



“Hard to Say Goodbye Over iPad”

Experiences of Palliative Care Providers and Lessons Learned During the COVID-19 Pandemic in Rural Communities of Indiana, United States

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The need for palliative care (PC) has gained increased attention during the COVID-19 pandemic. Palliative care adds an extra layer of support and care for patients with advanced chronic illnesses and their families. Because of pandemic restrictions, access and provision of PC services were challenging and resulted in huge suffering and caregiving burden among patients with advanced chronic illnesses and their families, especially those living in smaller towns and rural communities. The study aimed to describe the impact of COVID-19 on PC services and examine various ethical, moral, and practice issues and challenges experienced by rural providers. Using a community-based participatory research approach, a purposive sample of health care providers (n = 15) was obtained from smaller towns and rural communities in Indiana, United States. Online individual interviews were used for data collection. Thematic analysis showed several concerns including restricted visitation, communication challenges, “hard to say goodbye over iPad”, moral distress among providers, and preference for home hospice services. Findings call for strategies to implement best PC practices and programs to support providers and families in smaller towns and rural communities.

KEY WORDS

COVID-19, grief, moral distress, palliative care, pandemic, rural providers

Palliative care (PC) has gained increased attention during the COVID-19 pandemic. With more deaths, morbidities, and complications resulting from the virus, the need for PC has been profoundly recognized in health care facilities. Palliative care provides an added layer of support and care for patients with advanced

chronic illnesses and their families by contributing toward pain and symptom control, illness management, and psychosocial support.¹ During the pandemic, physical distancing and restricted visitation imposed in health care facilities caused additional stress, anxiety, and isolation among users and providers of PC. The huge burden of infection, limited health care resources, and lack of preparedness during the pandemic largely impacted the ability of nurses, doctors, and other health care professionals to offer adequate PC services in their facilities.² Health care professionals remained unable to provide timely consultations and treatment options and facilitate decision making and psychosocial support to critically ill and dying patients and their families.² Especially in small towns and rural communities, PC faced additional constraints due to limited funding support, resources, and facilities, resulting in the discontinuation of or inadequate PC services for patients and families in rural clinics and hospitals.³

Rural communities demonstrate unique needs, attitudes, and behaviors toward health and illness. Individuals with advanced chronic illnesses have complex physical, psychological, social, and existential needs⁴ and therefore require integrated PC services.⁵ A recent scoping review showed that most rural areas in the United States have limited access and provision of PC services because of lack of awareness, accessibility issues such as transportation or weather, shortage of trained staff, and limited funding and resources.³ Consequently, rural communities are more vulnerable to PC disparities in the management of chronic illness than their urban counterparts.⁶ As aforementioned, the pandemic-imposed restrictions have further intensified such inequities and require immediate attention toward the provision of accessible and adequate PC services in rural communities. During the pandemic, providers have been encountering practice hardships and psychological distress while providing care to dying patients and their families. However, little has been unfolded regarding health care professionals' PC experiences during the pandemic. To fill the knowledge gap, a study was therefore designed to examine health care professionals' perspectives about the challenges/barriers faced during the pandemic while providing palliative and end-of-life care services among patients and families residing in rural communities

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of Indiana, United States. The article aims to describe the impact of COVID-19 on PC needs and services, examine various ethical and practical issues faced among health care providers, and discuss potential strategies to promote and implement best PC practices within smaller towns and rural communities.

CONTEXT

Indiana is a state in the Midwestern United States, with a total population of 6.8 million in 2020. Indiana has 730 towns and cities where 491 towns are considered as small towns and 72 as rural. Nearly 6.3 million people are living with at least 1 chronic disease.⁷ A large proportion of these chronically ill populations reside in rural regions, largely representing the agricultural workforce who, in general, suffers from health care disparities.⁶ During the COVID-19 pandemic, there have been a total of 73151 hospital admissions⁸ and 14391 deaths⁹ reported in Indiana, and the numbers continue to rise with the emergent Delta variant. Most rural counties of Indiana are short of health care providers. Statewide, there are only 230.8 active physicians per 100000 people as compared with the median of 263.8 nationwide.¹⁰ These figures clearly indicate the intensity of health care inequities and disparities in the rural communities of Indiana.

METHOD

Using a community-based participatory approach, a qualitative descriptive study design was used to explore health care professionals' perspectives about the challenges/barriers in PC provision during the pandemic. The study was conducted in small towns and rural communities of Indiana, in collaboration with the Purdue Nurse Managed Clinics, Purdue Extension teams, and Indiana Rural Health Association. There are 4 nurse-managed and nurse practitioner-led clinics in northern rural counties of Indiana affiliated with Purdue University School of Nursing. Purdue Extension teams are in 92 rural counties and support the social and economic welfare of the rural communities, whereas the Indiana Rural Health Association is a non-profit agency that works for the health and well-being of rural citizens in Indiana.¹¹

A purposive sample of health care professionals (n = 15) working in hospitals, rural clinics, nursing homes, or hospice settings was obtained. Participants included physicians, nurse practitioners/clinical nurse specialists, registered nurses, case managers, social workers, and chaplains. The demographic profile is given in Table. Participants were recruited through email invitations, online flyers and posters, and social media postings. Snowball approach was also used for recruitment purposes. Data were collected from January to April 2021 during the earlier phase of the COVID-19 pandemic.

TABLE Demographic Profile

	n	%
Age, y		
25–35	7	47
36–45	3	20
>45	5	33
Sex		
Female	13	87
Male	2	13
Job title		
Registered nurse	7	47
Nurse practitioner/clinical nurse specialist	3	20
Palliative care physician	2	13
Social worker	2	13
Chaplain	1	7
Facility type		
Hospital	9	60
Hospice	3	20
Primary care clinic	2	13
Nursing home	1	7
Palliative care experience, y		
1–2	1	7
3–5	8	53
6–10	3	30
>10	3	20
Palliative care training		
Yes	9	60
No	6	40

Ethical approval for the study was obtained from the institutional review board of Purdue University. The study followed the revised ethical guidelines provided by the university during the pandemic. Invitation letters and consent forms regarding the study were sent through emails to eligible participants. Data were collected using telephone interviews, Microsoft Teams, and Zoom. Interview duration was about 30 to 60 minutes. All the interviews were



recorded, transcribed, and stored in an institutional-protected online repository after removing all the personal identifiers. A qualitative analytical software, NVivo 12.0, was used to store and organize the data. For data analysis, a thematic analysis approach was used to identify the underlying categories, patterns, and themes.¹² A final thematic list was generated after reaching a consensus in the research team.¹² To ensure credibility and rigor, separate logbooks, field notes, and reflective notes were maintained throughout the study.

RESULTS

Findings include several perceived barriers and challenges experienced by participants in the provision of adequate PC services during the pandemic. These are restricted visitation, communication challenges, “hard to say goodbye over iPad”, moral distress among providers, and preference for home hospice services.

Restricted Visitation: “The Visitation (Restriction) Has Been the Hardest Piece of Our Work on COVID”

COVID-imposed visitation restrictions brought multiple challenges for both PC providers and users. These challenges include but are not limited to the inability to meet the holistic care needs of patients and families, inadequate communication, and minimal family support. Participants reported that during the initial months of the crisis, they were told not to allow any visitors, especially for patients who were 18 years old and above. Sometimes, it was only 1 family member who spoke on behalf of the whole family. Such a situation was as hard on providers and caused major barriers in communication and decision making between providers and patients/families. Conducting family meetings on video calls put additional work demands and pressure on the care team. Rapid changes in health care systems and policies responding to COVID-19 imposed the need to learn new care processes and increased the workload and time constraints in care provision. As a result, providers found it difficult to maintain the balance between their professional, ethical, and moral responsibilities and struggled with providing holistic care to patients and families during the pandemic as evident from the following comments.

I think that (the) biggest impact in the pandemic is impacting the families and that affects how you care. Because we sometimes can't see the family face to face, so the phone calls have to be made, and oftentimes the family doesn't really see the condition of the patient. And I think that because the families can't see their patient, maybe they don't realize how much sick they may be. And that's really tough. (RN3)

The visitation (restriction) has been the hardest piece of our work on COVID, and even though we've been allowed to have visitors, it's still difficult. There was a time period where they [hospital] were telling us that anyone over the age of 18 was not allowed to have a visitor. (CNS)

The pandemic-imposed restrictions caused major communication barriers among providers and families and created major delays in care coordination and care transition, which is another theme that emerged in the study.

Communication Barriers: “Virtual Communication Not Personal for the Residents”

Communication barriers hindered the providers' ability to use a coordinated approach to care and limited their ability to involve family members in goal setting and decision making. Participants reported that although virtual communication existed to some extent in the forms of telehealth and the use of iPads and mobiles, it was not sufficient to build supportive relationships between patients and families or between providers and families. Oftentimes, it was difficult for the providers to juggle between video calls, prioritizing and providing timely patient care. Some patients and families were not comfortable using phones or other virtual communication tools and did not find virtual communication personal, private, and engaging.

In the end-of-life care, I feel like a big part of that care is taking care of the family. We don't see the family a whole lot anymore because of the COVID, so that does make it a challenge because some of them we don't even get established a relationship beforehand. (RN4)

It is a different situation and I'm calling people on the phone. I'm here on video doing family meetings because of visitor restrictions. I think that was harder on me than anything else. (NP1)

I just know it's [virtual communication] not personal for the residents. Some of them [nursing home residents] don't understand talking to a phone. (RN4)

We used iPads or FaceTime [to help virtual communication]. They were used intermittently. Unfortunately, we restricted its usage some people [PC patients] which was again a challenge because you had a lot of people. (MD2)

Limited availability of virtual communication devices and staff shortages posed major issues impacting patient care. Most rural facilities were short of technology and workforce resources. Fewer iPads were available for virtual communication between patients and families. Frail senior residents had rarely or never used such devices and relied on care staff to help them communicate virtually



with their family members. Consequently, staff members reported anxiety and burnout from increased workload and time constraints. In contrast, few providers viewed virtual communication as an innovative approach in PC practice and development. One of the providers said that until COVID, she would have never thought about delivering PC virtually. In addition, few providers felt that virtual meetings were sufficiently helpful for the communication with the families of terminally ill patients who would otherwise be absent because of pandemic restrictions.

Hard to Say Final Goodbye Over iPad: "...People Literally Were Saying Goodbye to People Over the iPad"

For most providers, it was painful and distressing watching their patients die with minimal or no family company because of pandemic-imposed restrictions, such as restricted visitation and the lack of in-person communication.

It was kind of a brutal time. They [Hospital] would not let anybody visit any COVID patients. So, people literally were saying goodbye to people over the iPad. (MD1)

And my neighbor also died presumptively of COVID, and I cared for him here in the hospital and had to call his family because they couldn't be present at the bedside. (NP1)

Providers felt immense grief and struggle finding space and time to ventilate their moral and psychological distress, informing another theme under the study.

Moral Distress Among Providers: "[COVID Death] Not Only Happened Once, It Happened Multiple Times Daily"

Seeing critically ill and dying patients and their families caused major suffering, compassion fatigue, and moral distress among providers.

We had a lot of moral distress among ourselves, our staff. And it was a lot of cumulative drop because that [COVID death] not only happened once, it happened multiple times daily. We tracked how many patients we withdraw from life support because it is time and labor intensive. And in the pre-COVID days, we were doing probably 1 or 2 a week, and in COVID times in our peak, we were doing 16 to 18 a week. And it was just horrendous. You couldn't even think or breathe before you turned around and had to do the next one, and it was extremely high pressure. (MD1)

Our hospital was hit pretty severely with COVID, and closer to the holidays this past year and I was doing a lot of it alone. So, I was seeing most of the COVID patients and that was definitely a lot, and I think to me actually, the fatigue laid more in the fact that these patients were alone and isolated

more than the fact that they were dying. I think that's been the main source of a lot of my compassion fatigue. (NP1)

A senior provider, who was considered highly vulnerable to COVID infections, was not allowed to consult his patients and families in person and therefore felt powerless and distressed.

Well, it was really frustrating for me because I really was not supposed to go into patients' room because I'm older. I was in a risk group. They didn't really want me going into patients' rooms who were COVID. Which means I kinda had to do this by remote, which was really difficult. (MD2)

Home Hospice Services/Referrals

Pandemic policies imposed several modifications in hospice care use and referral processes. Participants reported mixed views on these changes. Some providers felt that the pandemic caused an increase in home hospice admissions and referrals. Most families preferred their frail or dying loved ones to be home to minimize their exposure to COVID and to allow more bedside company. Staying at home with hospice support also allowed more personalized and dignified care.

But ultimately, I think the biggest stressor has been the visitation restrictions, which continue to impact things on the daily. I see more people going home with hospice because they want to be able to visit. (SW2)

I think for Hospice, it [COVID]'s probably made it more popular because people don't want to be in the hospital, or they don't want their family members to be in the hospitals because they can't go see them. I think it'll be short lived to be honest, but for the moment, it's helped a little bit, but only because people want to stay home. (RN2)

Contrary to the above findings, few participants found that some families refused home hospice referrals as they did not want hospice personnel visiting their homes for safety concerns during the pandemic. Similarly, some nursing homes also deferred hospice visits to avoid the spread of COVID.

We really dropped in census because of COVID; people were not wanting anyone coming into the house at all. So, we lost quite a few referrals because of it. (RN7)

DISCUSSION

Our findings inform various ethical, moral, and practice challenges experienced by rural PC providers during the pandemic. These challenges raise concerns regarding PC practices and direct us to rethink about the philosophy



and approaches in PC provision during the pandemic. Findings indicated that PC provision was challenged during the pandemic and may have caused additional suffering among patients and families, especially in rural communities. As a result of pandemic-imposed restrictions, patients and families were largely unable to communicate their care needs and preferences in person. Dying is a collective rather than an individual experience, and thus demands a collective approach to understand and respond to the needs of dying individuals and their families. The limited face-to-face communication in PC provision and the physical presence of families during the end of lives impact patients and families as well as providers, resulting in the loss of meaning and purpose, increased anxiety, grief, and existential and spiritual distress.¹³

Providers also reported that most families did not get a chance to say goodbye to their loved ones and were not able to attend their funeral that may have resulted in a delayed mourning process and bereavement issues. The technology-assisted communication was not enough to meet the psychological, emotional, and spiritual needs of patients and families. Because of personal protective gears and social distancing, PC providers felt restricted to maintain physical touch and nonverbal communication such as facial expressions, considered as powerful tools to comfort and provide emotional support to patients and their caregivers.¹⁴ Provision of grief and bereavement support remained unmet and may have potentially ended in feelings of ambiguous loss and complicated grief among caregivers. Other studies have also highlighted the risk of complicated grief and bereavement issues during the pandemic.¹⁵⁻¹⁸ In another study, researchers conducted qualitative interviews among relatives of deceased individuals and health care professionals during the pandemic and found that not being able to say goodbye to a dying loved one is a complicating risk factor for bereavement. Most families experienced difficulties coming to terms with and processing the losses because of pandemic restrictions and were unable to connect themselves with the reality of the worsening health and subsequent death of their family members.¹⁵ The absence of end-of-life rituals caused feelings of ambiguous loss, uncertainty, and distress among the families suffering from the death of their loved ones.^{15,16} The perception of not having seen the person right before the death or after the death made it difficult for the families to come to terms and accept the death, and they eventually may end up in complicated grief and delayed closure.^{15,19} Health care professionals can play a significant role in facilitating the beginning of the mourning process, reducing the feelings of anger among families, and helping families in their grieving process.¹⁵⁻¹⁷

Similarly, PC providers also experienced grief, compassion fatigue, and moral distress while providing care to critically ill and dying patients and their families during the

pandemic. Approximately 40% of all COVID-19 deaths took place in nursing homes and long-term care settings, with more than 100,000 deaths of residents and staff in the long-term care facilities being reported.²⁰ Nurses working in these settings are continuously exposed to long working hours along with the shortage of PPE, lack of staff, and lack of organizational support²¹ and are at increased risk of burnout, suicide, and psychological and existential crisis.²²⁻²⁵ Considering the increased workload, caring for critically ill and dying patients, and lack of staffing and other resources, nurses remain unable to address their grief. Consequently, such experiences can potentially lead to burnout and compassion fatigue among nurses. With the pandemic continuing in the second year, the prevalence of psychological trauma, moral injury, and stress-related disorders including suicide rates among nurses is higher than ever before and will continue to persist in the postdisaster recovery period despite the vaccination efforts.²⁶ Not addressing these concerns can result in high turnover and decreased job satisfaction, as well as substance use and other harmful health-seeking behaviors among the providers.²⁶⁻²⁹

Our study also informed several benefits and shortfalls of using telehealth in the PC settings in rural communities during the pandemic. Several health care institutions implemented telehealth to establish connections between patients, family members, and health care providers during the pandemic. A debate on the use of telehealth in PC services exists in the literature. Some studies favored the use of telehealth in promoting enhanced PC access and reach,³⁰⁻³² whereas other studies reported concerns such as staff discomfort, lack of training, equipment logistics, and impact of technology on human relationships.³³ Further studies are therefore warranted in this area.

Telehealth assisted providers in PC consultations and caseload management despite communication barriers and other restrictions. However, these services were limited to institutions and people with sufficient resources and funds. Other than financial barriers, lack of appropriate technical skills, language barriers, inability to participate, and cybersecurity were other reported concerns among the providers that may potentially reduce the acceptance and effectiveness of telehealth among patients and families.^{33,34} A multisite study during the pandemic explored the effectiveness of virtual PC and reported proper equipment setup, connectivity issues, and effective communication skills as major barriers. The authors reported that providers experienced difficulties in acquainting the participants, maintaining conversation rhythm, responding to emotions, and closing the visit while providing telehealth services to their patients and families. They also suggested providers be mindful of persistent technical difficulties, lack of prerequisite technology to conduct virtual visits, and patients who are too ill to participate or who find virtual visits



too technically challenging. Telehealth may serve as a powerful resource in fostering relationships; however, its effective use requires special consideration in communication, implementation of human-centered caring, and relational values. Further studies are needed to evaluate the impacts of telehealth or technology-assisted services, especially in smaller towns and rural communities.

The study addressed the need and preference for home-based hospice and suggested that hospice care needs and preferences, if introduced early in care planning, can assist in promoting compassionate and dignified care, can ease the caregiving burden, and can improve the patient and family care outcomes. However, given the small sample size under study, these findings cannot be generalized and therefore need to be further investigated from a rural perspective.

IMPLICATIONS

The lessons learned indicate a strong need for strengthening existing PC services and resources in smaller towns and rural communities. Provision of human-centered care, compassion, and effective communication are essential components of PC. There is a need to identify ways to address and apply these essential PC components in a practice setting, especially in a pandemic context. Findings inform the need for staff preparedness and revising PC policies in a pandemic context. Better policies with staffing input are suggested to promote optimal practices, innovation, and quality in PC access and delivery.

Our findings suggest the provision of self-care and resilience-building programs in PC settings to prevent staff burnout, compassion fatigue, and distress and to promote subjective well-being and personal growth. Such programs will improve staff retention and work satisfaction leading to a stronger and healthier PC workforce in rural communities. Mental health and bereavement programs are highly recommended to support family caregivers and to promote healing. Creating support group programs and mechanisms for the families, friends, and spouses who have lost their loved ones may be helpful in self-recovery, transcending feelings of loss and grief, and enhancing personal growth.³⁵ Adequate resources and funding are needed to initiate newer models of care and enhanced communication technologies. Successful telehealth services require user-friendly, reliable, accessible services with secure technologies and connectivity along with provider training.

CONCLUSION

Adequate access and delivery of PC in rural communities are essential. Pandemic and other disaster-related situations call for the rethinking of PC principles and innovative approaches to improve PC services in rural communities. Existing staffing policies need to be revised, and additional

resources are needed to prepare and support staff during times of pandemic and other disasters. Online technologies and services need to be further evaluated to extend patient-centered, culturally appropriate care for the patients and families in the rural health care facilities and community settings.

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