanced lung cancer who

was suspected of being COVID-19 positive. When he was well enough to be released to a nursing home, none would accept him because of the potential diagnosis.

Miano volunteered to care for him at his grandmother's home. While his cancer diagnosis remains grave, he has not exhibited COVID-19 symptoms for weeks. He brightened considerably, Miano said, after she was able to shed some of the protective equipment that early on she knew had distressed him.

Coronavirus Hospice

While some hospices are getting fewer patient referrals, for others the need is greater. Heart of Hospice previously operated only one in-patient unit, in Fort Smith, Arkansas, and provided most of its hospice care in homes or long-term care facilities across five states.

But as the coronavirus struck New Orleans hard, its CEO, Carla Davis, moved quickly to open a 15-bed, in-patient hospice for COVID-19 patients only. The center is in a former acute care facility attached to East Jefferson General Hospital in Jefferson Parish. It has been operating at or near capacity since it opened April 15.

"One of the drivers for us opening a pop-up COVID unit was to help these patients and help their families see them before they died," Davis said.

The advantage of having an all-COVID-19 in-patient hospice, she said, is that it can set a protocol on the use of personal protective equipment. The entire facility is adapted for negative air pressure to keep contamination to a minimum.

Davis said the state of Louisiana cleared red tape to enable the facility to open in little more than a week, rather than the months it might have taken in normal times.

Like other hospices, Davis said, Heart of Hospice had to scramble to secure sufficient personal protective equipment, sometimes with state help. Some of the federal CARES money has made its way to hospices, but executives say revenue is down, not only as a result of fewer referrals but also because Medicare doesn't reimburse for pandemic equipment. Hospices are on their own for that, Finn said.

The National Hospice and Palliative Care Organization has asked Congress for more direct financial aid to hospices and for help securing personal protective equipment. Edo Banach, its CEO, said there also is a vital need for testing to identify patients and staff who are COVID-19 positive.

Several executives said that even if some hospices are seeing fewer patients now, they expect the reverse to be true in coming months. They fear that many older people who are forgoing health care now will end up in hospice as the crisis ebbs.

While hospice workers acknowledge that the coronavirus has altered the way they work, many say they still feel intimacy with their patients.

Darcia Simpson, a spiritual care coordinator with Western Reserve for 18 years, is one. Her job is to help patients pursue spirituality, if that is their wish. That can mean connecting them with clergy, helping them perform rituals that are important to them or just talking with them about faith.

They still share their fears, disappointments and hopes for what awaits them when their time arrives. Some lament the cancellation of highly anticipated weddings or graduations because

Source: *Stateline* research

Stay-home order status

“In most of health care, the watchword is, ‘Don’t just stand there, do something,’” said Judy Bartel, chief clinical officer of the Hospice of the Western Reserve, an in-patient and home hospice care provider in the Cleveland area. “In hospice we say, ‘Don’t do something, stand there.’ It’s the gift of presence.”

And that gift has been diminished.

Caring at a Distance

Home hospice workers have sharply reduced their in-person visits to patients, shortened them, or eliminated them altogether in favor of virtual visits.

Even if the dying patients are thought not to have COVID-19, many hospices have adopted those same cautions, not least of which because patients and their families worry someone might bring the virus into their homes. Most hospices also are sharply limiting family visits to in-patient centers.

Although many hospice workers care for patients in nursing homes, many of those routine visits have been barred because of high infection rates. Some workers have visited nursing home patients from outside, through windows, said Bob Parker, chief clinical officer at the

of the virus, Simpson said.

Even if the visits are now by phone instead of in person, Simpson said, they talk and they talk and they talk. “More, sometimes, than if I were actually there,” she said.

Simpson was hospitalized with COVID-19 for a time. She lives in a small house with an older sister, a nurse, and her 95-year-old mother, both of whom also contracted the disease.

Her mother, who has heart failure, diabetes, kidney disease and high blood pressure, always said she wanted to die in her own home, and Simpson wasn’t going to let her go to a hospital and risk dying alone. Simpson enrolled her in home hospice care.

Her mother has recovered from COVID-19.

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