

# Community-based palliative care during the COVID 19 pandemic

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## ABSTRACT

Novel Coronavirus (COVID 19) has usurped human peace and mobility. Since December 2019, the virus has claimed the lives of 87,816 people across the globe as of April 9, 2020 with India reporting a high case fatality of 3.4%. Among the vulnerable population, elderly people, and patients with comorbidities such as diabetes, chronic life-threatening illnesses, such as COPD and advanced malignancies are susceptible to COVID-19 infection and may have poor clinical outcomes. Considering the imbalance in demand and supply of healthcare resources, initiating palliative care will be essential to alleviate the suffering of such patients. The current paper deliberates on the following aspects of palliative care delivery in the community; the need for palliative care in a pandemic crisis, the role of telemedicine in palliative care delivery in the community, the vital role of a family physician in providing primary palliative care in the community and a “wholistic” community palliative care package to serve the needy in the community.

**Keywords:** Community based palliative care, COVID 19, primary palliative care

## Introduction

December 2019 evidenced the beginning of a global deluge, with a series of cases of novel virus causing respiratory tract infections in humans in Wuhan, Hubei province of China which eventually turned into a global pandemic.<sup>[1]</sup> On Jan 30, 2020, World Health Organization (WHO) declared the current novel coronavirus disease 2019 (COVID-19) epidemic a Public Health Emergency of International Concern.<sup>[2]</sup>

The novel virus was named “severe acute respiratory syndrome coronavirus 2 (2019-nCoV/SARS-CoV-2)” and was first isolated

on 7 January 2020.<sup>[2]</sup> Patients who are asymptomatic at the outset may develop mild symptoms such as upper respiratory symptoms which may progress to pneumonia, respiratory failure, and death.<sup>[3]</sup> SARS-CoV-2 belongs to the Beta coronavirus genera,<sup>[4]</sup> an enveloped, single-stranded RNA virus that is initially transmitted<sup>[4,5]</sup> from animal to human and later human-to-human transmission occurs with a rapid spread among the contact population.<sup>[6]</sup> Genetic analysis of the full-length genome sequence revealed SARS-CoV-2 to be most closely related to bat coronavirus termed Bat CoV RaTG13, indicating bats as the likely origin.<sup>[7]</sup> The glycosylated cell surface protein of the virus contains two functional domains (S1 and S2); S1 domain strongly binds to host angiotensin-converting enzyme 2 (ACE 2) receptor thus initiating the cell surface adhesion and the S2 domain facilitates fusion of the viral cell membrane with the host cell required for cellular infiltration.<sup>[8,9]</sup> Further to this, the lungs and the virus are rich in enzyme “furin”, a protein convertase responsible to cellular cleavage.<sup>[9,10]</sup>

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The total confirmed cases of coronavirus disease globally until April 9, 2020 are 1.48 million with a mortality of 87,816 with India alone reporting 5736 and 166 confirmed cases and deaths, respectively.<sup>[11]</sup> A steep rise in the number of COVID positive cases are seen after 50 years of age with the highest reporting of cases (30.4%) in the age range of 50-60 years followed by 25.5% cases in the age range of 60-70 years.<sup>[12]</sup> India has reported a case fatality rate of 3.4%.<sup>[11]</sup>

## Vulnerable Population

With improvements in healthcare, the elderly population is surviving longer which makes them highly susceptible to COVID infection and resultant mortality. With the rising trends in the nuclear families in the country, the elderly population has to depend on external support system such as a paid caregiver or nursing home facilities, which increases their susceptibility to infection. With the implementation of lockdown, patients face challenges in seeking healthcare and transportation to healthcare facilities.<sup>[13]</sup> Elderly patients also suffer from multiple comorbidities such as diabetes, COPD, and other life-limiting lung and cardiovascular diseases. It can have a deleterious effect on the already compromised immune system increasing their susceptibility to infection and resultant mortality.<sup>[14]</sup> Previous studies have demonstrated a 3.4 fold rise in the risk of developing severe acute respiratory illness (SARI) in H7N9 patients with pre-existing comorbidities.<sup>[15]</sup> Patients with Covid-19 are highly susceptible to respiratory failure and death.<sup>[16,17]</sup> Diabetes is one of the common comorbidities seen in the elderly. In a study at Wuhan, China, of the 41 patients, 32% patients had comorbidities and 20% of them had diabetes.<sup>[17]</sup> Studies have shown high levels of ACE2 in the islets cells of the pancreas predisposing them to COVID 19 adhesion and attack.<sup>[18]</sup> Viral infection can lead to wide fluctuation in the blood glucose level in diabetic patients with resultant poor recovery and detrimental prognosis.<sup>[19]</sup> Higher expression of ACE2 in patients with hypertension and CVD has been postulated to enhance susceptibility to SARS-CoV2 which can portend a poor prognosis and recovery from a heart transplant.<sup>[20]</sup> There is a lack of formal treatment guidelines at this time. Cancer and its treatment can make the patients susceptible to SARI following COVID 19 infection due to poor immunity in these sets of patients. Studies have shown a case fatality rate of 5.6% as compared to the general population where the case fatality rate is 2.3%.<sup>[21]</sup> Patients with lung cancer, those with poor baseline lung function, and immunosuppressive chemotherapy are more prone to hypoxia and tend to deteriorate faster.<sup>[22]</sup> Patients with debilitating chronic lung diseases may present with hypoxemia secondary to COVID infection and may have poor clinical outcomes.<sup>[23]</sup> Overcrowding is a major challenge in many slums/remand homes/home for orphans or senior citizens. People living in such environment are highly susceptible to infection as it is challenging to follow the social distancing norm or self-isolation. This is further exacerbated by inequities in health care-seeking behavior and healthcare service delivery for such population. Handwashing and hygiene are reduced because of minimal access to soap, water, disinfectants, and bathrooms.

In addition, access to basic essential commodities such as food is scarce due to limited availability and accessibility.<sup>[24]</sup>

## Problem statement

Although measures were implemented to identify suspect carriers at the port of entry, mathematical models have shown to delay the epidemic by a maximum of 3 days and not weeks.<sup>[25]</sup> There is a high likelihood of missing more than 50% of the infected travelers on account of being asymptomatic and being unaware of exposure, emphasizing the need for post-travel symptom tracking.<sup>[26]</sup> Thus, accounting for such fallacies at screening, as a measure to mitigate the crisis, the Indian government announced a countrywide lockdown for three weeks starting at midnight on 24 March to slow the spread of COVID-19 as the number of people testing positive in the country reached 563 and mathematical models suggest a lockdown of 49 days to reduce the case numbers below 10.<sup>[27]</sup> However, this may pose a great challenge to the national economy.<sup>[28]</sup>

The health care institutions in the country have been gearing up to battle the situation by increasing the production of personal protective equipment and ventilators in order to care for patients with severe respiratory illnesses, however, the supply may not be commensurate with the rising demand. It will thus be mandated to triage patients where some patients with respiratory distress may need aggressive intervention in the intensive care unit (ICU), while a few with multi-organ failure or coexisting comorbidity might not benefit from aggressive measures<sup>[29]</sup> and will need palliative care and symptom management to alleviate physical, psychosocial and spiritual suffering.

## Tele-palliative care

The pandemic has created an unprecedented shift in the healthcare delivery for patients requiring palliative care. In the pretext to lessen the exposure of both patients and healthcare workers and the challenges associated with travel to health care facility in view of the lockdown, many institutions are shifting their focus from face to face consultation to teleconsultation.<sup>[30]</sup>

Family physicians play a vital role in the continuum of care for patients in the community and help patients and families navigate through the journey of chronic life-threatening disease. The proximity of family physicians and accessibility to care raise the importance of family physicians in community-based care. The family physicians are in a better position to provide home-based care, counsel the patient/family through the difficult decision making in the pandemic, and support families in the bereavement phase. Family physicians can be an interface between patients in the community and palliative care specialists in the hospital.

Table 1<sup>[31]</sup> depicts the triage model that can be used for the liaison primary palliative care. The family physician could obtain a thorough history and do a physical examination and the trio (family physician, palliative care physician, and palliative

care nurse) could determine the need for a patient to be brought in for a face to face consultation to the hospital.

For patients who have mild to moderate symptoms, who have developed new symptoms that warrant physical examination and/or need a change of prescription, it will be prudent to liaise with family physician who could examine the patient and in consultation with palliative care team could provide the prescription.

Patients who have mild symptoms/asymptomatic or need a titration in the existing doses can continue to be supported over teleconsultation by the palliative care team. It is essential to document the discussion and record of the same be retained with the palliative care team.

## Symptom Management and Palliative Care

### Symptom management

#### Breathlessness

Patients with COVID infection may present with severe respiratory distress that may often be exacerbated in co-existing chronic lung disorders and malignancy involving the lung. In some cases, the respiratory distress may be refractory to conventional medical management or oxygen therapy.<sup>[3,32]</sup> The intensity of breathlessness can be assessed using a numerical rating scale such as dyspnoea numerical rating scale (score of 0-10; with 0 being no dyspnoea, 1-4 being mild dyspnoea, 5-6 being moderate dyspnoea and 7-10 being severe dyspnoea.<sup>[33]</sup> The experience of breathlessness is also influenced by emotional, environmental, cultural and social factors, and optimal management requires a holistic approach [Table 2].

#### Cough

Cough in acute viral infection could be attributed to inflammation, epithelial damage, mucus impaction, and neuromodulatory changes.<sup>[34]</sup> There is limited knowledge in the management of cough. Because of concurrent breathlessness, opioids may also help in alleviating cough.<sup>[35]</sup> For management please refer to Table 2.

#### Delirium

Delirium is common in medical illness and almost universal in last days or hours of life. There could be fluctuation in the levels of sensorium and patients often manifest with hypoactive or mixed delirium.<sup>[36]</sup> Delirium could be attributed to sepsis, metabolic derangement, hypoxia, use of certain medications such as opioids and terminal disease.<sup>[37]</sup> For management please refer to Table 2.

#### Pain

Patients may have comorbid conditions such as metastatic cancer, age-related degenerative changes such as osteoarthritis or acute or chronic cough which makes them susceptible to pain. Pain can aggravate physical and psychological distress and portend a poor quality of life. Basic assessment tools such as numerical rating scale can help in assessing the intensity of pain. A holistic approach is necessary to alleviate pain and suffering associated with it [Table 2].

### Psychological suffering

Feelings of grief, sadness, despair, fear, anxiety, stigma, and loneliness are common emotional responses in a pandemic crisis.<sup>[47]</sup> Some patients cope effectively and the underlying mechanism for attainment of a degree of peace include good communication and trust among patient, family, and clinical team, the ability to share fears and concerns, as well as meticulous attention to physical comfort and psychological and spiritual concerns.<sup>[48]</sup>

Thus, timely identification, assessment, and management is key to successful alleviation of psychological symptoms. Family physicians must be well equipped with tools for identifying and assessing patients with psychological concern and adequately trained in managing the concerns using pharmacological and non-pharmacological measures. Benzodiazepines, antipsychotic, and antidepressants must be made a part of essential and emergency drugs.

### Spiritual suffering

Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way

**Table 1: Triage model for palliative care consultation**

	Conditions	Mode of consult	Decision
Emergency	Intractable pain or other symptoms such as breathlessness, bleeding etc. that endangers quality of life or increases the risk of death Status epilepticus Agitated delirium Risk of suicide	Teleconsultation with palliative care team in liaison with family physician	To transfer to the hospital for face to face consultation
Urgent	Moderate symptoms Developed new symptoms warranting physical examination by physician Need a change of prescription such as benzodiazepines, antipsychotics or narcotics	Teleconsultation with palliative care team in liaison with family physician	Family physician could provide the prescription in consultation with palliative care team Regular follow-up calls
Routine care	Mild symptoms Need dose titration of the existing prescription On a scheduled follow up	Teleconsultation with palliative care team	Regular follow up calls

they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred.<sup>[49]</sup> Spirituality may influence the way patients cope with the disease and the situation where in it is essential to identify spiritual distress and assess spirituality using standardized tools and find interventions to alleviate spiritual distress.<sup>[50]</sup> Resolution of spiritual concerns is not about meeting needs but in being sensitive to the concerns, giving the time and space to patient to explore their anxieties about life in the present crisis, death and their perceptions about the causation of their illness and their desire to be at peace with oneself, the moment, the crisis or the deity.

**Communication**

In view of the present crisis, it may be possible to have a family tele-meeting, however, one must ensure privacy and confidentiality of the information shared in the meeting. Most palliative care patients must have had a discussion with the palliative care team with documented evidence that may aid in the discussion. During the meeting following points should be addressed;<sup>[51]</sup>

1. Chronic life-threatening illnesses refractory to disease directed treatment that may not benefit from intensive care management or disease directed treatment.
2. Elderly population with comorbidities who may not benefit from life support.

3. Symptom management as an alternative to intensive care treatment to alleviate suffering including a peaceful and dignified death.
4. Conflict resolution between family and physician and between family members.
5. The details of the communication are best documented by the primary physician and signed by the healthcare professionals involved in the discussion and patient and family members. Patient’s condition must be communicated to the patient and family in a compassionate manner and the information provided must be clear and the physician must ensure that all the concerns are addressed. Table 3 provides some do’s and don’t’s of communication.

**Discussion about goals of care and advance care planning**

It is important that goals of care and futility of intensive care management be discussed with patients who have a chronic life-threatening illness as this may be relevant in COVID 19 pandemic where ICU care may be restrictive due to limitations in resources.<sup>[52,53]</sup> Of relevance in this pandemic would be documenting the goals of care including place and extent of care and having a documentation of the same for every patient with chronic life threatening illness<sup>[54]</sup> This reduces the likelihood of

**Table 2: Symptom management in a community-based palliative care**

Symptom	Mild	Moderate
Breathlessness <sup>[38-40]</sup>	sitting upright and leaning forward facial cooling with wet wipes (binning after each use, as for tissues) Avoid use of hand held fans for the risk of spread of infection droplets	In addition to the column 1 2.5 mg Immediate Release Morphine BD-TDS + 2.5 mg SOS for breakthrough breathlessness and titrate the dose daily by 2.5 mg/24h up to a maximum of 2040mg/24h upto maximum of 40mg/day; with/without benzodiazepine Tab. Lorazepam 0.54mg HSOD
Cough <sup>[41,42]</sup>	sitting upright and leaning forward Sips of water for adequate hydration	Tab. Morphine 5mg BD; titrate the dose of 5mg upto maximum dose of 10mg BD
Delirium <sup>[43]</sup>	regular orientation, avoiding constipation, treating pain, maintaining oxygenation and avoiding urinary retention Tab. Haloperidol 0.5mg BD to TDS	Tab. Haloperidol 0.5mg BD to TDS
Pain <sup>[44-46]</sup>	Paracetamol 2-4gm/24h Avoid NSAIDs in COVID patients With or without adjuvants such as gabapentin 300mg to 1800mg/24h	Tramadol 50mg QDS to a maximum recommended dose of 400mg/24h Tapentadol 50mg TDS if pain persists increase then increase the dose to 100mg 4hourly to 150mg 6hourly(to a maximum dose of 600mg/24h only) With or without adjuvants such as gabapentin 100mg at night to maximum dose of 3600mg/24h

\*Severe symptoms/intractable symptoms the family physician should liaise with the palliative care team for transfer to inpatient/hospice facility. \*\*Morphine and fentanyl might be a challenge to get from local pharmacies, it is therefore best prescribed by palliative care physician. The dose can be later titrated in consultation with the palliative care team

**Table 3: Useful tips for communication**

Avoid	Use
You cannot be shifted to the hospital as this will not help you	I understand that you are worried and anxious about your health, with the present infectious situation; hospitals can be unsafe for you unless your health demands it.
There is not much that anyone can do for the patient	We are trying all measures to care for your patient and keep her comfortable
Death was expected as discussed with you time and again	I can imagine it must be shocking for you. It is sad. (give some time to absorb information)
No specialist can help, all measures have been futile	I understand your frustration, but I will ensure that I have you connected to your palliative care physician over teleconference
We will ensure that the patient has a peaceful death with drugs	We will provide all measures to keep the patient comfortable and assure you that the patient does not go through any form of suffering

(Adapted from the Italian Society of Palliative Care Guidance) More detailed scripts are available as a toolkit at vitaltalks.org (<https://www.vitaltalks.org/guides/covid-19-communication-skills/>)

emergency visits or hospital admissions including inappropriate interventions, ensure assessment of meaningful outcomes, and reduce psychological morbidity of bereaved family.<sup>[55-57]</sup>

### Bereavement and grief support

Death is the only predictable event in an otherwise unpredictable human journey. As a physician, we have a broader responsibility at not only providing physical care to patients but also to address the bereavement needs of dying patients and family. A stronger patient-perceived relationship with a physician is associated with improved caregiver bereavement adjustment as caregivers have a feeling of being heard and supported.<sup>[58]</sup> A strong alliance between physician and caregiver can be cultivated by a combination of clear communication, respecting caregiver values and preference; providing empathic and emotional support; helping caregivers anticipate and prepare for the patient's death, and by attending to caregiver's coping, stress, and anticipatory grief.<sup>[59,60]</sup>

### Conclusion

Patients with chronic life-threatening illnesses and concomitant COVID 19 infection have equal rights to adequate symptom control and a dignified life. There is thus a need for a concerted effort by the palliative care team and family physician to ensure a seamless palliative care delivery to such patients in the community. A liaison primary palliative care model with the help of the family physician will help serve large majority of the patients in the community who are unable to travel to the hospital because of the present crisis and ensure that the patient continues to receive quality care seamlessly.

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### Conflicts of interest

There are no conflicts of interest.

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