

COVID-19

Provincial Guidance for Palliative Care Communication

Introduction

Palliative care has been described as an essential part of an integrated humanitarian response to global pandemics.¹ The Province of Manitoba has Regional palliative care programs in place that can be a resource to help with the care of COVID-19 patients and their families. These programs offer help for patients and families in the community, as well as within primary, secondary and tertiary care centres.

The COVID-19 pandemic has created an extraordinary situation in which the number of patients around the world who have, or will, become ill is unprecedented. Information is rapidly changing and evolving, and there are innumerable resources, making it difficult to determine the best, most accurate and most up-to-date information.

This document focuses on the role of palliative care teams in providing information, supporting communication about communication and symptom management.

It has been developed with an effort to use the most up to date and accurate information, while recognizing that information is likely to continue to evolve and change. Please continue to refer to Shared Health at <https://sharedhealthmb.ca/covid19/covid19-updates/> for the most up to date information.

The Role of Palliative Care

The Palliative Care Team has many strengths which can be of use in supporting health care teams in their practice. These include support for the following scenarios:

- A COVID-19 infection in a patient already registered with the palliative care program may have dire consequences, which may require the rapid reassessment of goals of care. The palliative care team is well-suited to having – or to supporting - these discussions.
- In instances where isolation may prohibit in-person visitation, the palliative care team is well-equipped to helping families have goals of care conversations over long-distances and in varied situations. Different forms of virtual health, or telehealth, can be utilized and the team can help individuals problem solve solutions.
- Patients with COVID-19 may have a variety of symptoms at all stages of the disease trajectory, and supportive and symptomatic care is the current standard. Palliative care has expertise in symptom management and can assist in these situations.
- The palliative care team is involved in the palliative education of other health providers and can continue to educate health care providers to provide symptomatic, and holistic patient, care.² (adapted from csupalliativecare.org)

Communication about COVID-19

Palliative patients and their families are understandably concerned about the impact COVID-19 may have on them and their caregivers. The palliative care team can support these patients and their families by:

- Sharing up to date information about the virus and appropriate safety measures to reduce the risk of exposure, including physical distancing and hand hygiene;
- Using language focused on living in the moment and “I wish” statements;
- Acknowledging there may be decisions that palliative care patients may want to consider, within the context of the pandemic, to improve their quality of life;
 - This may include the decision to not come into a hospital if it means experiencing separation from family because of restricted hospital visiting policies.

Goals of Care Conversations

Conversations about goals of care in COVID-19 are approached in a manner similar to other serious illness conversations. These conversations should include discussions about a patient’s diagnosis, prognosis, hopes, fears, and trade-offs they are willing to make for the possibility of more time. Once these are determined, a recommendation for goals of care is given, discussed with the patient and his/her family, and clearly documented in the chart.^{3,4}

Prognosis for Patients with Severe Disease (non-COVID-19)

Even in the absence of COVID-19, there are limits on what critical care can achieve. For example, a large multicentre Canadian study called the Recover Program Study, looked at the outcomes of patients who were in the Intensive Care Unit (ICU) for over a week. Of those people older than 65 years who stayed in the ICU for more than 14 days on mechanical ventilation, 40 per cent died within 12 months of discharge from the ICU. The majority of the 60 per cent of patients that survived had severe and persistent functional dysfunction and cognitive impairment, including inability to problem solve and memory loss. Only 19 per cent of the patients older than 65 who were ventilated for more than 14 days were discharged home directly from the hospital.⁵

Prognosis for Patients with COVID-19

Determining the prognosis for COVID-19 is challenging while in the early stages of the pandemic. However, there is significant reason to be hopeful, as estimates of overall survival have improved as knowledge of the virus improves. Improvements have also been demonstrated in the ability to provide better symptomatic care for those affected by the virus.

Below are some of the reported data as of April 22, 2020. As more knowledge becomes available, these statistics are likely to change.

- For 81 per cent of symptomatic patients, COVID-19 causes mild disease⁶

- Mortality rates were initially thought to be between 3.6-5.7 per cent⁷, but may now be closer to 0.3 - 0.99 per cent^{8,9} and are expected to drop further as more is understood about asymptomatic cases
- Mortality from COVID-19 currently seems to be higher in elderly patients and in patients with comorbidities^{7,10}
- Mortality rates for patients on mechanical ventilators are high, but the data is constantly changing and is challenging to interpret. It is likely that these rates will improve as more is learned about how to care for the critically ill COVID-19 patients.
 - Early reports out of China for patients on mechanical ventilators due to COVID-19, reported death rates of 81-97%^{11,12}
 - One large study from the UK quotes the mortality rate as 66%¹³
 - Two recent papers out of the Washington State^{14,15} suggest the mortality rates are between 47.9-52 per cent^{14,15} and a very recently released large study out of New York quotes a mortality rate of 88.1 per cent¹⁶
 - One paper out of Italy suggested a mortality rate of at least 26 per cent¹⁷
 - The papers from the US^{14,15,16} and Italy¹⁷ need to be interpreted with caution because many of the patients in these studies were still alive in the ICU at the time the papers were published, making true estimates of ICU mortality difficult to determine
 - The paper from the UK also reports a bias toward reporting patients with a shorter length of ICU stay¹³
 - Mortality estimates seem to vary relating to the age and comorbidities of the patients on the ventilators.^{7,13,15,16} Younger patients in the UK study, aged 16-49, survived mechanical ventilation 76 per cent of the time.¹³
 - At this time we do not have data on long term outcomes of the mental and physical health consequences for patients who survive mechanical ventilation.

It is important to remember that prognosis data does not predict outcomes for individual patients, and each patient must be assessed individually.

Goals of care discussions should ideally include prognosis data, if it is known, to best inform a patient and his/her family about potential outcomes. Goals of care decisions should be based on a collaborative approach that incorporates patient and family values, hopes, and any anticipated decisions that might be needed in order to achieve a health care goal.

An approach to a COVID-19 goals of care conversation, that incorporates discussions around potential health outcomes, is presented below.

Serious Illness Conversation Guide – A Conversation Tool for Clinicians

Adapted from Fraser Health Serious Illness Conversation Guide Adapted for COVID-19³

CONVERSATION FLOW – A Step by Step - GUIDED SCRIPT

STEP ONE - *Set up the conversation*

- Introduce purpose
- Prepare of future decisions
- Ask permission

Guide the Conversation

"I'd like to talk with you about COVID-19 and what may be ahead for you and your care. I would also like to hear from you about what is important to you so that we can make sure we provide you with the care you want if you get sick with COVID-19 - **is this okay?**"

Transition to Step 2 - *Utilize paraphrasing and demonstrate empathy to let them know they've been heard.*

STEP TWO - *Assess COVID-19 understanding and preferences*

- "What is your **understanding** about COVID-19 and how it is affecting at risk people?"
- "How much **information** would you like from me about COVID-19 and what is likely to be ahead if you get sick with it?"
- "How are you **coping** during this time of uncertainty?"

Transition to Step 3 - *Utilize paraphrasing and demonstrate empathy to let them know they've been heard.*

STEP THREE - *Share prognosis*

- Share prognosis
- *Caution: purpose is not to provide patient education - Frame as "wish, worry, hope, wonder" statement and allow silence, explore emotion*

Guide the Conversation

- "I want to share with you our current **understanding** of COVID-19 and how it affects people at risk, specifically those like you with _____ (specific health condition(s), e.g. heart/lung/renal disease, cancer, diabetes)
- "COVID-19 is a virus that spreads through contact with liquid droplets when someone coughs or sneezes, often entering through our eyes, nose or throat if you are in close contact. We know that it is particularly serious for vulnerable people, especially for those who have other health problems. It can also cause other very severe problems."
- "It can be difficult to predict what will happen if you get sick with COVID-19. I **hope** it would not be severe and that you will continue to live well at (current place of residence) but I'm **worried** that as an adult with other health problems, you could get sick quickly and that you are at risk of dying. I think it is important for us to prepare for that possibility."

Transition conversation to Step 4 - *allow for silence.*

STEP FOUR - *Explore key topics*

- Meaning
- Fears and worries
- Sources of strength
- Family/people who matter
- Best care

Guide the Conversation

- "What is **most important** to you right now? What means the most to you, and gives your life meaning?"
- "What are your biggest **fears and worries** about the future and your health?"
- "What gives you **strength** as you think about the future?"
- "How much does your **family/people that matter to you** know about your priorities and wishes?"
- "Is there anything else that we need to know about you so that we can give you the **best care possible**?"

Transition conversation to Step 5 - *Utilize paraphrasing and demonstrate empathy to let them know they've been heard.*

STEP FIVE – Provide Reassurance

"We want you to know that **our priority is to ensure that you are cared for and comfortable** if you become sicker. Regardless of the medical treatments that you get or do not get, your health care team will always provide treatments to help make you feel better. So it is important to let us know if you get a new cough, fever, shortness of breath or other signs that your health is changing. We will continue to support you as best we can to get the right help for you."

Transition conversation to Step 6 - *Utilize paraphrasing and demonstrate empathy to let them know they've been heard.*

STEP SIX - Close the conversation

- Summarize what you have heard
- Make a recommendation within your scope of practice
- Check in with patient
- Affirm commitment

Guide the Conversation

"I've heard you say that _____ is really important to you. Keeping that in mind, and what we know about COVID-19 and your current health, I **recommend*** that we...."

Focus: "....Talk again in a few days to reassess where you are at"

Wellbeing

Focus: "....Talk with your primary care providers."

Illness

Focus: "....Make plans for care at home."

Support

System

Focus:

Help

"....Get you more information about risks and benefits regarding specific critical care treatments (e.g. restarting your heart or using a breathing machine.)"

STEP SEVEN - Document the Conversation

- Communicate with primary care providers
- Communicate with key clinicians

Symptom Management for COVID-19 (Adapted from Hendin et al)¹⁸

Non-pharmacological management

- Recognize that nursing assessments of patients dying of highly transmissible acute respiratory infections are intensive, time consuming, and require a high degree of cognitive load. This will likely require a lower patient to nurse ratio and/or frequent relief of nursing duties.
- Review all medications and discontinue those not contributing to patient comfort.
- Discontinue devices not necessary for comfort or medication administration (i.e. monitors, nasogastric tubes, additional intravenous lines).
- Discontinue or minimize intravenous fluids and enteral feeding. If the decision is made to continue enteral feeding or intravenous fluids, monitor closely for complications including aspiration and pulmonary or peripheral edema.¹⁷

Pharmacologic symptom management

NOTE: The following may generate aerosolized virus particles and present a risk of infection to family members.^{19,20}

- Fan
- High-flow oxygen
- Continuous positive airway pressure (CPAP) or bilevel positive airway pressure (BiPAP)
- All nebulized treatments (bronchodilators, epinephrine, saline solutions etc)

Basic symptom management at end of life¹⁸

Airway Secretions:

- Glycopyrrolate 0.4 mg subcut/IV q4h prn OR
- Scopolamine 0.6 mg subcut/IV q4h prn

Agitation/Delirium:

- Haloperidol 0.5-1mg subcut/IV q2h prn
- If severe add Midazolam 0.5-1mg subcut/IV q30 min prn
- If severe add Methotrimeprazine 12.5 – 25 mg subcut q4h prn

Pain:

If opioid naïve

- Morphine 2.5 – 5 mg subcut/IV q30 min prn OR
- Hydromorphone 0.5-1mg subcut/IV q30 min prn

If opioid tolerant, refer to opioid equianalgesic conversion tables for equivalent subcut/IV dosing

Dyspnea:

If opioid naïve, low dose morphine (50-75% of dose used for pain relief) is the medication of choice

- Morphine 1-2.5 mg subcut/IV q30 min prn OR
- Hydromorphone 0.25-0.5 mg subcut/IV q30 min prn OR
- Fentanyl 12.5 – 50 micrograms subcut/IV q15min prn

If opioid tolerant, give breakthrough doses to effect (breakthrough dose calculated as 10% of the total daily dose in 24 hours)

- If severe add Midazolam 0.5-1 mg subcut/IV q30 min prn
- For severe respiratory distress, consideration can be given to ketamine (1-2 mg/kg IV or 4 mg/Kg IM) as a temporizing measure until the above medications can be titrated to effect.

Nausea/Vomiting:

- Haloperidol 0.5-1mg subcut/IV q4h prn OR
- Ondansetron 4mg subcut/IV q6h prn

Fever:

- Acetaminophen 650 mg po/pr q4h prn

A Chart/Poster Version of a Simplified Symptom Management Guideline Follows.

- It has been specifically created for use in Manitoba
 - It is based on adaptations of similar guidelines from the University of British Columbia,²¹ McMaster University²², and from the publication by Hendin et al.¹⁸

**MANAGING DYSPNEA IN PROGRESSIVE COVID-19 RESPIRATORY FAILURE
RECEIVING END-OF-LIFE SUPPORTIVE CARE OUTSIDE THE INTENSIVE CARE UNIT**

- FUNDAMENTAL CONCEPTS:**
- PROGRESSIVE RESPIRATORY FAILURE IS A MEDICAL EMERGENCY.
 - OPIOIDS RELIEVE RESPIRATORY DISTRESS, TREAT PAIN AND COUGH.
 - DOSES ARE INDIVIDUALIZED TO TREAT SYMPTOMS, WITHIN ACCEPTABLE ADVERSE EFFECTS.
 - RAPIDLY EVOLVING SYMPTOMS REQUIRE TITRATING SHORT-ACTING FORMULATIONS.
 - OPIOIDS DO NOT HASTEN DEATH WHEN GIVEN PROPORTIONATE TO THE DEGREE OF DISTRESS.
 - ASSOCIATED ANXIETY MAY BENEFIT FROM THE ADDITION OF BENZODIAZEPINES; PERSISTENT DELIRIUM MAY REQUIRE SEDATION.
 - END-STAGE RESPIRATORY SECRETIONS ARE MOSTLY ASYMPTOMATIC FOR THE DYING PERSON.

**Discuss and Document
Goals of Care
and ACP status**

Perform and Document Dyspnea Assessment:
Patient Report of Dyspnea
Rating on Numeric Rating Scale (0-10)
Clinical Assessment (RR, accessory muscle use, presence of restlessness or agitation)

Doses for Opioid Naïve Patients

MORPHINE

- Start with 2.5 - 5mg PO or 1-2.5mg subcut/IV q4hrs PLUS 2.5-5mg PO or 1-2mg subcut/IV q1hr PRN for dyspnea

Reduce dose (by half) in frail/elderly patients and those with severe heart, lung, or neurological diseases.

May also dose q6h instead of q4hrs

Avoid morphine if moderate/severe renal impairment

If using 4 or more PRNs in 24hrs, re-evaluate and consider titrating up.

HYDROMORPHONE

- Start with 0.5- 1mg PO or 0.5mg subcut/IV q4hrs PLUS 0.5-1mg PO or 0.5mg subcut/IV q1hr PRN for dyspnea

Reduce dose (by half) in frail/elderly patients and those with severe heart, lung or neurological diseases.

May also dose q6h instead of q4hrs.

If using 4 or more PRNs in 24hrs, re-evaluate and consider titrating up.

For patients already on an opioid

- increase the dose by 25%.
- Adjust the breakthrough dose to 10% of daily dose.

AVOID

Fans
High flow O2 (optiflow)
CPAP or BiPAP
Nebulized treatments
Deep suctioning
(may aerosolize virus)

If starting opioid dose not effective and still dyspneic: TITRATE

Increase regularly scheduled and prn doses by 50%. Monitor. Rate of titration depends on patient tolerance (e.g. somnolence) and how severe the symptoms.

For severe and persistent dyspnea despite titration, add in Midazolam or Methotrimeprazine and/or call Palliative Care Team for advice

Medications for Associated Symptoms

Anxiety:

LORAZEPAM
0.5 - 2 mg SL q1h PRN
Review doses used in 24 hours and consider q4-12h regular dosing

Severe anxiety / dyspnea:

MIDAZOLAM
1 - 4 mg subcut q30min PRN
Review doses used in 12 hours and consider q4h scheduled dosing or continuous infusion
MAY REQUIRE MUCH MORE

Agitation / Restlessness:

HALOPERIDOL
0.5-1 mg subcut/IV q2h prn

METHOTRIMEPRAZINE
2.5 - 25 mg PO / subcut q4h PRN (more sedating)
Consider q4h scheduled dosing

MIDAZOLAM (as above)

THESE RECOMMENDATIONS ARE TO BE USED WITH GOOD CLINICAL JUDGEMENT

Consider palliative care consultation for:

- Symptoms unresponsive to basic management protocol
- Symptoms not included on the basic management protocol
- Patients on pre-existing high dose opioids
- If medication resources are scarce and medication substitutions are required
- If alternate routes of medication are required

Conclusion

The provision of end of life care for COVID-19 patients may involve a variety of different health care providers in varied settings. This document has been developed to provide a basic framework to support clinical providers in Manitoba deliver compassionate communication and basic symptom management.

It is recognized that the rapidly evolving nature of information and emerging evidence will require members of the care team to be regularly updated and this document can be expected to change over time. What will not change, however, is the need for thought, collaboration and ongoing evaluation in the palliation of patients. This is especially true in the midst of this unprecedented global pandemic.

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