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Psychosocial Aspects of COVID-19 in the Context of Palliative Care – A Quick Review

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Abstract

In a resource-poor country like India, where the health-care systems are difficult to access, overburdened, and unaffordable to many, the impact of the coronavirus disease 2019 (COVID-19) pandemic can be devastating. The increased burden of serious health-related suffering can impact the well-being of health-care workers, patients, and their families alike. The elderly, the frail, the vulnerable, and those with multiple comorbidities are disproportionately affected. Palliative care, with its comprehensive and inclusive approach, has much to offer in terms of alleviating the suffering, particularly those caused by the distressing physical and psycho-socio-spiritual symptoms, the complex medical decision-making, end-of-life care issues, and grief and bereavement, and needs to be integrated into the pathway of care provision in COVID-19. Psychosocial issues contribute to and amplify suffering and are often underestimated and undertreated and not accessible to many. Empowering frontline professionals in the core concepts of psychosocial support and palliative care thus becomes an absolute necessity. This quick review was done by a group of palliative care physicians and mental health experts from India to develop recommendations for physical and psychosocial care in the context of COVID-19. This review was done as part of that process and highlights the role and challenges of the psychosocial domain of palliative care in the context of COVID-19 situation in India.

Keywords: Communication skills, coronavirus disease 2019, end-of-life care, palliative care, psychosocial care, spiritual care

INTRODUCTION

The coronavirus disease 2019 (COVID-19) has impacted millions globally, with over 2.92 million being affected and over two lakh deaths as of April 26, 2020.^[1] The unprecedented efforts at mitigating the disease, the socioeconomic consequences, the inadequacies of the health-care systems, and the race for cure have dominated the national and global psyche. Less attention has been paid to the efforts to manage and mitigate the effects of the pandemic on patient suffering, mental health, and well-being.

Psychological factors influence how individuals cope with the disease, their adaptation to loss, and adherence to public health measures^[2,3] A pandemic not only causes suffering but also amplifies suffering by increasing morbidity and mortality,

exacerbating anxiety and fear, and creating socioeconomic instability. Studies during outbreaks in China and Italy have demonstrated high levels of anxiety, depression, and stress in the general population.^[3,4] Fears of contracting the disease and concerns about the health and safety of loved ones are a constant source of worry during the pandemic, especially

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for multigenerational families in India. The uncertainty, loss of autonomy, dramatic media feeds and visuals, and the socioeconomic impact have given rise to a collective anxiety, compounded by the physical distancing measures and shelter-at-place policies.^[5]

The risk of psychological morbidity is higher among the elderly, the vulnerable, and women.^[6] For patients with cancer and other chronic life-limiting illnesses, the COVID-19 pandemic is fraught with new challenges. The repeated hospital visits for chemotherapy or radiotherapy increase their risk of contracting COVID-19. If they do contract COVID-19, the risk of morbidity and mortality in these patients is much higher. Mortality with COVID-19 is highest in the elderly: 3%–11% in those aged 65–84 and 10%–27% in those over the age of 85^[7] and in those with multiple comorbidities.^[8] Elective surgeries and palliative chemoradiation are being deferred due to COVID-19. This interruption in the treatment of primary disease ushers in a new wave of uncertainty leading to increased anxiety and fear. This abrupt change in goals of care can precipitate additional distress. Accessibility to palliative care services, opioid medications, and continuity of care has been impacted by the shelter-at-place orders in India. This can affect end-of-life care services and symptom control. The public health restrictions impede support systems, socioculturally accepted mourning rituals, and after death care. All these compound the serious health-related suffering among palliative care patients.

Palliative care in which the fundamental principle is whole-person care seeks to alleviate suffering by focusing on the physical as well as the psycho-socio-spiritual domains and should be an integral part of service provision in COVID-19.^[9] This is even more necessary in regions where health-care systems are already overburdened, difficult to access, or unaffordable for many. This study will review the psycho-socio-spiritual aspects of palliative care in pandemics and its role in alleviating serious health-related suffering. This review was carried out to enable a group of palliative care and mental health professionals to develop guidelines to provide psychosocial support for health workers managing COVID-19.

ROLE OF PALLIATIVE CARE IN COVID-19

Palliative care specialists with their experience in symptom management, complex medical decision-making, and familiarity with discussions regarding death, dying, and prognosis have an important role in educating, familiarizing, and guiding frontline health-care professionals. With this in mind, as the number of COVID-19 cases started rising in India, several professionals in the field of palliative care and mental health, both national and international, collaborated to create guidance/recommendations for palliative care management in COVID-19. This resulted in the creation of one-page algorithms on symptom management and psychosocial care. These algorithms were published as an e-book and disseminated among health-care providers. In addition, various

training programs were conducted over the ECHO platform with webinars by eminent faculties to train frontline health-care providers in palliative care.^[10] The following domains on the role of psychosocial aspects of palliative care were identified based on review of existing literature and are discussed in this context.

Empowering frontline health-care professionals

To improve communication skills with reference to clarifying goals of care, resuscitation plans, and advance care plan conversations

Mindful of the lack of uniform and clear legal guidelines regarding end-of-life care in India, improving the capacity, confidence, and competence of health-care providers to discuss and document patient preferences for end-of-life care, becomes even more important in the context of COVID-19 palliative care. For many palliative care patients, treatment decisions may be re-addressed in light of the pandemic, with disease-modifying therapies either being deferred or canceled in the absence of proven benefit. Early discussion regarding goals of care is imperative in these scenarios as patients with severe COVID-19 may deteriorate rapidly and have an unpredictable course. In this setting, frontline health-care workers are called upon to have these difficult conversations. Palliative care professionals can empower frontline health workers in initiating these discussions. The guidelines developed in the e-book provide detailed algorithms to assist these practitioners in managing these discussions sensitively and carefully. Better documentation of patients' wishes and goals of care assists with achieving optimum clinical and ethical allocation of scant resources including ventilators and ICU beds. It also assists in ensuring a dignified death for those patients for whom ICU management is not recommended due to predicted poor clinical outcomes.

In supporting the health-care workforce deal with the stress of caregiving and promoting self-care

Frontline medical workers are at increased risk of psychological morbidity like anxiety and stress, depression, burnout, and posttraumatic stress disorder as a result of responding to the COVID-19 pandemic.^[11] There is widespread fear about the ability of India's public health-care system to handle the surge of critically ill patients. Clinicians forced to care for an increased number of patients, in a new and unfamiliar work environment, for long hours, in the discomfort of wearing personal protective equipment (PPE), report physical and emotional exhaustion.^[12] Work stress is compounded by the personal fear of contracting the illness and infecting one's family, the physical distancing from the family, and the stigma and avoidance of the health-care workers by the society.

The complex triaging systems, the inability to deliver care as needed, resource shortages, and the ethical conflicts add to emotional stress and exhaustion. Inability to balance the duty of care for the individual against population-based resource allocation is associated with moral distress in health-care providers. This distress is further amplified when care decisions

are impacted by shortage of staff, supplies and space, and the absence of clear-cut decision-making guidelines and organizational support for frontline workers.^[13,14] Studies have shown that under normal working conditions, palliative care professionals experience levels of burnout similar to other physicians but experience higher levels of personal accomplishment.^[15] This is despite daily encounters with death and dying, which can be stressful and emotionally demanding. Palliative care professionals with their competency in empathetic communication, multidisciplinary team functioning, complex ethical decision-making, and self-care strategies may assist other frontline health-care professionals in handling difficult end-of-life situations.

In supporting the health-care workers in alleviating suffering by

Addressing emotional distress

The uncertainty of the situation, concerns about symptoms, fear of deterioration in one's own physical status and death, and socioeconomic concerns lead to heightened anxiety in the general population. These are likely to be exaggerated in people already going through serious health-related suffering. The elderly and the vulnerable in the joint family systems live in constant fear of contracting the disease from the younger family members, while the younger members fret about infecting the elders. If one does get infected, it can trigger a spiral of guilt, fear, and shame. The need to quarantine entire communities with the "shelter-in-place" orders has caused significant hardships, especially in migrant workers and other vulnerable population in India. There is an increased risk of social, psychological, and emotional trauma rising from the fear, neglect, and the inability to access medical care.^[16]

While many are able to deal with and adapt to the situation, in others the fear and anxiety can trigger maladaptive behaviors including substance abuse, domestic violence, and suicide.^[17,18] Self-medicating to assuage anxiety or using medications/home remedies to prevent or cure COVID-19 are maladaptive behaviors that are commonly observed.^[19] In palliative care, the consumption of stronger analgesics, especially opioids, has to be monitored closely, especially during pandemics. Compliance with existing medication regimes may be affected. Interesting behaviors related to public responses toward the COVID-19 crisis are being studied. Irrational behavior has led to panic buying, rushing to rail and bus stations in large groups, as well as the spread of misinformation and rumors. Noncompliant behavior has been reported to be strongly linked with economic consequences of isolation and the lack of primary needs such as food and shelter for migrant populations and the homeless.^[20,21]

Community-based palliative care teams with homecare and volunteer networks have an established relationship of trust and respect in the community. These individuals/teams can play a crucial role in helping frontline workers identify and address the psychosocial distress arising out of this unfortunate situation.

Addressing stigma

Stigma associated with COVID-19 is a major challenge in the Indian setting. Dignity in care at the end-of-life and after death is one of the basic tenets of palliative care. Instances of refusal to cremate/bury the bodies of those affected are emerging in India, contributing to emotional distress of the family. Stigmatization has fuelled attacks on health-care providers, leading to social avoidance, rejection, and denial of health care. Stigma interferes with utilization of support systems contributing to distress. In addition, the stigma associated with mental illness prevents many individuals with emotional suffering from seeking help, thereby increasing psychological morbidity. Community-based palliative care organizations and the workforce of volunteers can assist the health-care providers in implementing interventions to mitigate the stigma of COVID-19 in communities.

Addressing loss, grief, and bereavement

The world is struggling to cope with the loss of normalcy and predictability. In addition to the losses caused by illness and death, individuals are forced to confront multiple losses including their sense of safety, control, personal freedom, livelihood, and financial security.^[22] Education, employment, transport, economic and healthcare systems are disrupted which worsen the sense of collective loss and grief in the community.^[22] Death and bereavement can be complicated in COVID-19. Bereavement following sudden deaths is often longer, more intense, and more prolonged than following anticipated deaths.^[23] The rapid deterioration and death in COVID-19 leaves the family unprepared to cope with the loss, even in those with life-limiting illnesses. Deferring treatments for patients with cancer or other life-limiting illness can trigger a fresh wave of grief. Accessibility to quality end-of-life care and medications may be impeded by the national lockdown measures. Grieving is interrupted, resulting in anger, guilt, blaming, and hostile reaction, and may be especially targeted at health-care professionals and systems.^[24] The prohibitive public health strategies enforced for infection control may prevent goodbyes and impact the traditional mourning practices precipitating complicated bereavement.^[25] For many in India, the rites and rituals after bereavement are an essential aspect of mourning and imperative for the liberation of the soul. Families unable to be by the patient's side at the time of death or during burial/cremation may experience lingering mental health issues. Thus, the collective, community-oriented sense of loss in a pandemic is experienced at the individual and family level, as well as at the socioeconomic and political level. The duration of grief and bereavement may be variable based on the individual and cultural factors.^[26] Facilitating meaningful final goodbyes and funerals, conducted virtually over the phone or social media platforms, may aid grieving and facilitate grief work. Palliative care providers well versed with the concept of loss and mourning can train and assist frontline health-care providers in mitigating the effects of grief and bereavement.

Addressing spiritual distress

Spirituality refers to the way individuals seek and express meaning and purpose in life, and the way they experience connectedness to self, to others/nature/moment, and to the transcendent.^[27] In a pandemic, this sense of connectedness is threatened. Disruption in one's routine, roles, and work impact the sense of self. Inability to visit places of worship, partake in community activities, sporting teams, places of work, or schools may diminish the sense of meaning and purpose in life. Social distancing, isolation, and quarantine prevent visiting loved ones. Pandemics are portrayed as punishment for the sins and transgressions of the community by various religious texts.^[2] If a believer integrates this sense of punishment, this can worsen feelings of guilt and remorse. Values and beliefs are questioned when there is uncertainty, threat to life, and the loss of control over outcomes. Spiritual care helps to promote adaptation and foster resilience by overcoming fear and finding hope and meaning in uncertainty.^[28] Re-establishing connectedness by being available to others, demonstrating genuine concern and acceptance, actively listening, acknowledging and validating reactions, empathic communication, and attention to dignity helps to mitigate spiritual distress.^[29] The e-book provides simple interventions that can be adopted by frontline health-care workers to mitigate the psycho-socio-spiritual distress in those palliative care patients affected with COVID-19.

Challenges for psychosocial care in the context of palliative care Relevant to vulnerable populations in India

Communication

Communication in COVID-19 can be challenging even for a palliative care clinician. Establishing rapport in an acute care emergency situation may be difficult and the nonverbal means of communication impeded with the donning of PPE. Communications with family may be restricted to the phone or social media, where the nonverbal cues may be lost. In a society like India, where collectivistic decision-making is the rule, with multiple family members being involved, phone or social media conversations can be challenging. Communication and rapport can be achieved by pasting photos/names on to PPE for self-introduction, by communicating verbally using words expressing empathy, and to have frequent, clear, and honest discussions regarding care goals.

Delivery of psychosocial component of palliative care in India

In the current scenario, delivery of specific psychosocial care can be challenging, given the sociocultural and health-care context. In India, <3% of the population have access to palliative care.^[30] It is poorly integrated into the health-care system, except in the state of Kerala, which accounts for 90% of the services in the country. Even in centers equipped to provide palliative care, psycho-socio-spiritual care is not robust.^[31] In addition, difficulties in conducting regular home visits may affect the trusting relationship with patients' families. Inability to fulfill the needs of families may precipitate guilt and distress

in some team members. Good communication is essential in palliative care practice, and the pandemic poses an extreme challenge of maintaining trust and hope when the practices of therapeutic touch, attending to nonverbal communication, and physical presence are impeded.

CONCLUSION

Public health emergencies are known to affect psychological well-being of the individuals as well as the community, resulting in maladaptive emotions and behaviors. For most individuals, the effects are short term, they become resilient and learn to adapt, while for others, they progress to psychopathology, with some groups being more vulnerable than others. While the majority of the psychosocial responses can be managed by mental health experts, for those with severe disease and their families, palliative care, with its bio-psycho-socio-spiritual model, can offer the much-needed solace. Often, in humanitarian crises, mental health professionals themselves become a scarce resource. Palliative care needs to address the rapidly changing situation caused by COVID-19 and be prepared with new models and recommendations. The algorithms developed as a response to COVID-19 by PalliCovidKerala can be used with ease by health-care workers who have minimal prior experience managing emotional issues related to refractory symptoms and end-of-life care.

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Conflicts of interest

There are no conflicts of interest.

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