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Brief Communication

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End-of-Life Issues in the Era of the COVID-19 Pandemic

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Purpose: The coronavirus disease 2019 (COVID-19) pandemic has brought the world to a standstill and has exposed the lack of preparedness of most nations' health care systems. Even in usual times, palliative care has not received its fair share of recognition as an important component of patient care; instead, the emphasis is often placed on aggressive patient management. Now, with the entire medical community and decision-making committees focussed on intensive patient care, end-of-life care has taken a backseat. **Methods:** This article is a brief communication. **Results:** COVID 19 infection has been shown to lead to greater mortality and morbidity in patients with pre-existing illnesses such as hypertension, diabetes, renal failure, and cancer. Patients typically in need of end-of-life care, such as those with late-stage cancer or heart failure, are therefore at a higher risk of both contracting COVID-19 and suffering a more severe disease course. The strict nationwide lockdowns being imposed in most countries have deterred patients from seeking medical attention or hospice care. Every day new research is coming to light regarding COVID 19. This has helped significantly in creating awareness and limiting the spread of disease. However, misinformation is also rampant, leading to discrimination and mistreatment of infected patients. **Conclusion:** This pandemic has been a terrifying ordeal for all and has exposed our entire population physically, psychologically, emotionally, and financially to unimaginable stresses. In the present scenario, EOL care is as much a necessity as intensive care and should be given at least a fraction of its importance.

Key Words: Coronavirus infections, Pandemics, Terminal care

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Coronavirus disease 2019 (COVID-19) is an infectious disease caused by severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2). Most COVID-19 patients experience mild to moderate respiratory illness, requiring conservative management. However, elderly individuals and those with underlying medical illnesses such as hypertension, diabetes, coronary artery disease, renal failure, chronic infections, and cancer are more likely to develop serious illness and have greater morbidity and mortality [1]. Most hospitals are facing a stark shortage of requisite equipment such as ventilators and intensive care unit (ICU) beds, as well as available personnel for optimal patient management [2]. The immense burden that has been suddenly placed on health care facilities is forcing professionals to ration the limited resources at their disposal to a seemingly endless stream of patients, all in need of intensive care for survival. The strict nationwide lockdowns being imposed in most countries are deterring patients from seeking medical attention or hospice care in several areas. Lack of transportation, fears of contracting COVID-19 infection, and fears of being quarantined are all leading to a drop in the number of patients availing themselves of medical and palliative care services. End-of-life (EOL) care has mostly been spoken about

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in hushed tones and behind closed doors. In the practice of medicine, palliative care has frequently taken a backseat to zealous medical management of the disease condition, often with the overall well-being of the patient considered as an afterthought. With the unprecedented global spread of the COVID-19 pandemic, however, discussions about EOL care are emerging into the limelight to some (although still insufficient) extent in clinical and humanitarian circles.

A terminally ill patient contracting COVID-19 leads to a highly stressful situation for both the patient and their family. Concerns include decisions regarding medical treatment exclusively or EOL care as management options, home or hospice care, and the isolation required to limit the spread of infection to caregivers, among several others. The rapid progression of the infection and severe morbidity and mortality associated with it are factors that force patients and families to make difficult decisions in a very short span of time. Moreover, stigma towards COVID-19 patients often comes from neighbours, relatives, and caregivers, due to fears of contracting the infection themselves and the associated implications [3]. Patients therefore have to deal with the psychological burden of social stigma in addition to the physical manifestations of the infection and any pre-existing comorbidities.

One of the goals of EOL care is to allow for a dignified death, at home or at least in a familiar environment surrounded by loved ones, if so desired by the patient [4]. The decision to terminate curative therapy and pursue EOL care requires a great deal of counselling and guidance for the patient and his or her family. Presently, as we are facing an acute scarcity of medical professionals, with existing workers already employed at their full capacity and all of those available being channelled into the intensive care setup, the task of providing EOL care and counselling to patients and their families has taken a backseat. Unlike a few other South and East Asian countries, the Indian legal system does not have clear guidelines in place pertaining to the management of patients requiring EOL care, which may make physicians hesitant to suggest it as an option [4]. In the current pandemic, this lack of a framework and unified protocols for EOL care might affect the delivery of healthcare, both to acutely affected patients in need of intensive management and to chronically ill patients requiring less aggressive EOL care. In times such as these, good palliative treatment facilities for these patients ease the burden placed on ICUs, which can then be left free for the treatment of the ever-increasing load of salvageable patients who need short-term ICU care. More importantly, however, a good system for the provision of palliative care allows the patient to be in a more comfortable environment than ICUs are capable of providing and hence improves to some extent the quality of their life.

The only effective measure known to us to restrict the spread of COVID-19 is to maintain social distancing and to isolate known or suspected cases [5]. Placing a terminally ill patient in isolation for the last moments of his or her life seems exceptionally harsh. However, following standard EOL care practices and allowing interactions between the infected patient and his or her healthy family would lead to disease transmission and place more burdens on an already overstretched health care system. Palliative care involves the management of the medical, mental, and emotional needs of the patient. Some of the common obstacles that hinder the provision of good palliative care are convincing the patient and his or her family members to terminate aggressive medical management and to pursue EOL care as the best available option, the paucity of adequate and affordable centres for the provision of said care, and the availability of required facilities such as medications, personal protective equipment (PPE), and medical personnel and counsellors trained in palliative care, to name a few. The unique course of the COVID 19 infection has made EOL care an even more challenging task than it already was. At present, no health care system has enough resources to spare in the form of PPE to allow for the families of infected terminally ill patients to be present at the bedside, while ensuring that relatives can meet with patients with minimal utilization of medical resources [6]. Should the patient desire to receive EOL care at home, high-quality face masks or respirators should be provided to family members and they should be instructed in the proper use thereof. If none of these are feasible, the patient may be allowed to maintain contact with his or her family through regular video conferencing. This may help alleviate some of the fear and anxiety of being isolated and provide a modicum of comfort, both for the patient and the family. Measures such as online classes for medical and paramedical personnel can be undertaken to bridge this gap to a certain extent. To reduce face-to-face social interactions, counselling

services may be provided by telephone or over video conferencing.

Isolation away from one's family and familiar surroundings takes a heavy toll on mental health. There have been reports of depression and anxiety among patients who have been quarantined, especially the elderly. The emotional and often financial stress placed on already suffering individuals due to this pandemic is immense and increasing progressively as the number of cases detected and placed in isolation rises steadily. The telemedicine facilities that are being made available by certain organisations may serve as a teaching tool for the primary caregivers of home-quarantined terminal patients. These caregivers may be taught to attend to the physical needs of the patient (specifically, difficulty in breathing), as well as providing emotional support.

Nursing homes, old age homes, and spare wards in hospitals can be modified to provide palliative care after taking adequate precautions to limit the spread of infection with proper implementation of social distancing norms. Hospice care may be considered for patients with symptoms too severe to warrant home isolation. This includes patients with dyspnoea requiring assisted ventilation and medications such as narcotics. Morphine, both oral and nebulized, has previously been used for symptomatic treatment in terminal carcinoma patients with respiratory difficulties and is now also being considered by experts for patients with COVID-19 [7]. Morphine and equivalent opioids form an important tool in the armamentarium of palliative medicine since they provide excellent sustained pain relief and also alleviate the symptoms of respiratory discomfort. Consideration may be given to loosening laws governing the distribution of narcotics in developing countries like India [4], with adequate surveillance of course, to ensure that peripheral facilities also have easy access to these medications. The availability of PPE to ensure adequate medical care and the presence of family members, if possible, may also alleviate some of the anguish that these patients face. Trained medical personnel should be made available for the provision of symptom control, especially for pain and shortness of breath, to ensure a comfortable, pain-free, and stress-free environment for patients.

Another topic of debate is whether to intubate and mechanically ventilate patients with severe acute respiratory distress syndrome (ARDS) or to pursue a more palliative management strategy. The mortality rate for COVID-19-positive invasively mechanically ventilated patients with severe ARDS is 86%, and it is 79% in non-ventilated patients [8]; therefore, invasive ventilation does not seem to provide much mortality benefit. The final decision regarding EOL care should be left to the wishes of the patient and his or her family members, with medical professionals adequately explaining the advantages and disadvantages of both strategies and guiding them through the steps of the process. The rapidity with which the disease progresses also often comes as a surprise to otherwise previously functional healthy patients and may present a barrier to them, and especially their families, to accepting EOL care as the only available option. In addition, there is a large volume of new information available to the general public each day regarding the disease and its course. This leads to increased awareness, but also a great deal of misinformation and paranoia, which may be another source of anxiety among terminally ill patients and cause them to be reluctant to seek medical assistance or EOL care.

This pandemic has been a terrifying ordeal for all and has exposed our entire population physically, psychologically, emotionally, and financially to unimaginable stresses—although some have been affected more than others. In the present scenario, EOL care is as much a necessity as intensive care and should be given at least a fraction of its importance. All resources at our disposal must be put to use to provide good palliative care to terminal and rapidly deteriorating patients. While the losses caused in terms of human life can never be reconciled, providing satisfactory EOL care to those in need will be an essential component of determining the final outcomes of the pandemic and may change perceptions of palliative care for the better.

CONFLICT OF INTEREST

No potential conflict of interest relevant to this article was reported.

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Concept, definition of intellectual content: BG. Literature search: DG, BG. Manuscript draft preparation: DG. Manuscript editing, review and Final preparation: BG.

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