



Field Notes From the Frontline of a COVID-19 Outbreak

Dyspnea Management for Hospitalized Patients at End-of-Life

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Northern New Jersey was inside one of the worst initial coronavirus disease 2019 pandemic epicenters in the United States. At the peak of the pandemic surge in mid-April 2020, New Jersey saw 8045 hospitalized patients with severe coronavirus disease 2019 symptoms, of which 2002 were in intensive care unit beds (86.3% of statewide capacity), including 1705 requiring mechanical ventilation. Because of the severity of pulmonary dysfunction/hypoxia, the unprecedented numbers of critically ill patients, the national opioid shortage, and transmission prevention measures for standard palliative care treatment protocols in place for refractory and/or end-of-life dyspnea were found to be ineffective in providing adequate symptom relief. The aim of the following Notes From the Field is to provide concise, pragmatic, and experiential reflection by 3 palliative care advanced practice nurses from 3 different hospital systems within the pandemic epicenter. The novel methods and opioid strategies implemented by their respective palliative care teams to ensure continued effective and appropriate treatment for end-of-life

dyspnea are described. These accounts include Lessons Learned in order to assist others who may need to quickly implement changes in the future due to pandemic resurgence or second-wave events.

KEY WORDS

air hunger, COVID-19, dyspnea, end of life, opioids, palliative, pandemic, refractory dyspnea, shortness of breath

In the early months of 2020, as the coronavirus disease 2019 (COVID-19) pandemic reached the shores of the United States, New Jersey became one of the worst epicenters in the nation. This pandemic surge threatened to overwhelm the existing health care systems. Initially, the northern counties of New Jersey were hit the hardest both in numbers of cases and deaths. The first laboratory-confirmed case was diagnosed on March 3, 2020. At the peak incidence of hospitalizations (April 4, 2020), the statewide hospital census was 8045, including 2002 patients in the intensive care unit (ICU) (representing 86.3% of statewide available capacity), with 1705 patients requiring mechanical ventilation (54.7% of statewide ventilator capacity). In the first 100 days of the pandemic, New Jersey saw a total of 165 816 confirmed positive COVID-19 cases: the most occurring in Bergen County (18 667), followed closely by Essex County (18 206). The statewide rate of laboratory confirmed COVID-19 mortality was 7.5% (12 443 deaths): the most occurring in Essex County (1723), followed closely by Bergen County (1635).^{1,2} The unprecedented need for critical care services saw rapid expansion and conversion of existing regular medical floors into ICUs. Field hospitals were constructed by the Army Corp of Engineers at the Meadowlands Sports Arena (northern New Jersey), NJ Convention and Expo Center (central New Jersey), and at the Atlantic City Convention Center (southeast New Jersey). Draconian measures to “flatten the curve”, such as social isolation and closure of nonessential businesses, were undertaken.

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The goals of palliative care are to promote quality of life and relieve suffering due to the symptoms and stress related to serious or life-threatening illness. It is a widely accepted standard of care even on the global level.^{3,4} High-quality palliative care includes expertise in symptom management and therefore remains an essential facet in the multidisciplinary care for patients who require hospitalization due to severe COVID-19 infection. In this brief “Notes From the Field”, novel approaches for end-of-life dyspnea symptom management are described. The aim is to provide concise, pragmatic, and experiential reflection on methods used by 3 palliative care teams at differing hospital systems within the New Jersey COVID-19 pandemic epicenter to conserve scarce opioid resources during the surge while ensuring quality care.

The 3 hospital systems include Hackensack University Medical Center, the flagship hospital of the Hackensack Meridian Health System, a 770-bed nonprofit research and teaching hospital providing tertiary and health care needs to northern New Jersey and the New York metropolitan area; The Valley Hospital, part of Valley Health System, a 451-bed fully accredited acute care not-for-profit community hospital serving the 32 towns of Bergen County and adjoining communities; and East Orange VA Medical Center, part of the Veterans Administration New Jersey Health Care System, a 100+ acute care bed teaching hospital providing general medical, surgical, and psychiatric

services, as well as a broad range of specialty programs for the greater New Jersey area veteran population.

INTRODUCTION

The causative agent of COVID-19 disease is SARS-CoV-2 (severe acute respiratory syndrome coronavirus 2), a novel betacoronavirus, likely of zoonotic origin that rapidly spreads through person-to-person contact. As the name implies, it is characterized by acute and severe lung dysfunction that may progress to respiratory failure due to adult respiratory distress syndrome necessitating high-flow oxygen with 100% FIO₂ and mechanical ventilation, especially in the 5% to 14% of patients with severe hypoxia requiring hospitalization.⁵⁻⁷

Dyspnea is a subjective experience often described as air hunger, increased effort of breathing, or a feeling of suffocation.⁸ In addition to reversing underlying causes, the criterion standard for treatment of severe, refractory, or end-of-life dyspnea is the administration of opioids.⁸⁻¹⁰ For patients who cannot self-report, the Respiratory Distress Observation Scale (RDOS) is the only known valid and reliable tool for assessing dyspnea.¹¹ The RDOS tool, an 8-item ordinal scale, was utilized to guide effective treatment for COVID-19 patients experiencing end-of-life dyspnea. Scores of 0 to 3 indicate no distress; 4 to 7 indicate

Variable	0 Points	1 Point	2 Points	Total
Heart Rate per minute	<90 beats	90-109 beats	≥110 beats	
Respiratory Rate per minute	≤18 breaths	19-30 breaths	>30 breaths	
Restlessness; non-purposeful movements	None	Occasional, slight movements	Frequent movements	
Paradoxical breathing pattern: abdomen moves in on inspiration	None		Present	
Accessory muscle use: rise in clavicle during inspiration	None	Slight rise	Pronounced rise	
Grunting at end-expiration: guttural sound	None		Present	
Nasal flaring: involuntary movement of nares	None		Present	
Look of fear	None		Eyes wide open, facial muscles tense, brow furrowed, mouth open, teeth together	
Total:				

FIGURE. Respiratory Distress Observation Scale. © Margaret Campbell, PhD.



moderate distress; and greater than 7 indicate severe distress (Figure, RDOS tool).

All 3 of the institutions listed in this report had well established palliative care teams in place utilizing evidence-based end-of-life care protocols derived from resources including the Center to Advance Palliative Care (CAPC), National Comprehensive Cancer Network, Palliative Care Network of Wisconsin (PCNOW), and the National Coalition for Hospice and Palliative Care.¹²⁻¹⁵ Associated order sets for dyspnea management included pharmacologic guidance addressing the use of opioids and benzodiazepines, as well as nonpharmacologic interventions including the use of fans; complementary therapies such as therapeutic touch and aroma therapy; and environmental controls such as music therapy, reduction of extrinsic noise, and compassionate presence with loved ones.

Before COVID-19, the use of opioids for end-of-life dyspnea in general included the following escalation steps: initiation via the PO, SL, IV, or SQ route with PRN dosing; if inadequate control, add standing doses and continue PRN dosing; lastly, for refractory dyspnea or compassionate withdrawal of either mechanical or noninvasive ventilation, a continuous opioid infusion with as-needed up-titration and PRN rescue dosing, and the addition of PRN benzodiazepine.^{10,11} However, standard protocols were found to be ineffective in providing adequate relief for the high degree of dyspnea seen in the terminally ill COVID-19 patient population. Higher-dose opioids were required to ease dyspnea in both the opioid-naïve and opioid-tolerant populations compared with non-COVID-19 patients. In fact, most COVID-19 patients were opioid-naïve prior to their acute hospitalization; however, they benefitted from earlier opioid infusions and commonly required IV rescue doses.¹⁶ These trends were not limited to the local New Jersey area. In response, CAPC and PCNOW published updated symptom management clinical resources specifically for the COVID-19 patient population.¹⁶⁻¹⁸

Two main categories of factors contributed to this observed inadequate symptom management: the high severity of pulmonary dysfunction/hypoxemia and the constraints on usual practice. The former, as addressed above, relates to both the severity of dyspnea symptoms and the overwhelming numbers of critically ill patients. During the peak month of April, palliative care consults increased in range from the prior year between 30.1% and 90.5%. The latter relates to the inability to initiate usual protocols due to the need for strict isolation (loss of family contact and inability to utilize integrative interventions such as therapeutic touch, aromatherapy, or compassionate presence); the need to reduce possible aerosolization of respiratory secretions (inability to use sublingual opioids, fans, and removal of endotracheal tubes for compassionate withdrawal of mechanical ventilation); national shortages of intravenous opioids for both bolus dosing and continuous infusion¹⁹; and

lastly, palliative care teams being overstressed and members being reassigned to other critically needed roles.

Given the potential for rapid decompensation and high mortality even in those with no pre-existing conditions, early palliative care services are essential for hospitalized COVID-19 patients.²⁰ The palliative care teams in this Notes From the Field report faced the same challenges with respect to the treatment of severe end-of-life dyspnea that was refractory to standard dyspnea management protocols in the setting of a national opioid shortage. The Lessons Learned section describes how flexibility and adaptability functioned to overcome various obstacles encountered due to the pandemic surge.

NOVEL APPROACHES

The surge of COVID-19 patients at Hackensack University Medical Center (UMC) necessitated a progressive expansion of intensive care beds by greater than 350%. Unfortunately, because of the national opioid shortage and the sheer number of patients requiring opioids, intravenous fentanyl was in scarce supply.

Solution. The Hackensack UMC Department of Pharmacy alerted the ICU continuum and the Pain & Palliative Medicine Institute of the critically decreased supply of intravenous fentanyl. Collaboratively, the Department of Pharmacy created a clinical memo regarding the national medication shortage, identified an operational action plan for opioid infusion rotation, and created hydromorphone and morphine infusion and bolus panels in the electronic health record (EHR). The clinical memo was distributed to all clinicians in the medical and surgical continuum, along with the Department of Patient Care, via email, and the paper memo was located in the nursing units. This communication approach streamlined knowledge for all clinical professionals and advised clinicians to be mindful about required opioid practice changes.

The clear and concise clinical memo reinforced the pharmacokinetics of intravenous opioids and provided best practice dosing strategies. For example, when a current fentanyl infusion was completed, it was immediately opioid rotated to a hydromorphone infusion. In addition, the clinical memo gave equianalgesic instruction for converting fentanyl infusions to hydromorphone and morphine infusions. Of note, intravenous fentanyl was reserved and therefore available for patients with a true allergy to codeine/morphine.²¹ The Hackensack UMC Pain & Palliative Institute providers were available 24/7 if there were opioid calculation needs or symptom management questions. The Department of Pharmacy was supportive as a clinical check point; for example, if an opioid infusion was ordered outside the recommended protocol, a pharmacist would contact the prescriber and offer further review.



In addition, the palliative care leaders revised the CAPC COVID-19 symptom management guidelines to highlight formulary medications available within the health network. These documents were published internally and functioned as a clinical pearl promoting opioid safety for nonpalliative clinicians and supporting primary palliative care due to the increased need for quality symptom management and end-of-life care.

Parallel to other institutions, The Valley Hospital experienced a shortage of intravenous fentanyl and a critically low supply of intravenous morphine and hydromorphone. Oral formulations of morphine and hydromorphone remained available; however, as patients conditions worsened, swallowing difficulties increased.

Solution. Recommendations to increase opioid dosages, using the CAPC COVID-19 symptom management clinical resources, were provided to all clinicians and distributed to the departments of medicine, nursing, and pharmacy.¹⁷ For example, morphine for dyspnea treatment in the non-COVID population generally begins with 1 to 2 mg IV every 2 hours PRN. In the COVID-19 population, initial dosages necessitated a 3-fold increase to 3 to 5 mg IV every 2 hours PRN in order to achieve adequate dyspnea control.

With the concern for limited supplies of parenteral opioids, alternative routes of administration were explored, resulting in the implementation of the use of the Macy catheter, a US Food and Drug Administration–cleared catheter used for rectal route medication administration that has been widely used in the home hospice setting.^{22,23} Rapid implementation of the Macy catheter in the acute care setting required a multidisciplinary approach that included nursing leadership, hospice, palliative care, pharmacy, nursing informatics, the shared governance council, and information systems. The inpatient palliative care team collaborated with The Valley Hospice experts, as the Macy catheter was already in use with the home hospice population as part of the refractory symptom management toolkit.

Following contingency standard of care protocols, a policy and medication management order set were developed for acutely hospitalized patient use, and appropriate documentation in the EHR implemented for nursing and providers. A train-the-trainer approach was utilized to educate nursing staff on the use and maintenance of the catheter. Resource materials provided by the manufacturer, including product videos, were placed on the internal palliative care department webpage. The palliative care team provided 24-hour coverage for troubleshooting and symptom management issues. Additional support and resources were provided by The Valley Hospice nurses as well as the clinical educator from HospiCorp.

The Macy catheter has been used for patients with loss of venous access, increased oropharyngeal secretion with poor sublingual absorption, and refractory symptom management.²² It is made from a soft, flexible silicone that

allows for effortless insertion and promotes patient comfort. The catheter is kept in place using a securing device allowing for safe and discreet access for medication administration through its medication port. The rectal vault vasculature allows for rapid absorption of certain enteral/PO medications, as well as having the advantage of bypassing up to two-thirds of first-pass metabolism, resulting in prompt symptom relief. Several classes of medications are approved for rectal administration, including, but not limited to, opioids, anxiolytics, and antipsychotics for end-of-life symptom management.²² Medications contraindicated include long-acting formulations, medications that cannot be crushed, and medications that have poor rectal absorption, including glycopyrrolate, baclofen, phenytoin, oxcarbazepine, and gabapentin. Other contraindications for use include active gastrointestinal bleeding, recent rectal surgery, open rectal wounds, and diarrhea.

For purposes of COVID-19 management, the Macy catheter was utilized in 15% of the patients who were transitioning to an end-of-life care plan and were exhibiting refractory dyspnea and/or pain.

At the East Orange VA Medical Center, intravenous hydromorphone and morphine were in short supply. While enough supply was available for intermittent bolus dosing, their use for continuous infusions was precluded. Refractory dyspnea management was further complicated by a policy restricting the use of intravenous fentanyl to the critical care areas only. There were adequate supplies of intravenous and transdermal fentanyl.

Solution. As previously stated, the complexity of end-of-life symptom management due to the increase in severity of dyspnea necessitated increased opioid frequency and dosing. Initial treatment was modified to consist of standing IV hydromorphone, generally every 3 hours with every 1 hour PRN rescue dosing for RDOS >3, a benzodiazepine every 2 hours PRN for refractory dyspnea/RDOS >7, and for those whose life expectancy was >24 hours, initiation of a transdermal fentanyl patch. The effects of transdermal fentanyl, a long-acting opioid, requires at least 12 hours to attain initial onset of action²⁴; therefore, use in situations of very short prognosis was unlikely to provide benefit. Opioid dose and frequency requirements were closely monitored by bedside and palliative care providers for efficacy and adjusted accordingly.

For dyspnea refractory to initial treatment or with compassionate withdrawal of mechanical or noninvasive ventilation, a continuous opioid infusion was indicated. With only intravenous fentanyl available for continuous infusion and the impracticality of utilizing critical care beds for end-of-life care, the need to expand the use of fentanyl infusions to the non-ICU hospital units was identified. A multidisciplinary collaboration with the department of medicine, intensivists, nursing, nursing education, pharmacy, and palliative care produced an action plan that includes guidance



on the practical aspects of fentanyl use for end-of-life care and proper use of the RDOS tool. The regularly assigned inpatient unit staff nurses had previous training on morphine and hydromorphone opioid infusions for end-of-life care, but staff reassigned from other areas (ie, outpatient clinics) had little to no training or experience. Therefore, educational needs varied from an introduction of fentanyl dosing to a complete overview of end-of-life assessment and care. This education was provided via formal in-services, electronically available symptom management review, placement of hard-copy reference binders on individual units, and 1:1 instruction. Members of the palliative care team, intensivists, and ICU staff nurses remained available to provide ongoing support and guidance.

Once implemented, fentanyl infusions could be maintained on patients transferred out of the ICU after having been compassionately withdrawn from mechanical ventilation or high-flow oxygen. As well, fentanyl infusions could be initiated and up-titrated as needed on the regular medical units for the treatment of refractory end-of-life dyspnea. After initial identification of the problem, a successful change in policy and practice was initiated in less than 4 days, thereby ensuring continued quality end-of-life care.

LESSONS LEARNED

Rapid change in the setting of the COVID-19 pandemic surge proved to be an impetus to changing clinical protocols while maintaining quality patient-focused care. In addition, early identification of gaps of care, expanded patient needs, and organizational strain catalyzed high-quality innovative patient care. It was experienced that solutions needed to be proactive, reactive, evidence-based, and flexible to all stakeholders. Fortunately, because of proper intravenous opioid stewardship, none of the hospitals experienced a complete absence of intravenous opioids. All 3 acute care hospitals identified 3 main pillars of change and care that were imperative for patient-focused success: collaboration, education, and assessment/reassessment cycles.

The foundational lesson learned, the pillar of collaboration, was the main source of gap analysis and provided the mechanism for the hospital's change agents to be actionable. More specifically, once the hospital campuses' intravenous opioid par level was decreased, interdepartmental, multidisciplinary, and cooperative collaboration were essential to formulate the above discussed solutions. Ongoing communication and collaboration with key stakeholders led to early identification of potential gaps in care. Rapid identification and modification of symptom management protocols became key in managing patients.

These organizational and patient-centered successes can also be attributed to the teamwork and shared knowledge between the palliative care nurse practitioners fostered through membership in the New Jersey Palliative

Care Advance Practice Nurse Consortium, an organization of palliative care nurse practitioners representing more than 150 years of collective experience in providing palliative nursing care in New Jersey's health care system.²⁵ The ability to quickly liaise with other experts in the field proved to be an invaluable resource to quickly and efficiently effect the changes required to meet the challenges in providing high-quality palliative care for the hospitalized COVID-19 patient population.

The second pillar, education, supported the collaborative intention and solutions that were created. Staff education and buy-in were key to the successful changes that occurred. Flexible strategies incorporated educating clinicians who learn in various mechanisms. The overall goal was to support the unit-based clinicians to be participants of the change and to act as actionable champions rather than recipients of the change. Educational materials such as the CAPC COVID-19 symptom management and PCNOW guidelines were utilized to sustain best practice and evidence-based care for all clinicians. This was especially imperative for clinicians who were reassigned/deployed from other areas (ie, outpatient clinics).

The third pillar of lessons learned was monitoring the assessment and reassessment cycle. At the patient-focused level, prior to the surge, assessment and management of dyspnea were included in standard end-of-life orders. However, a validated dyspnea tool for patients who were unable to self-report was not being routinely utilized. Each organization identified that the implementation of the RDOS tool had a positive impact on the quality of end-of-life care through the promotion of objective assessments and consistent interventions.

During the pandemic surge, it was also essential to account for the safety and needs of the clinicians in order to maintain a patient-centered focus. To optimize safety and timely administration of intravenous medications, infusion machines and pumps were commonly located externally to the patient's door. This allowed the clinical team to bolus via the opioid infusion bag with ease. Depending on the room location and environment, an IV tubing line could be extended over 20 ft long. During the rounding and reassessment process, it was noted that patients receiving only IV push opioids required a larger postbolus flush volume because of this greater length of IV tubing. Therefore, the postbolus flush volume should be adjusted according to the length of the patient's IV tubing to prevent a delay in the opioid entering the bloodstream.

FUTURE RECOMMENDATIONS

Health care systems generally operate in conventional, contingency, or crisis modes. During the New Jersey COVID-19 pandemic in the spring of 2020, the 3 hospital systems in the surge epicenter cited in this work were

operating in contingency mode. Fortunately, the aggressive measures taken by the state worked to successfully “flatten the curve,” which threatened to overwhelm the existing health care systems. Hospitals were certainly strained by both the vast numbers of patients and the severity of their illness. All efforts were made, successfully, to avert resorting to crisis-mode standards of care.

Given the modern convention of global travel and commerce, end-of-life care protocols and policies should be updated to include contingency recommendations during future pandemic surges and “second-wave” episodes. Interdisciplinary collaboration and early discussions with multiple clinical departments can assist with timely clinical practice changes. Providing opioid guidance communications such as distributing equianalgesic conversion charts and clinical memos are successful interventions to modify clinical practice when necessary. Intravenous opioid-sparing strategies may include utilizing alternative routes of administration, such as the per-rectum and transcutaneous routes.

Improved clinician education regarding end-of-life and refractory dyspnea assessment and management is essential to ensure quality palliative care in both the non-COVID and COVID populations. Utilization of evidence-based assessment tools, such as the RDOS, will assist in avoiding inadequate symptom treatment and therefore should be integrated into the EHR. When additional staff from non-care settings are reassigned to the hospital setting, a “buddy system” that connects less experienced nurses with those who have acute care expertise can assist in filling in the gap between education and experience.

Lastly, continued research is needed to identify best practices for end-of-life and refractory dyspnea in the COVID-19 population. Such practices may become clearer as the mechanisms of pulmonary dysfunction become more widely understood. Until curative treatments are developed, and preventive vaccination programs can be established, the SARS-CoV-2 coronavirus will remain a threat to public health and safety throughout our world.

CONCLUSION

Palliative care is beneficial at any stage of serious illness. The definition of palliative care, from the National Consensus Project for Quality Palliative Care, is an interdisciplinary care delivery system designed to anticipate, prevent, and manage physical, psychological, social, and spiritual suffering to optimize quality of life for patients, their families, and caregivers.²⁶ While palliative care comprises much more than just end-of-life care, the degree of morbidity and mortality associated with COVID-19 infection during this pandemic required a high degree of flexibility and adaptability in symptom management expertise both for those who survived and for those who ultimately died of the effects of the viral infection.

Common to all providers/institutions was the need for interdisciplinary collaboration, flexibility in utilizing available opioids, and educational support for nursing and medical staff. Regardless of what routes were taken, based on culture and available resources, all 3 palliative care teams were able to successfully modify existing pre-COVID-19 dyspnea/air hunger protocols to achieve the goal of delivering high-quality palliative care for hospitalized patients.

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