



End-of-life care in patients with a highly transmissible respiratory virus: implications for COVID-19

Soins de fin de vie pour les patients atteints d'un virus respiratoire extrêmement transmissible : implications pour la COVID-19

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Abstract *Symptom management and end-of-life care are core skills for all physicians, although in ordinary times many anesthesiologists have fewer occasions to use these skills. The current coronavirus disease (COVID-19) pandemic has caused significant mortality over a short time and has necessitated an increase in provision of both critical care and palliative care. For anesthesiologists deployed to units caring for patients with COVID-19, this narrative review provides guidance on conducting goals of care discussions, withdrawing life-sustaining measures, and managing distressing symptoms.*

Résumé *La prise en charge des symptômes et les soins de fin de vie sont des compétences de base pour tous les médecins, bien qu'en temps ordinaire, de nombreux anesthésiologistes n'ont que peu d'occasions de mettre en pratique ces compétences. La pandémie actuelle de coronavirus 2019 (COVID-19) a provoqué un taux de mortalité significatif dans un court intervalle et a nécessité une augmentation des besoins en soins intensifs et en soins palliatifs. Destiné aux anesthésiologistes déployés dans les unités prenant soin de patients atteints de la COVID-19, ce compte rendu narratif offre des recommandations quant à la façon de mener les discussions à propos des objectifs de soins, du retrait des thérapies de soutien vital, et de la prise en charge de symptômes de détresse.*

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Cases of coronavirus disease (COVID-19) were first reported in December 2019 in Hubei province in China and the illness has rapidly spread worldwide. Since its first appearance, COVID-19 has proven to be a deadly disease, particularly in specific patient groups, carrying mortality rates up to 14.8% in the elderly¹ and even higher in those with serious co-existing morbidities and other frailties.²

Much attention has been paid to the need for critical care resources to support patients infected with COVID-19. Less discussed, but equally important, is the need for intensive palliative care resources to ensure symptom management and comfort for those people dying of COVID-19.³ In Canada, anesthesiologists deployed to critical care units will require enhanced skills in discussing goals of care, managing symptoms in the dying patient, and withdrawing life-sustaining measures

(WLSM). This narrative review aims to provide guidance in the setting of COVID-19.

Establishing goals of care

Establishing goals of care may present increased challenges in the context of a pandemic. Limitations imposed by isolation to limit infection transmission, personal protective equipment (PPE), and restriction of visitors may impact the communication skills that we are all accustomed to using and may lead to pressures that can impact goals of care discussions.³

In recent years, there has been considerable work on developing frameworks for discussing goals of care. The following frameworks share similar principles, and remain valid and unchanged in the setting of COVID-19^{4,5}:

1. Establish a therapeutic relationship;
2. Assess acute medical illness, baseline health (underlying conditions, frailty), and the patient's values and goals;
3. Assess decision-making capacity and identify a substitute decision-maker if necessary;
4. Explain and discuss options with the patient or patient's substitute decision-maker;
5. Recommend a plan of treatment and seek consent.

Therapeutic relationships are central to effective communication and decision-making in medicine.⁶ External limitations may alter how we relate to patients and their families. It is helpful to return to basic principles. Self-awareness, a basic assessment of the situation and key stakeholders, takes only moments and provides a foundation for the interaction.^{7–11} Attention to setting, privacy, comfort, and introduction of and opportunities for empathy and education contribute to establishing trust, rapport, and dialogue.^{12–17}

Critically ill patients are at risk of adverse outcomes including significant rates of disability and death. Validated acute illness and organ dysfunction scores may help clinicians quantify this risk in general but should be used with caution when communicating the prognosis for any individual patient.^{18,19} Early experience in COVID 19 suggests that older patients with pre-existing conditions such as diabetes and hypertension have a significantly increased mortality risk.²⁰ Pre-existing frailty also increases in-hospital mortality, 12-month mortality, difficulty in weaning from mechanical ventilation, and degree of resultant disability in all critically ill patients.^{21–24}

It is important to discuss prognosis with the patient in a way that ties into their core values. While some patients may value longevity, many prioritize other qualitative

aspects of life such as independence, enjoyment of life, awareness, and the ability to interact with loved ones. Canadian research suggests that prognostication on recovery has an important impact on patients' decisions about pursuit of life support interventions.^{5,25} Integrating the biomedical information and prognosis with the patient's values to form a recommended treatment plan is a core skill for consultants working with critically ill patients. Many critically ill patients will lack capacity to consent to medical treatment plans because of their illness and/or the treatments that they require. Canadian physicians working in critical care environments should familiarize themselves with provincial guidelines for capacity assessment and determination of the appropriate substitute decision-maker.^{3,26,27}

Standards of withdrawal of life support in a critical care setting

In 2016, the Canadian Critical Care Society (CCCS) endorsed guidelines for the WLSM published by Downar *et al.*²⁸ The guidelines divide WLSM into four broad categories: 1) preparing for WLSM; 2) assessment of distress; 3) pharmacologic management of distress; and 4) discontinuation of life-sustaining measures and monitoring.²⁸ Most of the guidance provided in the CCCS document remains applicable for patients with COVID-19, with some notable exceptions, as highlighted below.

Many institutions have introduced coronavirus-related restrictions on the number and timing of friends and family visiting patients in hospital. Preparing and supporting patients and their families around the time of death presents particular challenges. Compounding these challenges, family members themselves might be suffering from COVID-19 and could also have recently lost another loved one to the virus. Meetings between staff and family and between patients and their caregivers may need to occur remotely by phone or videoconference, which may seem foreign and impersonal. Video chat might also be impractical for those without access to or familiarity in using the technology. For family members with hearing impairment, it may be difficult to accurately receive information over the phone or via video chat. Additionally, privacy concerns related to certain virtual communication platforms may introduce further restrictions²⁹ and clinicians should refer to advice from national bodies such as the Canadian Medical Protective Association in conducting virtual communication.³⁰

Human and physical resources may also be overburdened. Provider-to-patient care ratios may be higher, and direct patient contact limited to reduce

infection exposure and conserve PPE. Infected patients may be isolated or cohorted, limiting the ability to move any single patient to an ideal setting for palliation.^{28,31} Some healthcare workers may be reassigned to less familiar roles. Recent publications on end-of-life care of patients with COVID-19 have encouraged augmentation of education for frontline staff on symptom assessment and palliative management.^{31,32} Validated symptom assessment tools can help guide these assessments.^{33–36} While there are a range of presentations of COVID-19 ranging from arrhythmias to thrombosis,²⁰ severe COVID-19 has presented predominantly as a respiratory disease,^{37,38} and providers caring for patients dying in this context should be particularly adept in the assessment and management of dyspnea.^{3,39–41}

Suggestions regarding the logistics of WLSM are also contained in recently published Canadian guidelines.²⁸ The discontinuation of mechanical ventilation is a specific concern for patients dying with a highly transmissible respiratory virus. As above, clinicians should pay particular attention to the assessment and treatment of respiratory distress while ventilatory support is withdrawn. Extubation, as recommended in the 2016 CCCS guidelines, is a potentially aerosol-generating medical procedure (AGMP). Local protocols that include palliation without extubation, or extubation with protection to manage AGMP (PPE, use of negative airflow rooms, physical barriers, antitussives) have been published.^{42–45}

The opportunity for organ and tissue donation is part of quality end-of-life care in Canada.²⁸ Currently, patients with COVID-19 are being deemed medically unsuitable as potential donors.^{46,47} Nevertheless, across the country many people remain in need of life-saving transplants and over 20% of Canadians have registered their wish to be organ and tissue donors. Organ and tissue donation organizations (ODO) and transplant programs are continuing to maintain as much activity as possible to serve these patients. Clinicians are still encouraged to contact their provincial ODOs about potential organ donation during the pandemic.

Non-pharmacologic management at the end-of-life

General principles of end-of-life care for patients dying of COVID-19 include reviewing the care plan, discontinuing or deactivating devices such as defibrillators, discontinuing medications and interventions that do not provide comfort, repositioning, mouth care, and oxygen therapy. To address patient and family anticipatory grief and spiritual needs, it is crucial to involve interdisciplinary colleagues from nursing, spiritual care, social work, and psychology if available.

Care of the patient dying of a highly communicable infectious disease such as COVID-19 in the midst of a pandemic requires some modifications to the usual palliative approach to care. The added complexity of reducing the number of entries into isolation rooms and the donning and doffing of PPE presents an additional cognitive load. Nursing assessments should nevertheless be tailored to patient needs and use validated symptom assessment tools for common end-of-life issues including pain, agitation, and dyspnea.^{35,36,40} These assessment tools use non-verbal cues and observable behaviours to assess symptom burden in patients who cannot report their symptoms. Supporting the healthcare team by maintaining an adequate patient-to-staff ratio and ensuring frequent breaks is essential for maintaining high quality of care.

Establishing an end-of-life care plan includes reviewing the patient's current medication list and discontinuing medications that do not contribute to patient comfort. Cardiac monitoring, routine vital signs, and extraneous tubes and lines can be selectively discontinued. Intravenous fluids and nasogastric feeding do not contribute to patient comfort at end-of-life, and may lead to complications such as pulmonary or peripheral edema.^{48,49} Discontinuing fluids and artificial hydration and nutrition is generally recommended. Families may worry that withdrawal of hydration and nutrition support may increase suffering at end-of-life. Discussing the risks of continuing these interventions and that patients often do not feel hunger or thirst when their body is dying can help substitute decision-makers make informed decisions.^{48,49} If artificial hydration and/or nutrition are continued, careful monitoring for complications of volume overload is needed. If a Foley catheter is not already in place, the clinician can consider serial bladder scans to ensure that urinary retention is not a source of patient discomfort or insertion of an indwelling catheter. Although there are no evidence-based guidelines addressing this, bladder catheterization once a patient is actively dying may be useful.^{50,51} It is reasonable to administer medications via an already established intravenous line but if that line becomes interstitial, a subcutaneous lock is a reliable way to administer medications for end-of-life care. This avoids the need to insert a new intravenous line, which is painful and can be challenging in this patient population.

Palliation of distressing symptoms

Dyspnea

As in respiratory failure from other illnesses, dyspnea is a prominent feature in COVID-19. Nevertheless, some

patients with COVID-19 may not display physical evidence of respiratory distress despite significant hypoxemia and the sensation of dyspnea. It is important to ask patients whether they are experiencing dyspnea and whether it is distressing to them. The overarching management principle is to optimize patient comfort while minimizing exposure to staff and visitors. Measures to address dyspnea such as a fan, high flow oxygen ($> 6 \text{ L}\cdot\text{min}^{-1}$), high flow nasal cannula, continuous positive airway pressure, and bilevel positive airway pressure are sometimes offered for palliation of dyspnea. Based on the current available data, several medical societies have suggested avoiding these aerosol-generating procedures if a private room with a door and appropriate PPE for all providers is not available.^{52–56} Fortunately, use of low flow oxygen or medical air via nasal cannula along with pharmacologic management are usually sufficient to address dyspnea at the end-of-life.^{57,58}

The pharmacologic management of dyspnea begins with titration of low dose opioids using a similar approach to pain management.⁵⁹ While there is no strong evidence for use of benzodiazepines in dyspnea, they are often used when non-pharmacologic measures and opioids are inadequate,⁶⁰ and are more helpful when dyspnea is combined with anxiety. Intermittent dosing and infusions of opioids and benzodiazepines are appropriate, depending on the severity of the patient's symptoms and can be titrated to patient comfort.

Cough

Cough is a common symptom in COVID-19, as it is in other respiratory diseases and can be very distressing to patients and their families. In the acutely dying patient, oral medications that require swallowing are not appropriate. Nebulized medications are similarly inappropriate because of the risk of aerosolization of the virus. Parenteral opioids are the mainstay in management and no specific opioid is demonstrably superior.⁶¹

Agitation

Acute confusion and agitation can develop in patients nearing the end-of-life. Reversible causes can be sought and corrected if the investigations and potential treatment are consistent with the patient's goals of care. In the actively dying phase, it may be difficult to identify a trigger for agitation. Agitation can be very distressing for family and healthcare providers and a safety risk for the patient and healthcare providers.^{62–64}

Anti-psychotics, classically haloperidol, are often used to manage terminal agitation without a strong evidence base. Agitation that is refractory to anti-psychotics may

require sedation near the end-of-life. Again, high-quality evidence is lacking to guide clinicians in their drug selection for sedation.⁶² Bolus doses and/or infusions of sedatives such as haloperidol (0.5–1 mg *sc/iv* every four hours, as needed), methotrimeprazine (5–10 mg *sc/iv* every four hours, as needed), benzodiazepines (1–2 mg *sc/iv* q1h, as needed) and dexmedetomidine (0.2–0.6 $\mu\text{g}\cdot\text{kg}^{-1}\cdot\text{hr}^{-1}$ *iv*)⁶⁵ can be used to suppress symptoms but do not reverse delirium.

Secretions

Acutely dying patients are often unable to effectively clear respiratory secretions. This creates a rattling sound with each breath that can be distressing to loved ones. Non-pharmacologic and pharmacologic treatments are commonly used without a strong evidence base.⁶⁶ Common strategies to address secretions include regular repositioning and mouth care performed with full contact and droplet PPE, including moistening the mouth with swabs or saliva substitutes as required. Deep oropharyngeal suctioning in the patient with COVID-19 is not recommended, as this is uncomfortable, can contribute to worsening oropharyngeal secretions, and may also aerosolize virus particles. The mainstay of pharmacologic management of secretions is anti-muscarinic drugs such as glycopyrrolate (0.4 mg *sc/iv* every four hours, as needed), and/or octreotide (300 μg *sc* q8h, as needed).⁶⁷

Pain

Anesthesiologists are adept in the management of pain and familiar with the pharmacology of opioids, which are typically used parenterally for analgesia in patients nearing end-of-life. In general, patients who are actively dying are unable to give an accurate account of their pain and non-verbal signs and symptoms of pain should be assessed. Either intermittent dosing or a continuous infusion of opioids is appropriate and should be titrated to effect.²⁸

Conclusions

Provision of end-of-life care can be emotionally intensive under regular circumstances. During a pandemic, the weight of witnessing an increased frequency of suffering and death places healthcare workers at heightened risk of burnout. It is important to be mindful of clinicians' well-being and is crucial that clinicians support one another.⁶⁸ Institutional, local, and national wellness resources should be made easily available to front line clinicians providing critical and end-of-life care so that those providing this crucial care are able to continue to do so.

While pandemics create an impetus for all clinicians to review the basics of end-of-life care, this knowledge and skill set are important even in ordinary times. Skilful discussions around goals of care are important not only in critical care but also in perioperative settings. In addition, anesthesiologists have a good understanding of the medications commonly used for symptom management in patients nearing the end-of-life, and are thus well positioned to be involved in their care. This review provides guidance around sensitive discussions about goals of care and the nuances of symptom management during the COVID-19 pandemic to ensure that anesthesiologists are able to provide the highest quality of care that all patients deserve as they approach the end-of-life.

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