Palliative Care in Coronavirus Disease 2019 Pandemic: Position Statement of the Indian Association of Palliative Care

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Abstract

The global pandemic involving severe acute respiratory syndrome–coronavirus-2 has brought new challenges to clinical practice and care in the provision of palliative care. This position statement of the Indian Association of Palliative Care (IAPC) represents the collective opinion of the experts chosen by the society and reports on the current situation based on recent scientific evidence. It purports to guide all health-care professionals caring for coronavirus disease 2019 (COVID-19) patients and recommends palliative care principles into government decisions and policies. The statement provides recommendations for palliative care for both adults and children with severe COVID-19 illness, cancer, and chronic end-stage organ impairment in the hospital, hospice, and home setting. Holistic care incorporating physical, psychological, social, and spiritual support for patients and their families together with recommendations on the rational use of personal protective equipment has been discussed in brief. Detailed information can be accessed freely from the website of the IAPC http://www.palliativecare.in/. We hope that this position statement will serve as a guiding light in these uncertain times.

Keywords: Coronavirus disease 2019, palliative care, pandemic, severe acute respiratory syndrome–coronavirus-2

Introduction

Coronavirus disease 2019 (COVID-19) has challenged the health-care systems of India and across the world. The high infectivity along with the rapid and progressive nature of the illness and associated morbidity and mortality poses unique difficulties.[1] Lack of shelter and basic sanitation, illiteracy, overcrowding, and challenges in enforcing physical distancing measures make many of the ongoing efforts of the government less fruitful.[2] Apart from these, shortage of personal protective equipment (PPE), disinfectants, high burden of suffering combined with inadequate health-care resources and medical technology, and reliance on informal

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cares pose added challenges to the health-care system.[3] As a result, many patients with severe COVID-19 who are reliant on the public health-care system are unable to access the limited supply of designated hospital beds or intensive care resources or hospital beds and are therefore dying at home, often in difficult circumstances.[4] Moreover, resource allocation for COVID-19 has increased the suffering and death of patients with other life-limiting conditions.[5]

Palliative care focuses on effective symptom control, promotion of quality of life, holistic care of physical, psychological, social, and spiritual health, and complex decision-making, all of which play a major role in the alleviation of this widespread suffering.[6] Essential skills of sensitive, effective, empathetic communication, discussion, and review of care plans, providing all help ensures a comfortable and dignified death. Furthermore, it is imperative to support colleagues and families in coping with the direct or indirect impact of the COVID-19 pandemic.[7]

How is this position statement relevant to doctors not working in palliative care?

As palliative care professionals, we are responsible for guiding nonpalliative care colleagues not trained in the subject about providing palliative care to serious COVID-19 patients and other patients with chronic and life-limiting conditions needing palliative care and but unable to access it.[8] All professionals have a responsibility to provide good symptom management and end-of-life care in seriously ill COVID-19 disease not eligible for or not responding to intensive care treatment.[9,10] They should be supported with honest conversations about goals of care, shared decision-making, and treatment (de) escalation. Planning should be initiated early to facilitate personalized care and support plans, which is have been developed and documented. The position statement aims to guide all health-care providers supporting patients and their families directly or indirectly impacted by COVID-19 in the hospital, hospice, or home setting.

The purpose of the position statement is to:

- Guide health-care professionals caring for COVID-19 patients
- Provide palliative care input into government decisions and policies concerning COVID-19
- Support the ongoing provision of palliative care in India
- Optimize preparedness of the palliative care services to respond to COVID-19 pandemic.

Position Statement of the Indian Association of Palliative Care on Palliative Care in Coronavirus Disease 2019 Pandemic

I. Indian Association of Palliative Care (IAPC) position on providing palliative care for hospitalized COVID-19 patients with severe/critical illness
   1. All patients with severe/critical COVID-19 illness not eligible for ventilation or not responding to ventilation should be appropriately triaged for palliative care provision
   2. Dyspnea, distress/delirium, and discomfort pain are the key symptoms in severe/critical COVID-19 illness. They should be promptly assessed and managed
   3. Patients with severe/critical COVID-19 illness not eligible for ventilation should be considered for the nonescalation of treatment. It can be achieved by[11]
      a. A preemptive discussion of goals of care and advance care planning
      b. Ascertaining medical futility
      c. Communicating medical futility and documentation
      d. Consenting for withholding/withdrawing life-sustaining treatment
      e. Documenting the above.
   4. All patients with severe/critical COVID-19 illness not suitable or not responding to ventilation and intensive care unit (ICU) measures should receive a good end-of-life care. Symptoms at the end of life in these patients should be anticipated, and anticipatory prescribing should be instigated
   5. Palliative care provided in the ICU setting for critically ill COVID-19 patients should be uniquely adapted to the COVID situation.

II. IAPC position on providing palliative care for adults with cancer and chronic end-stage organ impairment: having COVID-19 or treatment limitation due to prevailing COVID-19 situation
   1. Reorient administrative policies to ensure quality palliative care within the constraints of the prevailing COVID-19 situation. This is done through triage policies, defining roles, work schedules, leaves, work from home policies, capacity building for virtual care, stock monitoring, and plans for change in the profile of patients
   2. Ensure source control by implementing universal safety precautions for everyone entering the health-care facility: health-care personnel (HCP), patients, visitors through redesigning clinical spaces, education, and appropriate use of PPE. Additional protection should be based on the roles, exposure risk, and vulnerability
   3. Reorient and support clinical care processes by defining triage criteria, facilitating uninterrupted care across settings, clarifying roles for the HCP, building processes to maintain rapport and connection with patients, and refinement of the processes through constant feedback
   4. Manage complexities arising out of COVID-related situations based on patient-related, disease-related, and prognostication-related factors. This can be achieved through in-house vigilance and testing

as per regional/national criteria, strengthening collaborations, escalating/de-escalating care as necessary, with full integration of palliative care principles across all levels

5. Plan and prepare for a change in the profile/volume of patients. With health-care systems preoccupied with responding to COVID-19, patients with cancer and other noncommunicable diseases are disadvantaged, with poor access and guidance from specialists, access to medicines/interventions, and emergency care
6. The suffering of patients with cancer and other noncommunicable needs is heightened during this COVID-19 situation. This increasing psychological burden should be recognized, and patients and families should be supported by the multidisciplinary palliative care teams (physical consultations when possible otherwise through telephone/video conference calls)
7. To take necessary steps to ensure regular supply and availability of opioids for palliative care patients. To advocate for refill prescription of opioids via telemedicine consultation at least for those patients who are already using them for symptom management.

III. IAPC position on providing palliative care for children with cancer and chronic or end-stage organ impairment: having COVID-19 or treatment limitation due to prevailing COVID-19 situation

1. To adapt the basic principles of pediatric palliative care such as family-centered care, effective pain, and symptom management, quality and dignity at end of life, honest communication, shared decision-making of treatment goals, and provision of grief and bereavement support to children and their families affected by the COVID-19 pandemic
2. To integrate palliative care into the frontline response to COVID-19 infection for the optimal management of distressing symptoms and to provide psychosocial and spiritual support to children who are seriously ill and dying and to their families
3. To ensure continuity and provision of pediatric palliative care to children living with existing or newly diagnosed life-limiting conditions
4. To protect children from violence, exploitation, and abuse in pandemic times and ensure care for serious health-related suffering of children of refugee and migrant populations and those affected by conflict
5. To ensure availability and accessibility of life-saving supplies such as medicines including opioids, vaccines, sanitation, and education supplies
6. To provide support to COVID-suspected and COVID-positive mothers to breastfeed their babies and to encourage routine immunization among children during COVID pandemic.

IV. IAPC position on providing psychological, social, and spiritual support for patients and their families affected by COVID-19 and those with cancer and chronic or end-stage organ impairment whose treatment is limited due to COVID-19 situation

1. All palliative care patients with COVID-19 should be evaluated for distress using validated measures. The presence of mild distress can be managed by counseling and psychotherapy. Moderate-to-severe distress and the presence of mental health disorders warrant specialized interventions
2. Presence of red flag signs should warrant immediate referral to a mental health specialist
3. Loss, grief, and bereavement can be complicated in patients with COVID-19 and can contribute to psychological morbidity. This should be assessed in all patients and their family members and interventions should be initiated early
4. COVID-19 can complicate the spiritual concerns in palliative care patients. The disease-containment measures can further worsen the sense of isolation. It is important to identify and address this as a component of whole-person care
5. Stigma is a major challenge in India and has impacted disease prevention, containment, and mitigation strategies. All palliative care professionals need to identify and address stigma during care provision
6. Professional and nonprofessional carers are likely to experience increased stress, anxiety, and moral distress while caring for patients with COVID-19. A coordinated effort needs to be made from the institutions/organizations and teams to alleviate carer distress. Self-care techniques should be taught to all health-care providers.

V. IAPC position on providing home-based palliative care and nursing support for severe/critical COVID-19 patients dying at home

1. All persons who are dying at home with COVID-19 symptoms shall be tested and "universal precautions" and protective measures should be undertaken[12]
2. All decisions regarding making a home visit (virtual or physical) to be taken with knowledge and approval of the trained doctor in the team. If making a diagnosis of dying this needs to be explained sensitively to the family and carers
3. Always discuss and explain the risks, benefits, and possible likely outcomes of the treatment options with the family of a patient with COVID-19 or non-COVID and with a patient if appropriate
4. For documentation, use the Guidance and Care Plan for the Dying document of "Project India" of the International Collaborative for Best Care for the Dying Person as outlined in the "Blue Maple" document and use the home care version attached for ongoing observations. At home, do voice recording and detailed documentation later
5. Emergency palliation protocol for persons dying at home (COVID-19 and non-COVID-19) needs to be

put in place. If a person is taking an oral medication, continue with this route if possible. Where possible, initiate and train the family in the use of the subcutaneous route ("family driver") for giving medication when a person is not able to swallow and/or deteriorating rapidly requiring an urgent increase of medication (teaching slides and videos on "family driver" are available). Necessary PPE and precautions should be maintained at all times
6. Adaptations for effective and quick delivery of palliative care and bereavement support.

VI. IAPC position on recommendations on the rational use of PPE for palliative care providers:
1. Palliative care providers not considered as frontline providers have less access to PPE and are at increased risk to contract COVID-19. Therefore, health-care providers in palliative care services should be able to access adequate PPE for providing safe and efficient care to patients and their families
2. Palliative care providers in India should be trained in correct use, donning and doffing of PPE, and safe disposal of PPE
3. Palliative care services should develop institutional guidelines and adhere to the national guidelines on the appropriate use of PPE
4. Palliative care providers should consider the rational use of PPE based on risk stratification and transmission at different health-care settings such as screening area, helpdesk/registration, outpatient, and inpatient care areas after death care and in the community
5. PPEs are not an alternative to basic preventive public health measures such as hand hygiene, respiratory etiquettes, and social distancing which must always be followed.

Discussion

COVID-19 pandemic has affected the global health-care systems and economy leading to a tremendous increase in suffering and deaths.[13] The position paper provides recommendations from a group of palliative care experts in India about managing severe/critical COVID-19 patients and non-COVID-19 patients suffering from a chronic and life-limiting illness. Although most people recover from the infection, older adults and those suffering from chronic heart or lung disease or those with hypertension and diabetes are at increased risk of developing severe illness and may require ICU admissions.[14,15] This paper provides the position of the IAPC on triaging, managing symptoms, facilitating decision-making, advanced care planning, and improving quality of life and end-of-life care as applicable to the Indian setting. Detailed information can be accessed freely from the website of the IAPC http://www.palliativecare.in/.

Patients with life-threatening illnesses such as cancer or end-stage organ failures are faced with challenges related to the interruption of disease directed management, adaptations in management guidelines, and lack of availability/access to supportive and palliative care.[16] IAPC has guided adapting policies and processes to ensure adequate and safe care provision for these patients.

Acknowledging the current status of health care and palliative care in India, it is important to have clear guidance and understanding about the judicious resource allocation, ways to realign the palliative care provision in hospitals, home-based palliative care services, nursing care services, and telehealth services.[17] Telehealth is becoming very important in the current scenario of pandemic.[18] The Ministry of Health and Family Welfare, Government of India, has provided a guideline on telehealth. There are some restrictions and may need further modifications to appropriately adapt to the current pandemic situation.[19,20] This can help and improve symptom management of patients more practicable in home settings, thus avoiding unnecessary hospital visits.[21] Telehealth can also be used as a source for identifying, assessing, and providing adequate psychological, social, and spiritual issues that contribute to increased distress.[22] It can be used to teach self-care and address issues such as stigma and isolation.[23] In addition to this, palliative care providers also play a vital role in supporting the family members during and after the death of a patient in the form of bereavement support.

Another important but less addressed issue that may need special attention is the care of children and adolescents who are dealing with cancer or other chronic life-limiting illnesses. The pandemic situation has caused an immense impact on them and their families. These recommendations may help in guiding the palliative care providers to understand, assess, and adapt the processes involved in the care of such children and adolescents.

The number of available palliative care providers in India is limited and will not fulfill the increased need for palliative care during this pandemic situation. The role of generalists in providing palliative care to different groups of patients is essential and should be promoted and supported. These recommendations may be used to guide policymakers and health-care professionals to adopt the principles of palliative care to improve the quality of care provision for those in need.

Access to Resources

This manuscript only guides palliative care provision in the COVID-19 pandemic. The various resources mentioned in this position statement can be accessed freely from the website of the IAPC http://www.palliativecare.in/.

Conclusion

The nations of the world have been challenged by the unprecedented COVID pandemic. We are struggling to understand its ever-evolving manifestations. Palliative care needs to be adapted and included in mainstream medical care to offer compassionate care appropriate to the need within

the limitations of time, isolation, and resource availability. It is hoped that this position statement will serve as a guiding light amid the haze of distress and uncertainty.

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Conflicts of interest

There are no conflicts of interest.

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