COVID-19, Critical illness and the Dying Patients:

An Approach towards Assuring Dignity

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Abstract

The ongoing pandemic caused by SARS CoV-2 has led to an unprecedented healthcare emergency across the globe. It has not only posed an extreme challenge to the healthcare of common masses but has also wrecked a massive threat to the medical fraternity, governments and all other spheres of humankind in general. The pandemic has served to reinforce stigma on a new level altogether, between the infected and the non-infected. Maintaining physical distance, masking oneself, avoiding crowded public spaces have been cast as the web of new normality to keep oneself safe and free from the infection. This has led to stigmatisation of the infected lot as well as the healthcare professionals who act as primary caregivers and providers of medical treatment to the infected. Securing dignity of the critically ill and dying COVID-19 patients cannot be disbanded in totality when certain institutional, community level changes and alternation of perception can do the needful. The paper attempts to argue in favour of palliative care, a mode of treatment that is existent yet not much prevalent in modern medicine, as a therapy that can be used in treating COVID-19 infected patients who are critically ill or in their deathbed in order to assure them dignity.

Keywords: *COVID-19, Critical Illness, Dying patients, Dignity, Palliative Care*

Introduction

The present paper essentially attempts to track the continuing COVID-19 scenario by means of comprehending the status of the infected patients and formulating a path towards assuring some form of dignity to them. Since the disease is taking different trajectories in different COVID-19 infected bodies, the nature of illness experienced by different individuals are of varying degrees and kinds. While some are asymptomatic, many are critically ill and there are others who are succumbing to the virus. The nature and capacity of the spread of SARS CoV-2 has not only deepened social cleavages by means of physical distancing which serves to be a significant measure for prevention and containment of the virus but has also led to the social boycott of many of the patients and their kin. Although the fatality rate does not account for more than 2% of those infected with the COVID-19 yet with the tremendous surge of cases across the globe the numbers of the dying patients are mounting at an alarming rate with every passing day. The rapid spread of the virus coupled with other barriers like the measures of distancing, absence of any particular given cure therapy, shortage of medical staff and equipment merits an ally for rethinking healthcare policies and techniques.

A pandemic of the present magnitude like that of COVID-19 requires planning and management at various tiers ranging from political, economic, social, to the levels of medical knowledge-based agencies and the medical science fraternity in particular. As mentioned at the outset this paper will make a modest attempt to lay out an approach that may serve to provide dignity to the critically ill and dying patients affected by COVID-19. It will project how a mode of an existing medical therapy that is less prevalent can be utilised for patients infected with SARS CoV-2 to secure their dignity which they deserve by virtue of being humans. The paper will also chalk out why dignity should be regarded as an indispensible feature of human existence and must be guaranteed or tried to be provided in times marked with challenges threatening humankind such as the present pandemic.

COVID-19 and the Ongoing Scenario

Managing and tackling the problems posed by COVID-19 has led the world to explore newer ways of dealing with regular activities in terms of rendering ones job as demanded by private for-profit Multinational corporations to publicly funded educational institutions. It has brought to the fore new patterns of engaging and surviving in what can be termed as the 'new normal' manifested through behavioural changes, staying indoors dependent more and more on the internet operated devices. On the peripheral visage it only appears to be creating a physical distance identified by absence of people to people contact in their workplaces, streets, public transports and other different institutional set-ups. Conversely, the spread of COVID-19 has in reality fostered the deepening of social cleavages and imbued the minds of the non-infected or presumably so with a sense of stigma for those infected with the virus. This has pushed the patients infected with COVID-19 to the margins be it in their own area of residence, hospitals, critical care units, crematoriums or graveyards. Only physicians, nursing staff, attendants equipped with medically sanitised protective gears are able to serve the COVID-19 infected patients in hospitals and critical care units reserved for such patients. Even in crematoriums and graveyards the dead bodies of COVID-19 patients and suspects are being paid their last rites by hospital attendants and few other family members if any, who are equipped with safety gears covering them from head to toe. The virus has hence successfully managed to create and further deepen the existing social gaps of various kinds among people. In societies marked with glaring socio-economic inequalities COVID-19 has been instrumental in raising unprecedented challenges which are difficult to cope in an already segregated population.

The subject that is central to this present paper is to explore ways in which a certain amount of dignity as opposed to stigma and social boycott, that perhaps could be guaranteed to a critically ill COVID-19 patient and those whom the illness has rendered vulnerable due to its nature of irreversibility and risen their possibility of an impending death due to the virus. Hence, the paper would deal with questions of whether a certain form of dignity can be restored in COVID-19 infected critically ill and dying patients. It will also make an attempt to comprehend if providing some form of dignity is plausible through the framework of palliative care in such COVID-19 infected patients.

Modern medicine-based knowledge which categorises different lines of treatment, namely preventive, curative and rehabilitative, often dilutes the potency of palliative care in meeting specific existential needs of certain kinds of patients. Palliative care accounts for an overall care of a patient and can be provided along with other simultaneous treatments or even when different invasive therapies fall short of establishing panacea. To begin with, palliative care attempts to provide pain and symptom control to the patient. It also provides psychological support to the patient as well as the family. Palliative care primarily aims at providing dignity to patients who are terminally ill, suffering from irreversible ailments and nearing death. This mode of care if made accessible and available to dying and critically ill COVID-19 patients can serve as a major breakthrough in providing them dignified medical treatment in an infection which is highly contagious as well as full of stigma at the societal level.

Palliative Care: Development, Nature and Significance

The late twentieth century witnessed a massive development in the field of medical science and technology.[1] To many it appeared that all kinds of medical illnesses could be arrested through the new modes of treatment that were available. Various mechanisms of life supporting systems in order to keep a patient alive even with multiple organ

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[1] Cicely Saunders, "The evolution of Palliative care," *Journal of the Royal Society of Medicine* 94, no. 9, (2001):430-432, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1282179/

failure came up. Modern medicine had by then deduced several ways by which the lives of many suffering from chronic and non-communicable diseases could be prolonged. Irrespective of all these development in the field of medical science dying was invincible in cases of life threatening diseases that were diagnosed at later stages. No medical intervention in such cases could alter or arrest the conditions of such patients. Most patients in cases like these would die in immense pain and misery. Therefore an increasing need began to be felt for uplifting dying patients from misery and pain by various professionals in the 1950's.

The role of Cicely Saunders is instrumental in the movement that led to the establishment of what we understand as Palliative care today. After she had given up wartime nursing in the year 1948 in course of social work her experience with cancer patients and their families who were overwhelmed by pain and misery moved her. Saunders' encounter with a polish Jew who suffered from a fatal cancer led her to undertake new fields of scientific enquiry to find answers to uplift the dying patients from their pain. She conducted her research at the ST. Joseph Hospice where she could engage with patients in their later stage of cancer and provide them day-to-day care in cases where patients on oral dosage of morphine expressed of being pain-free. Apart from her personal account, there are also other initiatives that were being taken during the same period. A report that was published in 1952 by the Marie Curie Foundation which studied cases of cancer patients brought out their suffering and pain in the absence of end of life care.[2] Another large-scale national survey was conducted in United Kingdom in the year 1960. It had incorporated the study of several sites, charitable homes and opinions of physicians which paved way for further discussions on the appalling conditions of patients due to terminal illness.

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[2] Cicely Saunders, "The evolution of Palliative care," *Journal of the Royal Society of Medicine*, 94, no. 9, (2001):430-432, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1282179/

In contemporary understanding, care for the terminally ill in medical sciences is termed as Palliative care. The WHO along with the World Palliative Care Alliance (WPCA) has come out with a joint report titled ‘Global Atlas of Palliative Care’[3] that may serve as an essential tool for advocating the addition of palliative care at the global, national and regional levels of health care delivery systems. The report for the first time provides an estimate on the needs of palliative care for children, adults and elderly. It is believed that around 20 million people need palliative care annually in the advanced stages of their illness while another 20 million people are in need of palliative care due to life-threatening illness along with other simultaneous invasive treatment. However, it is only in few countries that policies for proper palliative are in place and are being implemented effectively. In many countries there is an absence of a drug policy, lack of trained physicians and staff in palliative medicine and no framework of national policy on palliative care. Hence palliative care for the terminally ill patients continues to be provided in tandem with other modes of care only in a handful of nations. In a study carried out in 80 countries, UK emerged as the nation that provides for the best palliative care.[4] The countries that ranked after UK are Australia, New Zealand, Ireland Belgium followed by others. The study however, does not show the rank of India with regard to palliative care implementation.

It has been estimated that 7 million people die every year in India, out of which a majority die in misery and pain. According to the WHO, 4 million out of this population could benefit from Palliative Care that is the most suitable form of care for the terminally ill patients. However, only 1% in practice receives some form of palliative care. The WHO defines Palliative care as that which “improves the quality of life of patients and families who face life-

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[3] Stephen R. Conner and Cecilia Sepulveda Maria Bermedo. *Global Atlas of Palliative Care at the End of Life*. (World Health Organisation :January 2014).

[4] Nick Triggle, "UK end-of-life care best in the world." *BBC News*, October 6, 2015.

threatening illness, by providing pain and symptom relief, spiritual and psychosocial support from diagnosis to the end of life and bereavement."[5]

Despite the growing need for Palliative care there has been little or no support from the Indian state with regard to promoting end of life care. There have been few frameworks put forward by non-state actors, namely civil society groups and NGOs that demand attention with regard to focusing on Palliative care in India. Apart from this, the community model developed in Kerala, which serves to be one of its kinds, has received great attention from different states and agencies worldwide. However, it is Kerala alone in India that has been able to achieve significant progress with respect to providing care for the terminally ill.

The Position statement issued by the Indian Association of Palliative Care (IAPC) urged the government to bring about a strong policy with respect to palliative care.[6] It highlighted that there is an absence of regulation with regard to palliative care for people with advanced diseases and are suffering from terminal cancers and the likes. It also mentioned that there is lack of trained physicians and other health care professionals for promoting palliative care. There is also absence of general awareness on the issue among many medical professionals and common people at large. The position statement authored by Dr. Navin Salins and others also pointed out the dearth of education and nonexistence of any legal standpoint with regard to end of life care for patients suffering from life-threatening diseases.[7] It came up with certain recommendations in order to make the delivery of end-of-life care effective in India. The most important

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[5] "Palliative Care", WHO, accessed August 20,2019, http://www.who.int/cancer/palliative/en/

[6] Stanley C Macaden et al. "End of Life Care Policy for the Dying: Consensus Position Statement of the Indian Association of Palliative Care." *Indian Journal of Palliative Care* 20, no. 3 (Sep- Dec 2014).

[7] Ibid

recommendation includes the need for the government of India to come up with legislation with regard to end-of-life care and the need for all hospitals to have an end-of-life care providing policy and set up.

Palliative care is viewed by its proponents as a form of therapy which primarily aims at reducing distress, pain and misery of the affected patient and his family by providing value and ensuring dignity to the diseased and those requiring end of life care. By means of psycho-social care along with other remedial measures it tends to secure the patient by adding meaning to their lives until death. Hence it lends them a certain amount of dignity as opposed to the feeling of regarding themselves as burdens upon their families or of an existence that is futile in nature. It further allows the bereaved family psychological support through counseling provided by trained palliative care teams to manage with the loss and in coming to terms with it.

Palliative Care for the Critically Ill and Dying COVID-19 Patients

Palliative care, however, has come be to be understood as much more than caring for terminally ill cancer patients with the notion with which it had been perceived. Its ambit of care is no longer confined to dying cancer patients or any other life threatening illness as believed by many. According to them palliative care should not be regarded as a form of care which falls in the last segment of the continuum of care for the dying patients. For them it is about the fundamental nature of palliative care, due to which it should be made available for all instead of just dying patients. According to this set of proponents who believe palliative care should be for all, they are of the opinion that the idea of palliative care is to 'comfort and enable'[8] and therefore should be provided to anyone who is ill even due to a common viral

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[8] Anthony Pillai, "Palliative care for all?" *British Medical Journal* 345, no. 7883 (2012)

infection. In such cases palliative care would not imply as a mechanism of care when curative mechanisms fail but a as mode of care to provide support and comfort for a patient who may suffer from any condition. However, in practice palliative care is rendered mainly to those who are terminally ill and to cancer patients in particular in the advanced stages of the disease.

Due to limited resources and lack of specialised knowledge in palliative care, it tends to be confined to those who are suffering from cancer or any other terminal illnesses. In this context mention must be made of the fact that there needs to be closer interaction between other medical specialists and palliative care specialists so that an overall care can be provided to a patient. However, according to the proponents of palliative care who believe in making it available for all, the terms terminal care and palliative care which are used interchangeably which needs to be avoided. As per their understanding, for those with terminal illness palliative care is the only mode of care that is available whereas for any other patient who has a common non-terminal illness palliative care should be utilised as one of the modes of treatments along with other invasive care mechanisms.

Human Dignity vis-à-vis the Critically Ill and Dying COVID-19 Patients

In trying to comprehend the concept of dignity, one comes across various contrasting and conflicting claims and conceptions of dignity put forward by different thinkers beginning with Aristotle and Kant to various other contemporary thinkers like Nussabum in political philosophy. In an attempt to study the concept of dignity one is confronted with various questions. Some of these questions that will be addressed here with regard to the concept of dignity are- what is implied by the concept of dignity? Who qualifies to have dignity? What is the basis for possessing dignity? Why is it relevant to possess some form of dignity? How can human dignity be understood? These questions will be analysed through Nussbaum's concept of dignity here.

Nussbaum lays out through her writings and lectures that she draws partly from both Aristotle and Kant, but however drifts apart from both of them in order to evolve her own conception of human dignity.[9] Nussbaum points out that Kant, like the Stoics propounded that moral value and capacity to reason are what characterises human beings. According to Kant, all principles are needed to be tested so that they can be applied universally in order to avoid any unfair favour for one's particular case. It is by doing so that a principle can gain acceptance as a universal law of nature and in turn imply that all humans would command equal respect through its application. For Kant, respecting human dignity is identified with treating them as end in themselves, rather than as mere means to one's end. Hence appreciation for morality and rational capacity of an individual is equivalent to respecting human dignity in Kantian understanding.

However, according to Martha Nussbaum this doctrine only takes into account morality and rationality of humans as markers of human dignity, while ignoring various other aspects of worthiness that human beings may acquire by luck or heredity. Also, external elements like status, wealth, relationships, health are not considered of value as per the doctrine. In Nussbaum's schema of human dignity attaching worth only to morality and rationality and thereby believing them to be basis of human dignity that is inalienable does not fit in. Nussbaum interrogates that if human dignity is considered inalienable as per the Kantian doctrine, what could it imply for those who are poor or those who suffer from inequalities marked by race, sex, disability and so on. Although Nussbaum adheres to the Kantian notion partly since it treats human beings as ends she confides that the framework cannot serve to answer these questions. She believes that

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[9] Martha Nussbaum, "Human Dignity and Political Entitlements," *Human Dignity and Bioethics : Essays Commissioned by the President's Council on Bioethics* (March 2008)

https://bioethicsarchive.georgetown.edu/pcbe/reports/human_dignity/chapter14.html this framework also cannot succeed in becoming the basis for a political arrangement since it does not make claims for basic entitlements like food, health or education and attributes one of possessing dignity by virtue of his morality and rational capacity together. Nussbaum contends that human capacities require support in different manner to develop aspects like love, care and their overall internal development.[10] A suitable political arrangement that guarantees opportunity is also a pre-requisite for one's development externally. She does believe that human beings possess inalienable worth due to their capacities for different kinds of activity and striving. For Nussbaum, the acquisition and enhancement of these capacities are dependent upon the opportunities for taking the shape of an actual functionings.

Nussbaum endorses the Aristotelian view that determines that human capacities are worthy of respect which require space and environment for their complete development. She further notes that human beings are bestowed with capacities to carry out different forms of activity and for the purpose of striving. Nevertheless, absence of a conducive environment and lack of opportunities can infringe upon the development of capacities and actual functionings. Nussbaum questions whether a life that lacks opportunities for development and exercise of human capacities can be identified of possessing human dignity. She regards that the political arrangements should be such that they provide space for complete development of human capabilities for respect for human dignity to persist. She also lays out the way forward towards formulating a dignity based approach relevant for a pluralist democratic society.[11]

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[10] Martha Nussbaum, "Human Dignity and Political Entitlements," *Human Dignity and Bioethics : Essays Commissioned by the President's Council on Bioethics* (March 2008)

https://bioethicsarchive.georgetown.edu/pcbe/reports/human_dignity/chapter14.html

[11] Ibid

According to her it must be based upon non-metaphysical and non- religious doctrines that would provide for establishing political principles making room for all to exercise opportunities irrespective of their differences. She provides a list of entitlements that are fundamental for human existence and pre-requisite for a life to be regarded as possessing value and of holding dignity. She puts forth ten central human capabilities, namely, "life, bodily health, bodily integrity, senses, imagination, and thought, emotions, affiliations, other species, play and control over one's environment"[12]. Nussbaum opines that these central capabilities leave ample amount of space for different communities and religious to add their own specific claims to which they can successfully adhere to.

Nussbaum points out the significance of a guardian for all those who are disabled and may require some form of support and assistance to exercise their capabilities. The guardian, however, she mentions does not need to act as a substitute but play the role of a facilitator so that a person with disability is in a position to exercise his choice and capacity.[13] Human dignity, hence in the framework propounded by her is associated with creating room for the development of individuals implying respect for individual capabilities and their flourishment.

Having laid out the fundamental nature of human dignity propounded by Martha Nussbaum it becomes imperative to state how a dignified framework can be developed within this understanding for the COVID-19 patients in general and those with severe symptoms to patients who project refractory symptoms caused by this infection which has resulted in large number of deaths across the globe. Palliative care which serves to be one of the therapies that is resorted to within the continuum of care practiced in modern

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[12] Martha Nussbaum, *Frontiers of Justice* (Harvard University Press, 2006), 75-77.

[13] Ibid, p.87

medicine can be regarded as a model that could be utilised in COVID-19 care to provide the patients some form of dignity. Palliative care, as discussed in the previous section mainly gained significance as a mode that tends to alleviate pain and distress of patients who do not respond to invasive curative treatments for the cancer patients in the beginning. As stated earlier, it also attended to the families of patients after their deaths due to cancer and helped them with bereavement support and care. Its purpose has majorly been reflective of valuing the patient, the caregivers and the family instead of unnecessarily prolonging life by means of life support mechanisms in cases when the patient's situation is irreversible. The contemporary advocates of palliative care have also been of the opinion that this mode of care should not be limited to cancer patients in advanced stages of the disease but must be extended to other patients with other kinds of illnesses. According to them it is a mode of care that can be provided to a patient with any form of illness along with other invasive treatments if need be while regarding it as the only mode of therapy for patients who stop responding to other curative techniques.

Taking into account the above considerations with respect to palliative care as a mode that can be utilised as a supportive mechanism for a variety of patients presenting different kinds of illnesses it is relevant to explore the possibilities of using it for COVID-19 patients. This becomes further essential since the affected COVID-19 patients are not only suffering pain, varied refractory symptoms and death but also experiencing stigma due to its highly contagious nature. The patient in many cases is not being viewed as the one affected by a contagious virus but also as a contagion himself. Due to its high propensity of infecting people SARS CoV-2 has served to create a divide between the infected and non-infected. Unlike other illnesses wherein one finds support, cooperation and empathy of friends and relatives, patients and their respective families affected due toCOVID-19 face stigma and contempt from people at large. The patients hospitalised with COVID-19 infections are placed in isolation wards along with others who project symptoms caused due to same infection. These patients are not allowed any visitations by their family members. Unlike other patients who upon being hospitalised can be paid visits and gain some family support and hand-holding the COVID-19 hospitalised patients are solitary and isolated. Additionally, the families of the COVID-19 affected patients while under home isolation even upon testing negative for the viral infection continue to face mistrust and stigma from the neighbourhood. Consequently the nature of the viral infection has resulted in severe healthcare exigencies along with divisive effects in the social sphere.

Palliative care which is regarded as a humane mode of therapy can be utilised for COVID-19 patients and their families. It is perceived to be effective and in line with the anticipation of the affected. The trained professionals in this form of medical care specialise in alleviating chest congestion, shortness of breath, cough and other symptoms that have impacted patients with COVID-19. These trained physicians in palliative care can be deployed in managing severe symptoms and complications caused by SARS CoV-2. The Palliative care experts are equipped in diagnosing and managing delirium by means of both pharmaceutical as well as non-pharmaceutical treatments. Sedation through morphines or other drugs used in promoting palliative care can be used for patients with COVID-19 in case they no longer qualify for intensive care therapy due to presentation of refractory symptoms. Patients who face severe symptoms posed due to COVID-19 infection need empathetic and kind treatment like in case of any other extreme illness.

As mentioned earlier these patients do not have access to family members due to restrictions imposed within the isolation wards with patients of highly contagious infections. Given the nature of conditions in place, the patients as well the family members need access to palliative care specialists who can communicate with them to meet their psycho-social needs and provide supportive care. The physicians specialised in palliative care make room for the family members to bid goodbye to the patients through supportive care. In case of COVID-19 infected patients resorting to palliative care could positively serve them and their family members in a huge way. Taking into account the situation of the COVID-19 patients and their families it is pertinent to realise its significance in maintaining the dignity of the infected patients and their families.

With the huge surge in COVID-19 infected patients the healthcare systems of the most developed nations too have been plagued heavily. With the influx of large number of patients the healthcare systems have been confronted with several challenges in meeting the needs of the patients due to shortage of medical equipments in form of oxygen supply, bed facilities and the likes. The healthcare professionals too have been facing extreme challenges due to shortage in personal protective equipments (PPE), long working hours and being infected themselves in the process. Not only common people in general, healthcare workers and physicians too have died in large numbers due to being infected while serving patients relentlessly. With mounting concerns on several grounds posing challenge to the healthcare sector palliative care seemingly has taken a backseat. However, the significance of palliative care cannot be undermined in a period wrecked with a pandemic of this nature and kind. Preserving the dignity of the patients and their family infected by COVID-19 can be ensured only by means of the palliative care mode.

Conclusion

The present paper intended to highlight the ongoing COVID-19 scenario vis-à-vis the problems of the patients mainly with respect to the loss of dignity suffered by them due to the associated issues of stigma due to the contagion. It pointed out that a clear sense of division has been created between the infected and non-infected based on the issues of stigma, contempt, fear and mistrust caused by the SARS CoV-2 and its highly infectious nature. The purpose of the paper has been to lay out the significance of palliative care in promoting dignity of COVID-19 infected patients as well as its role in maintaining the dignity of their family member who are largely impacted. COVID-19 infected patients and their family members due to norms of social distancing have confronted social boycott while in immense need of social solidarity. Social distancing has been equated with socially boycott of the diseased and their family members as well the caregivers who are mainly the healthcare professionals.

Palliative care is aligned with the framework of human dignity propounded by Martha Nussbaum on various levels. Medical experts trained in palliative care aim to foster and manage the lives of patients and work towards providing them a better living experience by valuing their existence. They provide the patient therapeutic oral drugs, morphine and sedatives to relieve them from excruciating pain, shortness of breath, delirium and so on. The palliative care specialists provide management of wounds for the patients. Above all they provide psycho-social care to the patient as well as their families. As Nussbaum mentions for those who are disabled or require assistance they need to be provided support through guardians who can help them in exercising their capabilities that result in their flourishment. Hence, palliative care is completely in line with Nussbaum's schema of human dignity, for those patients who are COVID-19 infected, critically ill or gradually nearing their ends due to the viral infection. Palliative care specialists can act as guardians for the patients in such scenarios and provide them supportive care to enable and comfort them. Apart from the task of guardianship in Nussbaum's sense, palliative care, the therapy in itself propels to converge with assuring dignity as it revolves around the idea of easing out pain through its pharmaceutical techniques and in other forms, helping the individual involved in his flourishment and sustenance.

It is imperative to preserve and ensure a certain amount of dignity which is due to the patients and their family members by virtue of them belonging to the human community. With the dignity of the affected being heavily compromised, incorporating palliative care within the care mechanism for COVID-19 infected patients is highly relevant to meet their basic entitlement of protecting their dignity along with assuring them other essential treatments. Hence, including palliative care for COVID-19 patients will play an instrumental role in adding value to the lives of the critically ill patients, those who require end of life care and ensure bereavement support to the families of the deceased.

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