

THE CHALLENGES OF PROVIDING HOSPICE CARE IN LONG-TERM CARE FACILITIES DURING COVID-19

The COVID-19 pandemic has created multiple impediments to a peaceful, natural death. One particularly painful and contentious clash has been over the care of hospice patients in long-term care facility. Hospice services in residential care communities have been highly compromised as nursing homes have struggled to protect their residents. This paper explores the salient issues on both “sides” and looks toward possible solutions.

While we often hear that we are a nation in grief, the complications for hospice deaths involve much more than grief. Common but devastating responses are:

- Persistent Complex Grief Disorders: Grief is not processed; reactions to overwhelming multiple losses do not resolve naturally and can become lifelong handicaps.¹
- Trauma: Responses to “helplessness and horror,” creating hypervigilance, cognitive dissonance, loss of trust in an assumptive world, “waiting for the other shoe to drop.”
- Moral Distress: The debilitating experience of having your deepest ethics and values violated.

While straightforward grief is a natural part of a dying process for both patient and family (however defined), dealing with complex disorders, trauma and moral distress is not. Treatment requires skilled identification and time and expertise for mental health professionals to apply therapeutic modalities and techniques appropriate to each. For most people, these events will be disenfranchised, minimized or unaddressed.

The Centers for Disease Control and Prevention and World Health Organization both issued statements about the mental and behavioral emergencies that COVID-19 created. Recent studies confirm this mental health crisis of pandemic proportions² that will not abate as infection rates decrease. Instead, the impact will have longstanding deleterious effects on families. As patients with ‘long COVID’ live into the years ahead, those impacts will become more complex.

Consistently, dying patients have expressed their greatest goals³ as

¹ It is critical to understand that grief is not solely a collection of emotional reactions to a loss; people may manifest grief physically, behaviorally and socially, destabilizing their immune systems and muting their ability to respond to stresses or accept support.

² Bereavement in Times of COVID-19: A review and Theoretical Framework, Stroebe, M. & Schut, H., OMEGA – Journal of Death and Dying (2021) Vol. 82(3) (500-522); Tracking the reach of COVID-19 kin loss with a bereavement multiplier applied to the United States Ashton M. Verdery, Emily Smith-Greenaway, Rachel Margolis, Jonathan Daw. Proceedings of the National Academy of Sciences Jul 2020, 117 (30) 17695-17701; DOI: 10.1073/pnas.2007476117

³ Journal of the American Medical Association, Vol. 284, No. 19, 11, 11/15/00

- Pain and symptom management
- Preparation for death
- Achieving a sense of completion
- Decisions about treatment preferences
- Being treated as a “whole person”

Only one of these goals points toward medical management. The rest reflect core end-of-life values that hospices address as part of their essential services. These goals have been mightily compromised by COVID-19. Hospices, residential care facilities, and medical providers have all struggled to balance personal autonomy, industry regulations with medical, end-of-life, public health and organizational ethics.

Many of these concerns exploded during the initial chaos of the pandemic. Some processes, such as tracking infection trends and viral symptoms, have become more stable over the last year and a half. Some, such as variants and vaccinations, are still in the process of discovery and implementation.

This paper describes some of the most difficult situations that hospices and residential care facilities have faced in providing mutual care for dying people during the pandemic. It reflects many of the same issues that have plagued health care providers in other settings. It does not address or include discussions about pre-existing issues about nursing home reform. It also does not address pre-existing schisms between care provided by non-profit hospices and for-profit hospices.

Administrators and Directors of Nursing from eight Colorado hospices – large and small, urban and rural, corporate and non-profit, were interviewed. Six Colorado residential care facilities of the same range were also interviewed, as well as having discussions with representatives from the Colorado State Long-Term Care Ombudsman Program, Telligen (a quality improvement organization), the Colorado HealthCare Ethics Resources⁴ Hospice Leadership group, and the Colorado Department of Public Health and Environment (CDPHE). They were asked about the issues, struggles and successes they have had working with each other during the pandemic, as well as thoughts and suggestions for improving partnerships and care.

Hospice services are available to dying people wherever they live, primarily in private residences or residential care facilities (including assisted living and skilled nursing facilities). Hospice provides creation and management of a fluid care plan that addresses the “wholeness” of a dying person’s life: physical pain, emotional, spiritual, mental and social needs. They provide medical, pharmacological, and psychosocial care that exceed typical facility staff training. They address existential fears and anxieties using medical and non-medical therapies. Hospice professionals are skilled in medical management of incurable pain that can be unremitting and excruciating.

Hospices work with the despair of those in severely deteriorating health with no expectation of improvement, sometimes with very short notice. They help patients fostering acceptance of the unfolding of a natural dying process. They work with patients to complete unfinished business and look

⁴ The Colorado Healthcare Ethics Resources group organized specifically to create awareness of the impact of COVID-19 on health care workers. Comprised of 54 organizations and 150 healthcare professionals and ethicists, they meet regularly to discuss and strategize how to address crises and provide resources for health care workers and systems across the state. <https://cohcwcovidsupport.org/>

toward their family's future without them.

This expertise and care model is unique to the hospice industry, and requires regular attention, review and awareness as a dying person's quality of life and goals of care are in constant flux. As death nears, needs often amplify for both patient and family. Clearly, when complete accessibility is not possible, hospice care is severely compromised. Specific practices among Residential Care Facilities – such as requiring pre-scheduled visits, or limiting visitation to specific hospice team disciplines – have created irreconcilable trauma for hospice patients and families.

Hospices have never been *visitors* to nursing homes. In collaboration with the care facility, they develop individualized care plans for each hospice patient. They also provide essential education, coordination and support for their other team members – the facility staff. Pre-pandemic, they were accepted as critical, integral care *partners* in the resident's primary medical care. As the pandemic unfolded, The Centers for Medicare and Medicaid (CMS), the Centers for Disease Control and Prevention, and the National Institutes of Health (NIH) deemed them “essential workers”, broadly giving them a central place in care facility support; however, in practice, many of these relationships have been critically disrupted and core hospice services have been limited or eliminated.

1. Compassionate Visits

CMS guidelines recognize *“the psychological, emotional and physical toll that prolonged isolation and separation from family have taken on nursing home residents and their families.”* In many instances, it is hospice that provides the essential care to ensure family is able to “just be family.”

CMS guidelines also state *“So-called compassionate care visits – when a resident's health has severely deteriorated – should be allowed regardless of vaccination status or the county's positivity rate.”* No one interviewed disputed a dying person's rights to these visits; complications described below resulted and result in everything from complex problems to absolute refusal to comply.

It has been painful to hear any stories of residents denied contact with their families, but the specifics of some experiences of dying patients and their families below explain the complex grief for everyone involved, and explain the traumatic nature of a “fractured dying process.” They also include powerful examples of the extreme moral distress experienced by hospice and facility staff.

- A Latino family whose father had dementia was not allowed to visit him in his skilled nursing facility. Culturally and personally the family was in crisis. The patient was frantic and confused about why they did not come to see him. *“Why does my familia no longer care about me? I have so many goodbyes to say.”* The family felt they had no choice; they had him admitted to hospice so they could use the compassionate visit policy despite the fact that neither the patient or family were ready for that monumental decision.
- Following facility policy, a dying patient could only see two family members in any one day. The family had to choose which two would be allowed to go; the patient died at the end of the first day. The family was in distress and conflicted about who got to say goodbye and who didn't. *“Why didn't anyone tell us he was going to die that night? We would have made sure he saw his grandchildren first. The rest of us had said goodbye in some ways before.”*

- A wife with health problems chose to take her failing husband home to live so she could be with him. Her guilt over her sense of ‘abandoning’ him had been overwhelming, even though she had neither the physical or financial resources to care for him at home.
- An elderly woman diagnosed with COVID in a hospital needed hospice care. Her husband couldn’t keep her at home so she was admitted to a nursing home, then quarantined for 14 days. The nursing home went on lockdown and wouldn’t let hospice in. She passed without hospice or her family.
- In one instance, the patient died shortly before a scheduled Zoom call with family, amplifying the anguish of not being able to say goodbye.
- The Ombudsman Program *“was made aware of issues with a resident going to a local hospice care center, which has different CDPHE guidance than nursing facility guidance. When the resident returned back to the nursing facility, it was reported there was tension between resident/family and facility as the facility’s COVID guidance from CDPHE was stricter than the hospice care center.”*

Families have blamed hospice for not being able to see their loved ones; they have been rageful about receiving inconsistent “sub-standard” hospice care; they have been traumatized by confusing, inaccurate conversations with facility staff, including one family member who was told by *“whoever it was who happened to answer the phone, that dad died. Then they put me on hold, and never came back on.”*

Facilities sometimes have called hospice only when they observed an obvious change of physical condition in a hospice patient; often their ability to accurately interpret what that change signals has been limited or non-existent and patients’ care may have been inappropriate.

Actively dying patients have had to rely on hospice chaplains and staff to hold their hand; in essence, they become the eyes and ears of the family. Hospice staff have created spontaneous bedside rituals, and have held the phone up to the patient’s ear and helped to interpret goodbyes. For hospice staff who have never met the patient or family before, *“this inability to do one of the things they were the best trained for, has taken a very deep heart-breaking toll on them.”*

Hospice workers have facilitated Zoom conversations between patients and their families. Many of these conversations have involved highly emotional discussions about dying or letting go, sometimes for the first time. Facility staff are not trained to “pinch hit” sensitive exchanges and have sometimes avoided helping facilitate the calls altogether.

When hospices felt that patient rights were violated or facility policies were prohibitive, the only formal course of action was to file complaints with the Colorado Department of Public Health and Environment (CDPHE), which has oversight for licensure, complaints and penalties for health care facilities. However, many hospices feared that complaints would only serve to create more problems for their facility partners or undermine their current relationships. (CDPHE reports that they did receive calls from hospices and there were many successful resolutions with facilities.)

Several facilities have to this date refused to have dialogue with hospices at all; their attitude continues to be 'do it our way or don't come in,' even though highly restrictive protocols at this point in time no longer follow CDC guidance.

2. Inconsistent Implementation

The second most disruptive factor for delivering hospice care in facilities has been the inconsistencies between facilities' policies about which hospice disciplines (e.g., nurses, social workers, certified nursing assistants, chaplains) have or have not been allowed in to see which patients, and when. The challenge to comply with one facility's sometimes daily needs and restrictions on PPE, masking, and testing has been frustrating. Each facility's policies differ, which creates undue burdens on a hospice trying to see patients, allocate staff and follow each care plan. Sometimes hospices don't know if they'll be allowed in until they arrive that day. One hospice reported: *"Whether I get to see the dying people whose care I am responsible for seems to depend on who happens to be on duty (as administrator) that day."*

Some hospices began checking in with their staff daily to report which facilities they think they would be allowed into each week. This has created a marked fluctuation in patient care as well as scheduling and staffing crises for hospices.

Hospice staff may not have received notice from the facility that there were active COVID residents or notification when one of their patients had died. Families calling facilities were given inaccurate descriptions of their loved ones' health, and in one instance, a wife was very unskillfully informed of her husband's death by someone who happened to answer the phone at the facility.

Some physicians refused to write hospice orders for residents that they could not see in-person; others wrote hospice orders sight unseen so that families could "qualify for" compassionate visits.

CMS Hospice Conditions of Participation initially and under non-crisis conditions mandate that a nurse see a patient every 14 days. CoPs also require individualized care planning for each patient and all members of the care team have visit frequencies that are agreed upon by the team, family, patient and facility. As facilities' rules varied on an uncertain basis, the adjustment for staff, services and care plan adjustment place hospices at risk for being non-compliant.

In an attempt to manage building access, one care facility informed the hospice that they, the care facility, would be providing comfort care (which they equated to hospice care) going forward. They have no culture, commitment or resources allocated to any end-of-life social work, chaplaincy, or grief supportive services, but feel they can provide good pain management. They stated it was a billable service and they could then provide end-of-life care without having to deal with an outside entity.

There was also a concern that the general stigma of hospice in general led to a facility developing policies that "concentrated on the living." The same concern extended to facilities who had shown that they did not fully understand hospice services.

When facilities felt the need to place hospice patients into skilled care, sometimes they did so without changing hospice visitation possibilities or providing sufficient notice to the hospice to maintain their current care plans or team support. Within one facility, protocols differed between independent living, assisted living and skilled nursing.

Hospices experienced displaced anger when a family was not informed by the facility when visits were possible, and panic and anger over the lack of consistency in hospice availability for their loved ones.

Without unrestricted hospice support, some patients in nursing homes experienced deaths that were frightening and painful. Concomitantly, families experienced traumatic responses that will not naturally resolve on their own.

3. Clash in Care, Not In Care Goals

In order to understand some of the most distressing, contentious points of intersection between hospices and care facilities since the beginning of the pandemic, we have to examine the internal environment of a care facility, which one administrator described as “trying to live a normal life in a war zone.”

Long-term care facilities (defined as nursing homes, assisted livings, skilled nursing facilities) have always had to deal with the complex legal and ethical issues around maintaining a professional facility which contains homes. They are CMS-regulated, licensed businesses with legal obligations and limitations. Assisted Livings were designed to be a composite of “the hospitality, health care and housing fields,” with a philosophy of consumer autonomy. They are also people’s homes – but each building is a combination of private spaces and public community spaces that require and allow different activities.

These buildings each provide various services 24/7, resulting often in more than one person fulfilling a position. Some of roles of staff or essential workers include:

- Nurses
- Aides
- Personal Care Providers
- Housekeeping
- Laundry
- Food service
- Technicians
- Social workers
- Behavioral health workers
- Dieticians
- Administration
- Office staff
- Occupational Therapists
- Physical Therapists
- Medical Directors
- Activity directors

They have responsibility for creating community and providing health care and safety to all, at the same time protecting the integrity, rights and confidentiality of the residents.

Communications from administrators are critical to maintaining trust and safety, but they can be harmful too. In more than one care facility, residents struggled with wanting to know if they were safe (which was particularly frightening to them if they had nowhere else they could go) or not wanting anyone to know if they or their families were infected.

(An example of an ongoing issue for care facilities is when a resident taken away in the middle of the night in an ambulance and never returns. Administration must (and wants to) deal with the questions and legitimate concerns, sadness and fears that result from residents not knowing what happened, if they will return or how to get ahold of them, as well the insecurities triggered about their own health

issues. However, the facility may be legally constrained from giving them any information at all about the person who is now “gone.”

At any given time, a residential community population may fluctuate daily to include:

- residents with whom they have had long relationships
- residents who had recently moved in who have not established “home” yet
- residents who have nowhere else to go and no family
- residents with varying levels of mental incapacity and specialized care needs
- residents with varying levels of functional impairment and distinct care needs
- residents with behavioral issues
- residents who are dying
- memory care residents
- short-term rehab residents

The most compelling argument for unlimited visitation by hospices is that by limiting hospice’s access to their patients, patient rights are violated. I spoke with no one who denied that legal right, but facilities argued that the “foxhole” that everyone was operating in was addressing crisis, not regular standard care.

4. Infection Control

Residential care facilities were the hardest hit communities at the beginning of the pandemic. In a memorandum from the Centers for Medicare and Medicaid Services on March 10, 2021⁵, “Nursing homes have been severely impacted by COVID-19, with outbreaks causing high rates of infection, morbidity, and mortality. The vulnerable nature of the nursing home population combined with the inherent risks of congregate living in a healthcare setting have required aggressive efforts to limit COVID-19 exposure and prevent the spread of COVID-19 within nursing homes.”

During the time it took to develop the federal government’s response plan and strategies, popular media was left to report poorly grounded information from weak information sources. In essence, data availability, distribution, reliability, timeliness or interpretation were much more erratic than was inevitable in the initial global COVID chaos. As one nursing home’s Director of Nursing reported, “We were flying the airplane while they were building it.”

The residential care industry suffered a form of cultural “victim blaming,” as Dr. Joanne Lynn wrote, “The scorn heaped on nursing homes for their infection and death rates is for the most part, misplaced.”⁶

As health care around the country braced for unprecedented numbers of swift, horrible deaths, a nursing home administrator reported: “*We did the only thing that we could: we did a hard close on the doors.*”

⁵ <https://www.cms.gov/newsroom/fact-sheets/cms-updates-nursing-home-guidance-revised-visitation-recommendations>

⁶ Journal of The American Geriatrics Society JAGS 00:1-2, 2020

The outcry against visitation restrictions was loud from the first day of lockdowns. No facility I interviewed denied that patient rights were violated. Care facilities reported being embroiled in trying to recognize and stop infection outbreaks over all else, at the same time trying to find acceptable alternatives to address social, emotional, legal and ethical implications of isolation for residents and families. Despite the pressures to maintain an open culture, the one resounding and relentless reality that all facilities I interviewed echoed was that *“regardless of whatever else we have to figure out, we all knew that our residents’ physical safety took precedent over everything else. That’s what our job was. Period. End of sentence. And that has never changed.”*

The overwhelming collective fear of unstoppable, uncontrollable, unpredictable rapid onset of fatal infections was stunning and incapacitating, as evidenced by a residential care community executive director who said *“Imagine what this was like as things started getting worse, to wonder if everyone was going to die on your watch this week.* She reported that on March 19, 2020: *“Corporate told me to have all of my case managers call every resident’s MDPOA (medical durable power of attorney, or health care agent) and help them get their family member enrolled in a hospice right now.”*

All of the facilities interviewed for this paper were aware of the devastating impact that preventive restrictions had on their hospice patients. The level of moral distress among nursing home staff was extreme. Attempting to protect patients, families and staff from infection, early policies looked for the most obvious potential carriers.

There was a suspicion that hospice workers who were in multiple facilities working with very sick people would be more likely to bring COVID into the buildings. In reality, most hospice staff presented low risk to facility infection rates. They are acutely aware of nursing home protocols, regulations and cultures and have experience collaborating on patient care. More than most essential workers coming onsite, as health care workers they were utilizing appropriate (when available) PPE and they understood and followed infection control protocols skillfully. There was as high, if not higher, risk from facility employees going home at night, shopping, etc. and returning to work the next day.

Strategies to prevent outbreaks, which including blocking hospices, included:

- Demanding that a dedicated hospice team would only work in their facility, essentially refusing any hospice that was not large enough to carve out a dedicated team to provide care for their patients. (Conversely, one facility was offered a dedicated team by a hospice on the condition that they transfer all hospice patients to their care.)
- Limiting hospice access to only one or two hospices (sometimes forcing patients to change hospices without their consent)
- Working only with hospices with which they had previous relationships with
- Limiting hospice visits to only a nurse, or a nurse and certified nursing assistant (If a patient or family specifically requested a chaplain or social worker, the request was generally accommodated.)
- Requiring hospice staff to comply with their requirements for PPE and testing for their own staff, even though those conditions may be changing daily.

While these strategies are no longer appropriate, there were enough additional outbreaks in the following year that for some it remained the only singular practical response they had. *We knew we*

weren't doing everything by the book. The book had been thrown out. You might as well have been trying to hold an ethics consult in a foxhole.

Trying to manage infection control meant being alert to any and all possibilities for breach:

- A resident figured out how to “de-alarm” a door and was sneaking his wife in for late evening visits.
- One hospice entered the building to see one patient but then moved surreptitiously from patient room to patient room without changing PPE, which was available.
- Dealing with staff distress about the fears of taking the virus home, bringing it in to the facility, or getting sick themselves.
- One hospice did not report one of their own staff's suspected infection to the facility, using the rationale that of course their staff had clearly been exposed to dying COVID patients but that they had doubled their infection precautions for their staff.
- Knowing that the testing could be highly ineffective in discerning infected persons; temperatures were completely unreliable in detecting infection but as guidance became more complex, different protocols applied to different groups (e.g., protocols for vaccinated persons vs. unvaccinated persons are different depending on whether the resident is vaccinated). *“This is like trying to play ‘Who’s on First’ with people’s lives.”*

One State health official remarked that he had never in his lifetime had to deal with something like this, where infected people could be completely asymptomatic, infecting others.

5. Devastation In The Long-Term Care Community Culture

Moral distress situations decimated facility administrators and staff, leaving them with very personal experiences of grief and trauma. Some of these experiences have caused administrators to quit their jobs.

- A nurse aide in a nursing home broke down when they were pushed by family to predict a patient's death trajectory so they could take advantage of compassionate care visits. Aides reported the debilitating sadness and extreme pressure of knowing that patients were dying alone and not having time to comfort or sit with them or say goodbye.
- Staff, most often untrained, have been asked to facilitate phone conversations with families who were in deep distress, sometimes hysterical, wanting information about their loved one's dying process or death, or begging to say goodbye.
- When residents died quietly with no or few noticeable symptoms of approaching death, a nurse feared she would be the one to take the brunt of the family's anger or anguish, or the hospice's admonition if they'd only been allowed in more, it would have been different.
- One employee who quit her job reported, *“One of my favorite Alzheimers residents used to wander the halls and the kitchen singing. She had no idea why she couldn't hug us anymore. I felt like I was pushing her back in her room all the time. I couldn't do it anymore.”*

- Staff anticipate continuing to have to deal with the heartbreak and outrage of people who had seen their family member, only to be locked out again during a second or third wave. Anticipation of this fear is high as the Delta variant bears down on the country.
- One facility described the pressure of trying to remain a viable business as they lost staff and residents. *“I almost gave up when we heard that corporate had fired our marketing person for ‘not being able to fill enough beds.’”*
- The fear of complaints being filed or lawsuits being brought by families were high-pitched themes of concern and anxiety. *“No one seemed to understand how impossible it was to balance the ethics of personal autonomy and public health orders.”*

6. No Time To Regroup

In an industry already beleaguered with staff shortages, facilities were handicapped by staff fear of infecting their families at home, fear of bringing infection into the facility, fear of getting infected on their own, and being shunned in public places as potential “carriers.” Many of the residents were dying quickly and there was no time to grieve or regroup with solid strategies beyond doing a “hard close on the door.” Staff turnover was so high that it was impossible to train new staff fast enough to be effective.

In a small community, the DON of an assisted living facility reported, *“On Tuesday I was in a meeting trying to deal with three new infections. On Thursday I had two employees out on infection watch and two had quit. When you called, I was driving between my two buildings where I was doing dishes, passing out meals, and helping with laundry.”*

Another reported: *“Every day I was dealing with my responsibilities to protect my vulnerable residents, make sure I had enough PPE and other resources, managing staff assignments when I had staff who were home infected or who had quit, protecting everybody’s health, reviewing all the new guidance and reporting to 3 regulatory agencies every day. And then my admissions coordinator quit. I used to feel competent; I could do all those things when we were moving at our regular speed. Now I can’t do my job in any of those areas, and they’re all “the most important.”*

A nursing home medical director said *“things are going to continue to get exponentially more complicated, not less. Every single outbreak in every one of my buildings is different and now we have at least one variant that is going to mean we have to modify and create whole new additional sets of protocols for everything. We’re all exhausted in every health care setting, staff members are leaving every day. The overwhelm makes everything seem hopeless.”*

7. Guidance Chaos

A short time into the pandemic, a group called Colorado Healthcare Ethics Resources developed a document called the Crisis Standards of Care for hospices. It outlined what protocols, legalities and standards hospices were held to in *conventional* times. It then delineated how all the practices, approved by CMS, could be legally compromised in a time of *contingent care*. Finally, it gave permission for hospices to ration care when the community was in *crisis*.

In contrast, all long-term care facilities reported they had Emergency Preparedness Plans in place, but they were inadequate in most aspects to address the scope, speed, and duration of a pandemic.

The facilities interviewed reported they felt they had little to no concrete, clear and confident guidance. Papers providing mandates, rules and guidance arrived sometimes daily from CDPHE, CMS, CDC and NIH, as well as state and local health departments.

Language in those documents sometimes clearly stated requirements, mandates or guidance for compliance with CMS and other regulatory bodies. However, guidance also more vaguely “urged,” “encouraged,” “recommended,” or “suggested” actions that administrators could take to protect their facilities and encourage open doors. Facilities felt both encouraged and admonished to take responsibility. While everyone agreed that the balance between legal compliance and personal discretion was critical to addressing facility needs daily, the various directives were often contradictory or changing so quickly that implementation and compliance were impossible.

Not only was there great confusion over what to follow; there was great concern over which set of rules they would be held liable for. Reports were required from as many as five agencies daily, and reporting requirements changed as often. (On one occasion, the facility had to inform their county health department that Colorado’s governor had issued a press release changing exposure and mask guidelines.)

When facilities had to toggle between guidance given by CMS, CDC and CDPHE, most agencies we interviewed followed either CDPHE because of their direct reporting relationship, or whichever guidance was the most conservative. Corporate guidance was the most closely adhered to and it was sometimes more conservative than that from government agencies. Almost all interviewed reported all of their policies were built on the broadest level of “extreme caution.”

Directives such as that from the paper written by the American Health Care Association, the National Center for Assisted Living, and the National Hospice and Palliative Care Organization stated:

It is critical that LTC and hospice staff partner together to ensure simple, clear and supportive communication.... To prevent the spread, facilities and health care workers need to significantly reduce the number of people entering and interacting with residents and staff.... The risk-benefit must be made on a case-by-case basis... [emphasis added]. This decision process will need to be adjusted as the COVID-19 situation evolves in each local community and building.”

The document encourages LTCs to “consider engaging hospices for resources for patients not enrolled in hospice.... There may also be an opportunity for hospice admission for those who are actively dying”.⁷

One facility reported that a hospice that had no current patients cited the above document, asking to be allowed into the building to assess and admit dying patients who needed (their) hospice.

⁷ <https://asprtracie.hhs.gov/technical-resources/resource/8743/guidance-on-the-role-of-hospice-services-in-ltc-facilities-during-covid-19-pandemic>

Within the chaos and fear of outbreaks, there were few opportunities to confidently address issues proactively; most decisions were made based on what appeared to be best practice in that moment. *“I was never sure if I was making the right choice for that day. I was making calls that I felt were right, even though they might put my license in jeopardy.”*

Today, concerns about infection status, testing, PPE, and vaccinations still encompass complex questions regarding daily assessment.

Should a facility tell a hospice worker about a patient who was suspected of having COVID but had not tested positive? Were facilities reporting only diagnosed cases and not those suspected? Was there any consistency between reports from facilities to the State?

What does “exposure” mean? Being exposed to someone suspected to have COVID when you were masked up? Being exposed to someone suspected to have COVID when you were wearing full PPE? Who is defining that?

How often should visitors and essential workers be tested? What kind of test is effective? Should hospices be subject to the same testing requirements as facility staff? (Facilities that demanded to see hospice staff tests violated those staff’s HIPAA rights. One collaboration that worked was between a hospice that agreed to verbally report test results to their partner facility but also agreed that if the State required the document from the facility, they would share the employee test.)

Can facilities ask about hospice staff vaccination? Can they demand it? Can hospices ask whether residents were vaccinated? How do facilities deal with families who won’t bring or leave their family member here unless they can prove that all of their staff and essential workers are vaccinated? The fear of loss of business and reputation is significant.

8. “Visitation policies will remain one of the great tragedies of this pandemic.”

Hospices are among the supportive communities that continue to deal with the traumatic, complicated grief left to families whose legacies are full of pain and anguish and anger. Visitation policies created barriers among people at one of the most vulnerable times of life, when there are no second chances and when many people would have been seeing all of the most important people of their lives in unrushed, reflective times. There is no scale that will ever balance the horror of trying to contain a disease which, as one health professional said, “could kill you without ever showing its face” against the crushing weight of the deep grief of one person whose loved one died alone.

The care facilities interviewed here struggled deeply with defining visitation for terminally ill people when it was almost impossible to predict a time of death, as well as knowing when visits were appropriate.

One administrator said, *“I knew she wasn’t ‘dying’ according to definition, but her husband was so frail, he could have died before her, and I just couldn’t not let them say goodbye. So what if neither of them were vaccinated. I masked him up, brought him to her room, and he sat next to her holding her hand and they talked about being married for 64 years and, I think it was divine intervention, she got a smile on her face and died right then. At first, I cried because it was so important and I had helped it happen. And then I felt horrible because I knew I should be doing it for everybody and I couldn’t. I then I thought what*

would be worse would be if I had to make choices for some people and not for others. At the end, I felt so bad I just wanted to go home and not come back."

Another reported, I'm sure I sounded callous refusing people. I was just so tired of having every family and hospice and so many residents and even staff asking me how I could keep people apart when they were dying. Everyone deserved to be with their loved ones and I was the one stopping them.

Some of the challenges for hospice patients in facilities have clearly self-resolved as guidance and practices have changed and clarified. However, several long-term care facilities reported by those interviewed here still hold their organizational lines in the sand and have not shifted their willingness to relax or compromise. Most significantly though, there continues to be a sense of helplessness at getting them to engage in dialogue. Several hospices continue to experience the stone wall as *"Do it my way or you don't come into my building."*

9. A Pandemic is a Lot Like a Forest Fire

In 2005, President George W. Bush said, "If we wait for a pandemic to appear, it will be too late to prepare. A pandemic is a lot like a forest fire. If caught early it might be extinguished with limited damage. If allowed to smolder, undetected, it can grow to an inferno that can spread quickly beyond our ability to control it."⁸

Although we face new challenges regularly, responding to the Delta and other variants, vaccination battles, openings, repeated closings and re-openings, economic hardships and long COVID still revealing themselves, hospices and care facilities have enough hours clocked to describe what may be helpful to them in the future.

Some suggestions were "wish lists": *I know what I'm asking is probably impossible because staffing problems in facilities aren't going to magically go away, but maybe right now when we've seen how bad things can get, we can just change our priorities so it doesn't happen the same way again.*

The strongest themes for success in the interviews were relationship, communication, leadership and respect. The suggestions below reflect thoughtful and sympathetic considerations of how these two distinct personal care communities can support each other in collaborative brainstorming.

Partnerships between hospices and care facilities that had been strong pre-pandemic were more likely to maintain some degree of connection. Even when visitation was heavily restricted, the relationships endured. This was easiest in small- to medium-sized communities or service areas that had fewer facilities, fewer hospices and/or more homogenous populations.

- One community created a regular meeting format for all of their residential care facilities to monitor current conditions and outbreaks in the community, discuss guidance interpretation, as well as look at opportunities to share and locate PPE, discuss testing facilities, monitor infection patterns, and laugh with each other.

⁸ [#georgewbush #pandemic #coronavirus #covid19](https://abcn.ws/34h1Naw)

- Another community-wide meeting of care facilities and hospices served to take the pulse on the community, participate in data-gathering, and brainstorm the most immediate needs they could help each other with. With strong teamwork already laid, hospice's ability to provide staff support from day one was an integral part of their ongoing relationship.

Corporate facilities had regular calls with their headquarters. In dialogue, they were given direction on how to interpret and work with current concerns and contingencies and felt confident being supported when they followed that guidance, even if it was in conflict with the latest guidance from CDPHE. Additionally, they were aware of problems and solutions going on in other buildings that gave them a sense of a larger landscape as well as security knowing what their accountabilities were.

All facilities who took part in weekly or regular meetings with CDPHE or their County health departments felt that those were important supports.

The Hospice Leadership work group of the Colorado Healthcare Ethics Resource group was formed in November of 2020 to support hospices statewide through COVID. This group meets regularly with three goals:

- To share current information about issues they confront, e.g., PPE, staff sharing, testing, visitation and access to LTCs, hospital to hospice discharges.
- To collect and collate data on current infection rates, hospice discharges and case dispositions using a short, online survey.
- Networking, collaboration and support between hospices. This is the largest and most active working group of hospices in the state.

This group listserv includes 172 members from Colorado hospices, and they post minutes of all meetings and up-to-date resources on the Hospice Analytics website.⁹ They also developed and distributed a powerpoint presentation in October of 2020 for long-term care facilities describing the major issues and points of connection that may be problematic between them. It has since been updated to reflect successes and challenges.

The Long-Term Care Facilities subcommittee of the Colorado Healthcare Ethics Resources group, consisting of doctors, nurses, social workers, palliative care and hospice staff, formed to provide resources that help residents and their families understand how to make medical choices and how to prepare for health crises during COVID-19.¹⁰

Advances in telehealth have allowed hospice providers to have (limited) visual access to patients. We need to make sure, crisis or not, that these avenues for connection will continue to develop.

⁹ <http://www.nationalhospiceanalytics.com/hospice-care-products-and-services/co-crisis-standards-of-care>

¹⁰ <http://healthfacilitiescommunity.blogspot.com/2020/04/message-from-colorado-healthcare-ethics.html>

The CDC released a handout called Supporting Your Loved One in a Long-Term Care Facility¹¹ that hospices were able to expand on to support their facility partners. Hospices sent cards and letters, put signs on the lawns thanking facility staff, and did “drive-bys” wearing silly outfits and popping out of their cars to sing to the facility.

Hug tunnels, plastic inventions that allowed people to hug each other without touching, visited nursing homes and got both hospices and facilities positive and heartfelt media coverage.¹²

Other singular suggestions proposed by organizations interviewed included:

Review and revise the facility Emergency Preparedness Plans in Residential Care Facilities to include pandemic-proportion long-term policies and strategies now.

Explore together how to develop more robust use of tele-health channels, including how to smooth out the teamwork between hospice and facility staff.

Encourage more family members to come in to feed residents, both to provide contact and to make sure, during staff shortages, that meals provide more than one kind of nourishment.

Meet the ombudsman in every facility you work in. Help them understand specific challenges you face as a hospice provider and work with them to provide respectful, effective responses to resident/family issues. They are well-trained for these kinds of interventions, and their inclusion alleviates the image of the hospice as “the bad guy.” If a situation is untenable or intractable, let them make the contact with CDPHE. Don’t delay out of fear.

Have one staff member in each facility trained to be the communicator with families and hospices. To act as a single focal point to make sure that communications were consistent and cohesive. They could also interface with their counterparts in other agencies to make sure that guidance, directives, suggestions, etc. are reaching the most agencies at the same time. We can’t afford to do this, and we can’t afford not to.

Do more to ensure that hospice liaison and staff working in a LTC are trained to be better matches. It’s not just a formal relationship, as we just learned.

Have hospice liaison training include a short course in mediation and conflict resolution, to give them better skills to deal with unexpected conflicts or emergencies.

Hospices and long-term care facilities should meet at least yearly to understand each other’s industry regulations, scrutinies, responsibilities, expectations and liabilities. Reviewing hospice regs and LTC regs together would help each become more aware of what roles and reporting requirements the other is responsible and liable for. Some hospices were not clearly aware of the impact that state surveys could have on long-term care facilities. Likewise, many long-term care facilities were not aware of compromises in care that would cause hospice to lose funding.

¹¹ <https://www.cdc.gov/coronavirus/2019-ncov/downloads/supporting-loved-one-in-long-term-care-facility.pdf>

¹² <https://apnews.com/article/us-news-colorado-coronavirus-pandemic-denver-suburbs-8d97da7f60ac0da30d04e22abd84a5f8>

Make formal agreements to prioritize meetings between hospice reps and facility management to maintain “front-line” lines of communication that match that day’s needs.

Knowing what we know now about how badly our joint care of patients can fall apart, we should think of the relationships of facilities and hospices as *partners* and conduct all of our business as though that were our framework, as though it was an advantage that will make both of us stronger.

Hospices should work together to design a central state operations center which would be ready if this crisis escalates. Maybe this Hospice Leadership Group should do that since they already have the bones.

Let hospice staff help! LTCs should be regularly reminded of what hospices actually do and when to call them. They don’t just give meds. They know how to feed people, and give them baths when we’re short-staffed. And they have nurses and social works available 24/7 when we need them! They’re trained to listen to family members when you don’t know what to say. They’ve spent years supporting staff in difficult situations, doing memorial services we really know we need now even when we think we don’t have time. They can do presentations to your staff on what impending death looks like and what to watch for. They don’t like seeing people die either, but they’re not afraid of it like we are. Just that calmness in the building has been important.

Share education tools that support mutual learning and confidence building. For example, a “Fast Fact Tip #423” from the Palliative Care Network of Wisconsin entitled “Clinician Tips for Virtually Connecting Dying Patients with Loved Ones” can be the basis for developing a plan for a hospice and facility together.¹³ Learning how to assist with these visits could be part of staff orientation or training.

Join the Colorado HealthCare Ethics Resources groups. They have and keep producing really valuable materials¹⁴ for all of us focused on living with COVID. They have a LTC subcommittee and a hospice leadership work group and they’re all working together.

Train one appropriate employee in each facility to be the liaison with resident families. Training would include the scope of what they can share, appropriate languaging, active listening skills, how to deliver sad or frightening information, and who else to include in a significant discussion (e.g., calling hospice if a hospice family is highly distressed during or after a call).

In July of this year, the CDC announced: “Decisions to add or remove effective prevention strategies should be based on local data and public health recommendations. The emergence of more transmissible SARS-CoV-2 variants, including Delta, increases the urgency to expand vaccination coverage and for public health agencies and other organizations to collaboratively monitor the status of the pandemic in their communities and continue to apply layered prevention strategies to minimize preventable illness and death.” [Emphasis added]¹⁵

¹³ <https://www.mypcnow.org/fast-fact/clinician-tips-for-virtually-connecting-dying-patients-with-loved-ones/>

¹⁴ <http://healthfacilitiescommunity.blogspot.com/2020/04/message-from-colorado-healthcare-ethics.html>

¹⁵ CDC Morbidity and Mortality Weekly Report July 30, 2021/ 70(30); 1044-1047

The agencies interviewed here noted repeatedly their reliance on CDPHE for their primary guidance. They suggested that the CDPHE take over leadership and coordination of the state COVID health care responses to a greater degree.

- If all the facilities knew that they could look to the CDPHE for regular guidance and rules, there could be a uniform response and expectation of visitation and testing requirements in every facility. So much time is wasted discovering and catering to each building's different policies. *PPE, information availability, testing methods, vaccination policies, lockdown alerts – they are all facility specific.*
- Have CDPHE create or override the guidance coming from different counties, or make them accountable to following their (CDPHE) mandates.
- CDPHE should be our central information hub. If they would have the regs that are sent to nursing homes, sent at the same time to hospices, vendors, ombudsmen and outside providers, we could all be on the same page and responsible to the same rules at the same time. I know where to find my regs but I can't work with the nursing homes if I can't find theirs.
- We need skilled state leadership that understands the pandemic, the rules and the problems we're having, together and separately. We need to know the difference between what's "required" and what is "encouraged". *"In the face of 'recommendations', you might as well be inviting anarchy."*
- *CDPHE strike teams on-site would be the most helpful. Not to make us feel like we're doing badly, but to walk through the building, show us how to use PPE properly, just educate and support us about how to get through this, even if they aren't sure how themselves.*
- *We already rely on CDPHE and they know our environment better than any national organization. They should develop the gold standard for long-term care regulations and compliance during a crisis like this, and provide the facilities with regular guidance so that anyone that follows their direction and adheres to the standards they present can feel protected from getting sued if someone gets exposed.*

After a while, I think we started to be afraid of each other, scared of being honest or vulnerable because the stakes were so high. I think what would have made the biggest difference is if we could have remembered to treat each other with empathy and respect and patience, like making a suggestion and not expecting an immediate response.

We have to remember over and over that we're all in this together – hospice CNAs, directors of nursing, residents and patients, families and ombudsmen and our health departments, and everyone else in our paths. One week the thing that made the most difference for my female residents was when I told them, "I won't get my hair done again until you can." That's what I mean.

10. Conclusion

Many hospice patients living in long-term care facilities since the beginning of the pandemic have died physically, mentally and emotionally traumatizing deaths as hospices have been inconsistently allowed into or blocked from facilities. Long-term care facilities overwhelmingly made decisions that supported their critical primary objective -- to keep their residents physically safe. The unavoidable lack of preparedness for the magnitude of COVID-19 compromised or collapsed the teamwork needed for hospices to support dying patients and families who were living with pain and suffering.

The hospices and long-term care facilities interviewed for this paper were clear about the catastrophes that befell these patients, families, residents and employees. However, the lack of clarity and consistent national, state and county guidance for the long-term care industry strangled their capacity to create effective fluid responses to daily challenges.

This group of hospice and long-term care facility workers reflected on their desire and suggestions to remedy and restructure their relationships with each other for the sake of patient and resident care. Ranging from individual and community teamwork to new collaboration models to updated industry standards, they collectively reported the need for mutual respect and curiosity as well as more aggressive statewide leadership.

With deep respect for everyone who shared their time and thoughts with me,

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