



Delivering Hospice Care During the COVID-19 Pandemic

Meeting Nursing Home Residents' Needs

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This discussion article highlights the challenges of providing hospice care in nursing homes since the start of the COVID-19 (coronavirus disease 2019) pandemic and illuminates practice changes needed in nursing homes. The article provides an overview of the expectations of hospice care, explains the differences in delivering hospice care during the COVID-19 pandemic, examines social isolation and emotional loneliness and the role of familial caregivers, and describes policy changes related to the COVID-19 affecting hospice care delivery in nursing homes. This article answers the following questions: (1) How did residents receiving hospice care have their needs met during the COVID-19 pandemic? (2) What areas of nursing home care need to be improved through governmental policy and restructuring? This article also summarized the lessons learned as a result of the COVID-19 pandemic and provided practical implications for nursing, specific to changes in hospice care deliveries for nursing home residents.

Centers for Disease Control and Prevention in the United States, adults 65 years and older accounted for 8 of every 10 COVID-19 deaths reported.² Among 3946 residents in 31 nursing homes in Venice, Italy, COVID-19 infection was associated with a higher risk of all-cause mortality than those not infected COVID-19.³ Among nursing home residents diagnosed with COVID-19 in the United States, 19.2% died within 30 days.⁴ The 30-day mortality rate of nursing home residents with COVID-19 has decreased from 20.9% in early April 2021 to 11.2% in early November 2020 in the United States. The 30-day mortality rates were calculated based on 12 271 nursing home residents with COVID-19 from a single provider of 282 post-acute care facilities and nursing homes in 24 states.⁵ This downward trend could be due to genetic changes in the COVID-19 virus, improved clinical care delivery changes within nursing homes, and personal protective equipment (PPE) supply and use.⁵

The risk of mortality increased with age, impaired cognition, and functional impairment.^{5,6} Older adults living in nursing homes are particularly vulnerable to the COVID-19 infections.⁷⁻⁹ The rapid spread of the COVID-19 virus among nursing home residents early in the pandemic in early 2020 led to nursing homes securing their front doors and not allowing any outside visitors, including hospice staff initially. Preventive measures aimed at keeping the residents safe often affected the provision of hospice care.¹⁰

An alarming anecdote (the case study below) from a hospice nurse practitioner in the southern United States sheds some light on the unique needs of the nursing home residents who required hospice care during the COVID-19 pandemic. In addition, this anecdote addresses the importance, timeliness, and urgency for health care providers to address the reemerging issues in nursing home care, such as the emotional loneliness of the nursing home residents and the required changes in hospice practice emphasized by the COVID-19 pandemic (Figure).

Case Study

(An anecdote adapted from hospice nurse practitioner as an exemplar, written by one of the authors)

Mr C. was a gruff, retired military man who, for many years, had been caring for his wife at home. After surgery

KEY WORDS

COVID-19, hospice, isolation, loneliness, policy changes

Nursing homes in the United States comprise a disproportionate share of the cases and deaths of COVID-19 (also called the coronavirus disease 2019 or SARS-CoV-2 [severe acute respiratory syndrome coronavirus 2]). Nursing homes accounted for more than 131 000 resident deaths and more than 645 000 confirmed cases of COVID-19 as of April 2021.¹ According to the

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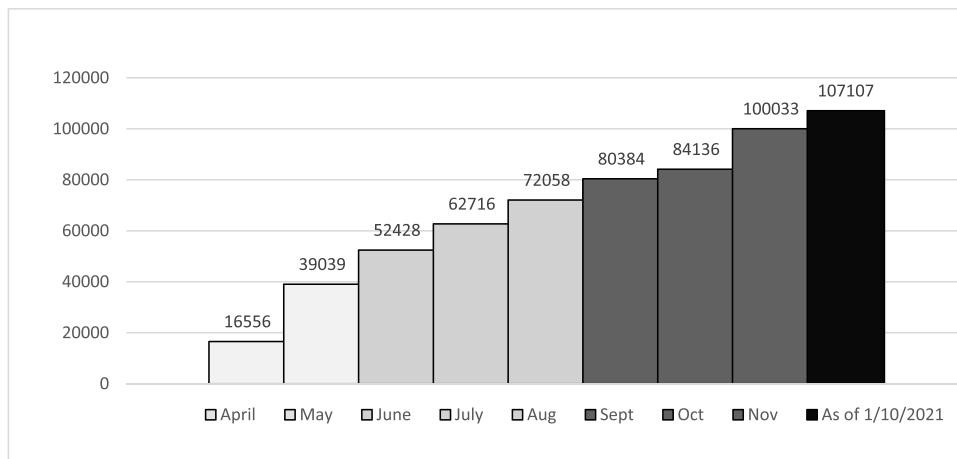


FIGURE. Number of reported nursing home resident deaths from April 2020 to January 2021 in the United States.^{10,11}

approximately 15 years prior, she had experienced a debilitating stroke requiring enteral feeding and all of her needs to be anticipated. One night, Mr C. fell, lying on the floor in pain until the personal caregiver arrived in the morning. He went to the hospital for treatment while respite care at a local nursing home was arranged for Mrs C., as she was already receiving hospice services. After discharge from the hospital, he was admitted to the same nursing home as his wife for rehabilitation. Unfortunately, his fall occurred at the beginning of the COVID-19 pandemic, so hospice staff could not see Mr C. or Mrs C. because of their nursing home's closure. Mr C. continued to decline and was eventually admitted to hospice services virtually. The constant visitors in their life, including the hospice staff and their caregiver who spent weekdays at home, had not been able to see the couple. Mr C. was in tears when the hospice nurse practitioner arrived to complete Mrs C.'s face-to-face recertification. The gruff, military man became a shadow of the person he was at home. He could hardly speak and was so upset that they had not had any visitors. He said he felt abandoned. His decline continued rapidly, and he died 3 weeks after his fall. Mrs C. died 2 days after her husband.

PURPOSE OF THIS DISCUSSION ARTICLE

This article highlights the challenges of providing hospice care in nursing homes since the start of the COVID-19 pandemic and illuminates practice changes needed in nursing homes. The article provides an overview of the expectations of hospice care, explains the differences in delivering hospice care during the COVID-19 pandemic, examines social isolation and emotional loneliness and the role of familial caregivers, and describes policy changes related to the COVID-19 pandemic affecting hospice care delivery in nursing homes. This discussion article answers the following questions: (1) How did residents receiving hospice care have their needs met during the COVID-19 pandemic?

(2) What areas of nursing home care need to be improved through governmental policy and restructuring?

Expectations of Hospice Care

In 2018, 1.55 million Medicare beneficiaries received hospice care from 4639 Medicare-approved providers, a 4% increase from 2017.¹¹ Hospice developed as an exemplar of care for people facing a serious or life-limiting illness or injury with a life expectancy of 6 months or less if the disease follows a typical course. Hospice care is provided wherever the person is—at home, the nursing home, and other facilities or hospitals. Using a team-oriented approach, hospice provides for pain and symptom management through expert nursing and medical care. An interdisciplinary team providing care allows for early detection of a worsening condition and offers continuous monitoring for new problems. Pain management, symptom control, medications related to the terminal diagnosis, supplies for wound care or continence care, and medical equipment are some of the services offered through hospice.¹¹

Hospice care focuses on quality of life for residents with a life-limiting illness, rather than quantity.¹¹ Support is provided to both the residents and their family members through an interdisciplinary approach involving nurses, physicians, social workers, chaplains, and volunteers. Emotional, psychosocial, and spiritual support is provided within the multidisciplinary team approach. The hospice team is expected to provide all care that the residents may need during the remainder of their life, although their primary care providers can still see the residents if they choose.¹¹

CHANGES AFFECTING HOSPICE CARE DURING THE COVID-19 PANDEMIC

Nursing Home Preparedness

During the periods of late 2019 and early 2020, no one was prepared for the widespread challenges of a worldwide



pandemic, including nursing homes.¹² Many nursing homes did not have sufficient staffing, PPE, surveillance testing, and other needed resources required to care for residents and prevent the spread of the virus.¹³ Nursing homes were unable to obtain the necessary protective equipment for staff because most available equipment was being directed toward acute care facilities.¹⁴ Initially, the inability to acquire the required PPE greatly affected nursing home preparedness and how care was provided to residents who contracted COVID-19.¹³ As late as July 2020, approximately 1 in 5 nursing home facilities was still encountering severe shortages of PPE.¹⁵ The lack of protective gear for nursing home staff decreased the number of staff willing to work because of possible exposure to the COVID-19 virus.¹⁵

The spread of COVID-19 in nursing home facilities since early 2020 has heightened awareness and suspected impact of nursing staff stability on the quality of nursing home resident care (eg, infection control measures to prevent the spread of COVID-19).¹⁶ During 2017 and 2018, the mean and median annual turnover rates for total nursing staff were estimated at 128% and 94%.¹⁶ Annual turnover rates for total nursing staff were defined as the percentage of nursing staffing care in hours that turned over at the nursing home facility in a given year during 2017 and 2018.¹⁶ Continually hiring new nursing staff, paying staff overtime to cover shifts, and having many newly hired workers without a nursing background all contributed to the lack of preparedness many nursing homes experienced.¹⁷

Protecting Nursing Home Residents

Another factor related to the increased number of nursing home cases of COVID-19 was that residents presented vague symptoms. Many residents had symptoms of fatigue, decreased appetite, confusion, and low-grade fever without respiratory symptoms.^{18,19} The lack of traditional COVID symptoms led to delays in isolating infected residents, allowing for the virus's rapid spread throughout the nursing home.¹⁸ Without adequate PPE and nursing staff to create areas of isolation within facilities, the virus can spread without difficulty.²⁰

Adequate nurse staffing levels in US nursing homes are a requirement to ensure resident safety.²¹ Understaffing can contribute to decreased quality of life of the residents related to reduced quality of care.²¹⁻²⁴ Concerning the pandemic, facilities with higher nurse hours led to fewer outbreaks and fewer deaths than nursing home facilities with fewer nurse hours.²⁴ Thus, the strongest predictor of how a nursing home would fare during the pandemic was related to the number of the COVID-19 cases in the local community.²⁴

Restrictions and Infection Control Measures

According to the Centers for Disease Control and Prevention guidelines, nursing homes implemented visitation restrictions to decrease the spread of the COVID-19 virus.²⁵

In March 2020, the Centers for Medicare & Medicaid Services (CMS) quickly provided guidelines for infection control and prevention of spreading the COVID-19 viruses in nursing homes.²⁵ Initial guidelines included the restriction of all visitors and nonessential health care staff except for certain situations such as imminent death.²⁵ Visitors encountered locked front doors and notice signs stating no visitors were allowed inside the nursing home. Once a visitor, such as a hospice nurse, was able to enter a nursing home, screening was required to assess for signs and symptoms of respiratory infections, sometimes requiring a negative COVID-19 test to enter.²⁵ Personal protective equipment, such as masks, gowns, and gloves, is also required to remain 6 ft from the person.²⁵

At the onset of the pandemic, hospice staff promptly began altering the care being provided. Before the limited visitation in nursing homes, many hospice aides provided frequent and sometimes daily visits to their residents to assist with daily living activities such as bathing and dressing. Aides have the most frequent contact with residents and their families, often developing close relationships.²⁶ Aides were not allowed in nursing homes to assist with daily living activities such as bathing and dressing for several months.²⁷ Nurses often have 1 to 2 weekly visits with their residents, depending on the plan established with the interdisciplinary team. The required registered nurse visits and recertifications by a nurse practitioner continued, although many visits were conducted virtually using virtual conferencing.²⁷

With significant concerns, a hospice nurse practitioner (one of the authors) expressed to the authors that in 2020, some hospice visits could be completed using the large windows in the nursing home and the use of the facility telephone to speak with the resident. Thus, social workers and chaplains, who spend much of their visits providing emotional and spiritual care, were "seeing" residents virtually or calling for updates from nursing home staff.

Virtual Hospice Visits and Assessment

This hospice nurse practitioner felt troubled and expressed her profound concerns about the quality of hospice care, especially the physical assessment needed for recertifying hospice care. She explained that when the doors to the nursing home were closed to outside visitors, unconventional visits were used to assess residents to document clinical decline and deterioration in overall condition. The unconventional visit relied on the assistance of nursing home nurses, especially for virtual visits, or possibly assistive personnel without a hospice background. While the help from nursing home staff was appreciated, critical assessment details may be missed.

Another issue encountered with virtual hospice visits for nursing home residents was coordinating a time with the nursing home staff to complete a virtual visit. Nursing



home staff often had to use their smartphones to connect with the hospice providers to conduct the virtual visit. These visits were usually hurried and dependent on the nursing home nurse's assessment skills rather than the virtual visit provider. The visits made through the facility window or virtually were especially difficult when the visit was being made for the first time. This hospice nurse practitioner indicated her worries about the hospice care deliveries during the COVID-19 pandemic, specific to the restricted face-to-face contact for conducting a physical assessment.

Families as Essential Caregivers

Familial caregivers of nursing home residents, especially those receiving hospice care, often provide daily visits to be involved with direct care of their family members and assist with care planning to ensure a good death.²⁸ Family members provide a fundamental role in the quality of life of nursing home residents. They are the ones who “care the most” regarding what happens with their family member and the care they receive or do not receive, and they can assess the quality of care being received.²⁸ Family members are aware of their loved one's needs and preferences for end-of-life care. Limited or no family visitation unless imminent death has contributed to increased feelings of guilt, helplessness, and emotional loneliness of family members.^{29,30}

Social Isolation and Emotional Loneliness

An anecdote (the case study below) from a hospice nurse practitioner revealed the devastating negative health impact of social isolation and emotional loneliness among nursing home residents during the COVID-19 pandemic.

Case Study

(An anecdote adapted from hospice nurse practitioner as an exemplar, written by one of the authors)

Ms. B. was moved to a nursing home near her family in February 2020. She began settling into the nursing home's routine and was participating in many of the social activities. In March 2020, COVID-19–related restrictions were put into place, and all visitations became limited or not at all. Social activities were canceled until further notice, and residents were required to stay in their rooms. Ms B.'s niece, a hospice nurse, and other family members would visit and see Ms B. through the window in her room. When visitation resumed during the summer, the appearance of Ms B. shocked her niece. She had lost more than 20 lb, and her dementia had progressed a significant amount. Ms B. was no longer able to get out of bed unless staff moved her using a lift. Ms B.'s niece felt that loneliness and lack of family involvement led to her decline.

Social isolation specifically refers to the absence of relationships with other people, while loneliness is a subjective,

cognitive evaluation of social participation.³¹ Loneliness is considered a risk factor for physical and mental illnesses, resulting in negative health outcomes.^{29,32} Older people living in nursing homes have increased rates of loneliness when compared with community-dwelling aging populations.³¹ Activities that encouraged socialization and developed relationships among residents, including communal meals in the dining room, were canceled as part of isolation techniques used to decrease the spread of infection.³³ Since the COVID-19 outbreak, nursing home residents had limited family member visits (often via phone only without videos due to technology requirements), began spending more time alone in their rooms, and had limited to no interaction with nursing home staff and other residents. Sadly, increased rates of depression and need assistance with daily living activities and decreased coping abilities have been reported in residents during the pandemic.^{29,31,33}

Health Care Providers' Concerns and Frustration During the COVID-19 Pandemic

One of the authors is a nurse practitioner who has been delivering hospice care to older adults living in nursing homes during the COVID-19 pandemic. She has experienced and observed health care providers' frustrations with the COVID-19 guidelines and restrictions, including their isolation while working from home and collaborating through virtual methods such as Zoom, Skype, or Microsoft Teams. Moral distress among the interdisciplinary team has also been a factor related to residents' isolation at the end of life, inability to make physical contact with residents, and lack of expression of human connectedness such as funerals.³⁴ The barriers preventing access to residents in nursing homes have led to increased virtual resident visits. While virtual visits may be convenient, the connection formed when sitting near someone and listening to their needs and concerns cannot be duplicated.³⁵

Another concern of health care providers included acquiring COVID-19 while providing resident care or unknowingly passing the virus on to their family members.³⁶ Initially, a lack of PPE led to nurses distancing themselves from family members and imposing self-quarantine measures. Distributions of PPE to hospice providers began in May 2020 and helped alleviate some of the strain placed on hospice agencies and nursing homes.¹⁷

POLICY CHANGES AND ADDITIONS RELATED TO COVID-19

Significant new policies related to hospice care during the COVID-19 pandemic included the CMS Waiver 1135 and the Coronavirus Aid, Relief, and Economic Security (CARES) Act 2020. The CMS Waiver 1135 waived the requirement that volunteers provide at least 5% of hospice care and waived the onsite visits for hospice aide supervision.³⁷ Time



frames for completing comprehensive assessments increased from 15 days to 21 days, and the annual training of all individuals delivering care was postponed.³⁷

The CARES Act 2020 provided funding for PPE, respiratory supplies, and other costs associated with telehealth and technology.³⁸ Other benefits of the CARES Act funding included increased training and screening protocols, allowed hospice recertifications to be completed via telehealth, and provided paid leave for staff who have been exposed to COVID-19.³⁷ Another vital initiative related to COVID-19 is that everyone in the United States will have access to the COVID-19 vaccine at no charge, with the copayment/coinsurance and deductible being waived through Operation Warp Speed.³⁹ Other important initiatives implemented in July 2020 authorized rapid point-of-care diagnostic testing in nursing homes, specifically the hotspots identified by CMS.¹⁷ In addition to the testing in the nursing homes for both staff and residents, Task Force Strike Teams were developed and deployed to help decrease COVID-19 from coming into the nursing homes, rapidly identify COVID-19 cases within the facility, and help nursing homes reduce the risks among residents.¹⁷

Significant actions instated by the US government in nursing homes because of COVID-19 included notification requirements of new infectious diseases and the relaxation of licensing, credentialing, and training requirements of new-hire staff.³⁷ With COVID-19 and the closure of nursing homes, the facilities also had to notify their residents or the residents' representatives to keep them up to date on the COVID-19 infections and the conditions inside the facility.⁴⁰ Nursing home facilities typically provide a written report regarding communicable diseases to the Centers for Disease Control and Prevention.⁴¹ In May 2020, a new provision, 42 C.F.R. § 483.80(g)(1), required facilities to electronically report information regarding suspected infections, supplies within the facility, staffing, available COVID-19 testing, and the number of deaths among residents and staff.⁴¹

In March 2021, new guidance regarding indoor visitation in nursing homes was released by CMS. One significant change with this guidance was that a resident in the nursing home facing a decline in his/her health or was nearing end of life was allowed visitors, regardless of his/her or his/her visitors' vaccine status.⁴² The new guidance also made the recommendation that visitors should not be made to show proof of a negative COVID-19 test or vaccination as a condition of visitation.^{25,42}

LESSONS LEARNED AS A RESULT OF THE COVID-19 PANDEMIC

Loneliness, Disconnect, and Isolation

Loneliness and social isolation have been significant contributors to adverse outcomes in the aging populations even before the COVID-19 pandemic. Social disconnectedness

has also been associated with increased anxiety and depression severity.³³ Nursing home and hospice staff know their residents' preferences, personalities, and baseline mental status, which allow for early and timely intervention for increased depressive symptoms.⁴³ Identifying those at risk of loneliness or isolation early can also help decrease adverse health outcomes.³¹⁻³³ Several screening tools are available to evaluate the degree of loneliness or social support, such as the De Jong Gierveld Loneliness Scale or the Lubben Social Network Scale.⁴⁴ These tools assess changes in mental health status and may prompt clinicians for early introduction of appropriate interventions.⁴⁴

In addition, many nursing home activity directors have been proactive in creating activities for residents that could be done safely in a group in person.⁴⁵ For example, as observed by a hospice nurse practitioner during one of her nursing home visits, who is one of the authors, the activity director in a large facility held regular "doorway bingo" plays to engage nursing home residents who have been asked to stay in or nearby their rooms and to avoid group gathering. This activity director would walk up and down the hallway with a microphone and speaker to call out the bingo numbers. As a result, nursing home residents could see each other and interact in a fun manner while following social distancing guidelines.

Supporting and Alleviating Distress

The incredible number of deaths resulting from COVID-19 has reinforced the importance of support through the stages approaching death.⁴⁶ Part of having a "good death" entails finding comfort and finding some meaning for their life.⁴⁷ According to the Institute of Medicine, a good death refers to one that is (1) free from avoidable distress and suffering for persons themselves, their family members, and caregivers; (2) in general accord with persons' and families' wishes; and (3) reasonably consistent with clinical, cultural, and ethical standards.⁴⁸ Psychological distress due to anxiety and depression at the end of life is taxing on both the person receiving hospice care and the caregiver.⁴⁶ It is crucial to provide increased support for those at the end of life, especially when their family is not present.⁴⁶

Needed Reforms to Support Caring for Aging Populations

As the aging population continues to increase in numbers, nursing home residents will continue to expand. Approximately 1 in 5 Americans is projected to be older than 65 years by 2030, and approximately 90% will have at least 1 chronic health condition.^{49,50} The development of governmental policies that contribute to the effectiveness of the health care system, specifically nursing homes, is urgently needed. For example, end-of-life care in nursing homes requires CMS funding support through policies that can fund quality hospice care.^{49,50}



Despite being called a “nursing” home, many facilities have a “chronic” shortage of registered nurses or licensed practical nurses and are understaffed.⁵¹ Staffing includes both licensed and unlicensed nurse personnel who provide direct care to the persons. Historically, nursing home pay is less than other nursing positions in acute care settings, making employee retention difficult.⁵¹ The COVID-19 pandemic has revealed how quickly a virus can move through a nursing home facility that does not have sufficient nursing staff to enforce infection control measures.⁵¹

Significance of What Hospice Entails at Its Core

The focus of hospice is concerned with the quality of care in a holistic manner (also called holistic care) rather than attaining a cure. Part of quality care is helping create a plan that provides comfort for both the person whose health is declining and the family so they can be in agreement regarding their loved one's end-of-life care.⁴⁷ The current pandemic has reinforced the importance of having discussions regarding preferences for end of life. Advance care planning could provide instruction on a person's wishes if and when they cannot speak their wishes.⁵² Families could have these discussions while health is still being maintained rather than, for example, through video conferencing with the hospital as the nursing home residents are actively dying.⁵²

PRACTICAL IMPLICATIONS FOR NURSING

As nursing homes begin to open their doors to visitors and return to a level of pre-pandemic visitation, the problems that have troubled nursing homes must be addressed. Nurses may advocate for their aging clients and encourage advance end-of-life planning. However, the COVID-19 pandemic has shone a spotlight on the importance of palliative and hospice care not only in the United States but also throughout the world. Planning for end of life and the associated challenges that come with end-of-life care must be addressed before an individual in the active stages of death. In addition, legislation needs to address the needs of hospice care at the place of the dying person's choice. The reason is that most people would prefer to die at home, but current legislation does not provide enough support for family caregivers to make that a feasible option.

The COVID-19 pandemic forced isolation upon nursing home residents and their families without any warning. Social isolation and loneliness among nursing home residents should be improved. Nursing homes may continue to use techniques rapidly developed early on in the pandemic to encourage continued socialization, such as videoconferencing. A designated communication room for in-person small group meetings (eg, holding joint resident, family, and care team conferences while maintaining physical distancing for infection control purposes) or videoconferencing (eg, connecting nursing home residents with their family members via FaceTime, Zoom, or Skype) is warranted. Such

communication room should include at least a large, television-sized, wall-mounted computer screen to assist with visual and auditory impairments. The communication room may also serve as a family room or bereavement room.

CONCLUSION

The COVID-19 pandemic has challenged the health systems, especially nursing home care deliveries, and revealed the importance of quality end-of-life care. Hospice at nursing homes contributes critical support during the end of life that allows for the residents' and family's values, preferences, and beliefs to be a part of the preparation for death. Thus, end-of-life care delivery at nursing homes continues despite the challenges (eg, infection control measures and staffing shortage) associated with providing quality hospice care during the COVID-19 pandemic.

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