

# Palliative Care Challenges and Strategies for the Management Amid COVID-19 Pandemic in India: Perspectives of Palliative Care Nurses, Cancer Patients, and Caregivers

Radhika R Pai, Malathi G Nayak<sup>1</sup>, Sangeetha N<sup>2</sup>

Departments of Nursing Foundation and <sup>1</sup>Community Health Nursing, Manipal College of Nursing, Manipal Academy of Higher Education, Manipal, <sup>2</sup>Department of Education and Research, Bangalore Hospice Trust - Karunashraya, Bengaluru, Karnataka, India

## Abstract

The WHO selected 2020 to recognize the work of nurses and midwives because it is the bicentenary of the birth of the founder of modern nursing, Florence Nightingale. It has been demonstrated amply now as the nurses are the largest sector of health-care workers in every country, playing a pivotal role in response to the novel coronavirus (COVID-19) pandemic worldwide. Every day, nurses are working tirelessly by leaving their homes to assist the sick, allay community fears, and address concerns. This article is written by interviewing the staff nurses working in the wards/outpatient departments of a reputed palliative care center in Karnataka State, reviewing the recent nurses' blogs, editorial commentaries, WHO guidelines, CDC guidelines, and recent short communications on COVID-19 pandemic. The authors in this article attempted to address the palliative care challenges and strategies for the management during the COVID-19 pandemic in India.

**Keywords:** Cancer patients and caregivers, challenges, COVID-19, management, nurses, palliative care, pandemic, strategies

## INTRODUCTION

*"Nurses are the backbone of any health system. Today, many nurses find themselves on the frontline in the battle against Covid-19. The global shortfall of nurses is a stark reminder of the unique role they play, and a wakeup call to ensure they get the support they need to keep the world healthy."* Dr. Tedros Adhanom Ghebreyesus, WHO Director General.<sup>[1]</sup>

The Government of India declared a nationwide 3-week lockdown on March 24, 2020. It was mandated that Indian residents confine to their houses for a minimum period of 3 weeks; later on, April 21, 2020, the lockdown was extended till May 3, 2020, for a period of 2 weeks and further it was extended till May 17, 2020, for a period of 2 more weeks. Certain necessary services were relaxed from the lockdown, including banking, emergency health-care services, and day-to-day household. Outpatient department (OPD) services of most health-care facilities are closed, keeping emergency department functioning. These actions were taken to prevent the spread of COVID-19. These events have posed different challenges in providing palliative care to cancer patients.<sup>[2]</sup> There

is an insufficiency of data on the epidemiology and clinical features of severe acute respiratory syndrome-CoV-2 among cancer patients, but if this virus outbreak happens to spread to a broader community, there will be an increased risk for immunocompromised cancer patients to acquire the infection.<sup>[3]</sup>

A pandemic disease often leads to increased intensity of suffering by causing physical illness, death, stress, anxiety, financial concerns, and social variability. Response to the pandemic requires mitigation of suffering in all the methods as a significant step. Providing effective and safe palliative care and end of life care during a state of exhausted health-care systems under COVID-19 become essential and challenging.<sup>[4]</sup>

**Address for correspondence:** Dr. Malathi G Nayak, Department of Community Health Nursing, Manipal College of Nursing, Manipal Academy of Higher Education, Manipal, Karnataka, India. E-mail: malathinayak@yahoo.co.in

**Submitted:** 24-May-20 **Accepted:** 26-May-20  
**Published:** 30-Jun-20

This is an open access journal, and articles are distributed under the terms of the Creative Commons Attribution-NonCommercial-ShareAlike 4.0 License, which allows others to remix, tweak, and build upon the work non-commercially, as long as appropriate credit is given and the new creations are licensed under the identical terms.

**For reprints contact:** WKHLRPMedknow\_reprints@wolterskluwer.com

**How to cite this article:** Pai RR, Nayak MG, Sangeetha N. Palliative care challenges and strategies for the management amid COVID-19 pandemic in India: Perspectives of palliative care nurses, cancer patients, and caregivers. Indian J Palliat Care 2020;26:S121-5.

### Access this article online

#### Quick Response Code:



**Website:**  
www.jpalliativecare.com

**DOI:**  
10.4103/IJPC.IJPC\_182\_20

Nurses are the frontline workers in health-care units to reach needy patients to ensure that they can do their best to keep the patient requiring palliative care safe and comfortable. Nurses require support with all the necessary resources such as personal protective equipment, patient care equipment, and safe accommodation as they are at risk of facing anxiety and fear of acquiring infection at the workplace.<sup>[5]</sup> A study reported the prevalence of psychological distress, anxiety symptoms, and depressive symptoms as 15%–9% (95% confidence interval [CI]: 14.8–16.9), 16.0% (95% CI: 15.0–17.1), and 34.6% (95% CI: 33.2–35.9), respectively, among health-care workers including doctors and nurses.<sup>[6]</sup>

Universally, nursing is known as a profession that is related to the increased stress in both professional and personal lives. Because of the change in the needs of patients with advanced illnesses, nurses working in palliative care might experience strainful workloads associated with death and dying.<sup>[7]</sup> Access to health care during this COVID-19 pandemic, which includes palliative care, end of life care, bereavement care, and support, is highly inadequate when facing the increased demands in most of the health-care settings. Patients in palliative care will experience increased separation, suffering, and even those who are mourning also will experience a certain level of anxiety and stress. Following firm social distance, patient isolation, and guidelines to decrease the disease transmission can indicate that patients who expire from COVID-19 will not have their loved one next to him/her, which can lead to preventing them wishing a last goodbye and traditional grieving ritual undertaking.<sup>[6]</sup>

With all the difficulties, when everything is under lockdown, all the hospice nurses are proud to work with the patients to provide quality of life to overcome the situation. Every day, they ensure that the patients and their family receive good palliative care by facing different kinds of challenges. One of the young nurses said, “We are committed to bringing a smile.” Amidst lockdown, our services continue uninterrupted.” The interprofessional palliative care team approach that involves a palliative medicine doctor, palliative care nurse, social worker, and spiritual care provider can help patients and their families to meet their emotional, psychological, spiritual, and social needs.<sup>[8]</sup>

In rendering palliative care to the patients and their families, nurses do face many challenges when performing their routine tasks with increasing new obstacles during COVID-19 crisis. These challenges are discussed in this article under two main aspects: (A) challenges faced by the nurses and (B) challenges faced by the patient and their families.

### **Challenges faced by palliative care nurses**

Challenges faced by the palliative care nurses are categorized as per the CDC classification<sup>[9]</sup> of stress during an infectious disease outbreak.

#### *Fear of acquiring infection and risking own health*

Fear of acquiring COVID-19 infection is the main worry that most of the nursing fraternity who are in direct contact with the

patient are now facing.<sup>[10]</sup> With every new admission or with symptomatic cases, the fear and anxiety of nurses increase significantly, as they are not sure if the patient or the relatives are positive for COVID-19 or otherwise. Another primary concern for the nurses is the lack of proper screening for every possible case for COVID-19. Uncertainty about the patient’s positive status is also posing a significant hindering factor for rendering effective and comprehensive care. Staff shortage or working with minimum staff also makes a nurse to have lesser opportunity to talk and freely express their concerns.

At least 2629 health workers have been infected and 13 doctors died of coronavirus since the onset of the outbreak in February, representing 8.3% of total cases in Italy by March 19, 2020.<sup>[11]</sup> Nurses are facing the fear that they will become infected or their family members become infected, or colleagues will become sick. Once they complete their shift, it is common to see that few staff nurses wonder if slight shortness of breath, headache, or flu-like symptoms are as a result of infection with COVID-19 or otherwise.<sup>[10]</sup>

Concerning the deaths happening at palliative care centers, nurses are becoming extremely anxious and worried due to lack of personnel, family members, and feeling left alone in the process of assisting patients in dying and death. Factors contributing to stress can be their inability to contact the family members and helplessness to fulfill the wishes of the patients and difficulty to arrange the transport of dead bodies due to lockdown status. This process of information to police, getting a pass from the corporation, arranging safe transport, handing over the documents, and belongings to the patients are other daunting tasks, which adds more complexity to their work.<sup>[12]</sup>

#### *Fear of harming family members or losing loved ones*

Nurses do possess a morbid fear and anxiety within about spreading the infection to their families. Frustration is widespread in this situation where they are not able to contact their family members often or network issues to communicate. Since their routine household work is compromised, and in the rotation, they are supposed to work with minimal staff, a constant worry of the unmet task of care of staff nurses’ family becomes a significant concern. Ethically bound to perform duties and to work for longer duration also is a severe issue for the psychosocial health of the staff.

#### *Changes in sleep, eating patterns, and concentration issues*

Duty schedules have become more hectic and intense during this COVID-19 pandemic, leading to changes in eating patterns and resting habits. Increased burden of patient care has led to the inability to eat adequately, timing issues, and more patient care workloads. Continuously recalling the events at the workplace and worrying about patient care and family issues have significantly affected the sleep pattern. Longstanding duties have led to difficulty in concentration in the workplace.<sup>[12]</sup> Fear of pressurized and having working conditions under feeling under pressure and working under risky situations are currently experienced by the health-care

workers. Work hours are getting increased and sleep disturbance due to increased workload as well as attending a large number of patients with minimal staff is posing an extra burden on the health of the cancer nurses.<sup>[11]</sup> This unrelenting mental stress that these health-care workers are facing could generate increased psychological concerns such as sleep issues, helplessness, depressive tendencies, posttraumatic stress indications, and even panic attacks.<sup>[13a]</sup>

### *Worsening of chronic health problems*

It is physically and mentally draining for the staff nurses to work with the minimal workforce. Staff nurses with existing health issues face difficulty to work continuously as well as they were having issues to cope with this pandemic and patient care. While allocating duty to those staff with comorbid issues, it should always be considered that their health is too utmost given due consideration and priority. Staff nurses' physical fitness is to be monitored before assigning their respective duties to avoid overburdening or worsening the previously existing health issue.

### *Fear of avoidance from the community*

Experiencing avoidance by the nurses' family or community is a matter of concern concerning stigma. These situations can pose additional stress on these staff nurses if there is no support extended to them for continuing to work.<sup>[14]</sup> Health-care workers do experience stigma and avoidance of interaction, interpersonal social separation from family and problems in social support and concern regarding infection exposure to their friends and family. These unexpected changes in the role of being a health-care worker to COVID-19 suspect clients have led to increased helplessness, adjustment issues, and frustration.<sup>[15]</sup> Fear of tagging, branding, and differentiation can hinder even health-care staffs to approach counseling and psychiatric help.<sup>[13b]</sup> Violence against COVID-19 warriors such as doctors and other health-care workers has been reported in India making the whole process of COVID-19 pandemic infection treatment more traumatic than ever.<sup>[16]</sup>

### **Challenges faced by the patient and families during COVID-19 pandemic**

We understand that the palliative health-care team does possess good strength and provide an astonishing level of compassionate care every day, in each contact patients, families, colleagues, and societies. Health-care teams' role during this COVID-19 is mainly to keep the main essence of care in their practice even when the system, patients, and families are under restrictions imposed due to COVID-19. During COVID-19 crisis, the challenges faced by the patient and families are as follows.

#### *Access to palliative care services*

At this time of COVID-19 PANDEMIC, one of the fundamental challenges is access to the palliative care daily in the OPDs. As per the report from the OPD nurses in a reputed palliative care center, Bengaluru, Karnataka, many patients expressed their concerns through the phone call that due to the financial limitations they are finding it difficult to come and avail the

outpatient services. Even the patients residing at this hospice center are unable to meet their family members for a long time due to the severity of the coronavirus outbreak. The families are prohibited from visiting the patients because of the recommended social distance and conveyance difficulties, but they are emotionally connected. Even though the workload exceeds, hospice nurses are spending their valuable time with advanced cancer patients to reduce their burden with the illness. Furthermore, they are engaging patients with different kinds of activities such as art, craft, and games.<sup>[17a,b]</sup>

#### *Decision-making*

Decision-making is increasingly challenging. Engaging in conversations exploring goals of care or treatment options can be difficult with the absence of caregivers due to the lack of transportation. Nurses at present are utilizing telenursing services for helping the patients by calling and texting to the caregivers. Nurses need to ensure that the patients will develop a positive attitude toward taking decisions regarding their health and the effective closure of life as directed by the patients. Besides, after the death of the patient, with compassion, nurses are helping the family to get transportation services.<sup>[18]</sup>

#### *Advanced directives and death preferences*

A range of 49%–100% of terminally ill patients preferred their death at home. Some of the literature findings suggest that when the patient chooses advanced directives for the place of death, there was an improvement in grief-related outcomes. Planning for home care gives added responsibility to patient relatives for taking care of patients with advanced illnesses. Family members experience anxiety, stress, tiredness, sleeplessness, weight loss, social separation, and problems in their health. Palliative care can lessen carer stress and burden by providing supportive care.<sup>[19]</sup> Unfortunately, providing the home service in this situation is very much restricted. At the same time, home care nurses are making all effort to provide constant support to the patient and family through telephonic communication.

#### *Fear of death*

Adding to this, the majority of patients are suffering from the fear of death due to the coronavirus infection rather than the advanced cancer illness. Coronavirus is making it more palpable and being a constant reminder of the fragility of their lives. Night duty nurses are facing the highly challenging task of handling their emotional difficulties with their suppressed immune system.<sup>[20]</sup>

#### *Spiritual needs*

Spiritual care is an essential domain of palliative care. Even before the pandemic, spiritual care is a significant challenge with hospice patients. Before, they were tired of fighting only with cancer but now with the virus too. The demand for spiritual care has increased significantly. The nurses need to handle this challenge efficiently by working with the caregivers, clergymen, and multidisciplinary health-care team.

## STRATEGIES FOR MANAGING THE CHALLENGES EMERGING DURING COVID 19 PANDEMIC

Hospital personnel, including caregivers, support staff, administration, and preparedness teams, all will be stressed by the challenges of a prolonged response to COVID-19. Hospital administrators need to take measures to realize the importance of self-care as a vital aspect of the response. Direct and thoughtful communication is also an essential aspect of coordination, which could build trust in the health-care workers, which might, in turn, help reduce anxiety.<sup>[21]</sup> Measures to cope with the stress can be alleviating the symptoms, providing patient-centered care, care for patients and families, and using a multidisciplinary team approach.<sup>[22]</sup> The following measures might help the staff nurses to cope during the crisis of COVID-19.

### Counseling and emotional support

Staff counseling is essential during this pandemic. Especially nurses need a forum to ventilate their feelings to avoid stress and burnout. The emotional support from colleagues, friends, and family is essential for the nurses and health-care providers toward the smooth functioning of patient care. Trying to build a good relationship with colleagues will help get confidence and motivation to continue the care of patients.<sup>[10,14]</sup>

### Appreciation and reward

Nurses need moral support from their colleagues and administrators for their dedication to carry on their duties amid COVID-19 crisis. As few nurses expressed that, fighting COVID-19 is making them feel more devoted to their profession, and they are determined to push through and help their patients.<sup>[12]</sup> Nurses need to trust that everyone is doing all they can to make the situation better.<sup>[10,23]</sup>

### Staff rotation

The rotation policy for the health-care workers need to be planned in such a way that the health-care teams follow social distancing practices, and coordination of care should not be adversely impacted on the health-care delivery services.<sup>[10,23]</sup>

### Rational distribution of medical resources

With increasing positive cases of COVID-19, it is high time for the management and nurse administrators to think wisely regarding the resources available and its sustainability over a long period to render the most appropriate care as per the demand and situation of the pandemic.<sup>[24]</sup> Fair distribution can enhance the working harmony among the staff nurses as well as readiness for the reception of the patient and the triage system can be made more systematic.

### Eating and sleeping schedule

Avoid overeating or undereating as a solution to stress. Make a plan and keep an alarm and see that all the staff in the unit go and get timely, adequate food and come back to work without much strain. Keeping a rotation plan for eating at the workplace can enhance the nurses to work more effectively, taking care of their health.

### Telenursing services

Home care nursing services can be converted into telenursing services where patients and family members can interact with the palliative care nurse for any concerns requiring medical attention. Patient and family counseling and education can be rendered through this effectively.<sup>[18]</sup>

### Yoga and meditation

Self-care is highly recommended in palliative care. Nurses need to take some time off for themselves to sit and relax, and light exercises will help them to relax and soothe their disturbed minds. This indeed helps a lot to cope up with the stress, especially when the nurses are in quarantine after exposure to COVID-19 patients.<sup>[25]</sup>

### Patient and family education

Giving proper awareness regarding the current situation of the COVID-19 crisis and patient condition is of utmost importance for avoiding any kind of inconvenience. Patient and family members need to be explained regarding the type of services offered by the hospital during this lockdown and the symptoms which they can manage at home.<sup>[18]</sup>

### Community mass awareness

Every individual in the community needs to be aware of the COVID-19 pandemic with special emphasis on the method of transmission, spread, isolation precautions, and management of this infection. There is a mass awareness regarding this pandemic infection initiated by the Government of India through the utilization of mobile ringtones, programs in television, newspaper communications with special emphasis on respect to “COVID warriors” means health-care professionals. This awareness can enhance the patients’ positive attitude toward reporting the symptoms and getting proper treatment, thus can reduce the stigma and social burden.

### Team approach

Due to the limited availability of the health-care workers during the COVID-19 crisis, staff nurses need to work as a team along with the palliative medicine doctor, social worker, and psychologists to render the care services timely and proficiently.<sup>[23]</sup>

### Well-trained help desk

Help desk services in the hospital need to be well trained in terms of coordinating with the police, local municipal authorities, insurance companies, and ambulance or transport facilities to ensure effective delivery of health care during this crisis.

## CONCLUSION

COVID-19 pandemic is increasing day by day that is jeopardizing the health-care workers and adding additional stress to patients and caregivers in a most dreadful way. Concerning this situation, palliative care nurses significantly face many adverse events amidst this COVID-19 crisis. They still live with a fear of getting infected and compromised family life. This lockdown has brought a lot of challenges

to the patient and family members, and this is high time that the nurses are given due attention and reward as well as all possible support for patient care to cope with the difficult situations. Adequate resource allocation can make a significant change in patient care which would ensure safe and effective practice for the nurses. Nurses need to make all possible efforts to overcome these challenges by obtaining multidisciplinary team support, proper guidance from the hospice and palliative care management, and maintenance of the self-care.

### Acknowledgment

We acknowledge the support rendered by Dr. Nagesh Simha, Medical Director, Bangalore Hospice Trust-Karunashrya, for permitting us to gather the necessary data and to interact with health-care providers, patients, and their family caregivers.

### Financial support and sponsorship

Nil.

### Conflicts of interest

There are no conflicts of interest.

## REFERENCES

- World Health Organization. First Ever State of the World's Nursing Report Launched Amid COVID19 Pandemic. WHO; 2020. Available from: <https://www.who.int/news-room/detail/06-04-2020-world-health-worker-week-2020>. [Last accessed on 2020 Apr 30].
- Srivastava P, Tilak TV, Patel A, Das CK, Biswas B, Mahindru S, *et al.* Advisory for cancer patients during the COVID pandemic. *Cancer Res Stat Treat* 2020;3:145.
- Bansal N, Ghafur A. COVID-19 in oncology settings. *Cancer Res Stat Treat* 2020;3:13.
- Rodgers P, Storey P, Matzo M, Gatto M. Palliative care in health emergencies: Tools for planning (325). *J Pain Symptom Manag* 2011;41:207.
- Jackson D, Bradbury-Jones C, Baptiste D, Gelling L, Morin K, Neville S, *et al.* Life in the pandemic: Some reflections on nursing in the context of COVID-19. *J Clin Nurs* 2020;29:2041-3.
- Radbruch L, Knaut FM, de Lima L, de Joncheere C, Bhadelia A. The key role of palliative care in response to the COVID-19 tsunami of suffering. *Lancet* 2020;395:1467-9.
- Lim J, Bogossian F, Ahern K. Stress and coping in Australian nurses: A systematic review. *Int Nurs Rev* 2010;57:22-31.
- Arya A, Buchman S, Gagnon B, Downar J. Pandemic palliative care: Beyond ventilators and saving lives. *CMAJ* 2020;192:E400-4.
- Centre for Disease Control and Prevention. Coronavirus Disease 2019 (COVID-19) Stress and Coping. Centre for Disease Control and Prevention; 2020.
- Walford J. COVID-19: Amid Fear and Anxiety, We Must Look after Each Other; 2020. Available from: <https://rcni.com/nursing-standard/opinion/comment/covid-19-amid-fear-and-anxiety-we-must-look-after-each-other-159301>. [Last accessed on 2020 Apr 30].
- Shankar A, Saini D, Roy S, Jarrahi AM, Chakraborty A, Bharti SJ, *et al.* Cancer care delivery challenges amidst coronavirus disease – 19 (COVID-19) outbreak: Specific precautions for cancer patients and cancer care providers to prevent spread. *Asian Pac J Cancer Prev* 2020;21:569-73.
- TIME. We Carry That Burden.' Medical Workers Fighting COVID-19 Are Facing a Mental Health Crisis. TIME; 2020. Available from: <https://time.com/5817435/covid-19-mental-health-coronavirus/>. [Last accessed on 2020 Apr 30].
- aRana W, Mukhtar S, Mukhtar S. Mental health of medical workers in Pakistan during the pandemic COVID-19 outbreak. *Asian J Psychiatr* 2020;51:102080; bZheng W. Mental health and a novel coronavirus (2019-nCoV) in China. *J Affect Disord* 2020;269:201.
- World Health Organization. Mental Health and Psychosocial Considerations during the COVID-19 Outbreak; 18 March, 2020. World Health Organization; 2020.
- Sarla G. COVID dairies: An Indian perspective. *J Med Res Surg* 2020;1:1-3.
- Sarla GS. Violence against Doctors: A rising trend. *EC Emerg Med Crit Care* 2019;3:639-43.
- aHilliard RE. Music therapy in hospice and palliative care: A review of the empirical data. *Evid Based Complement Alternat Med* 2005;2:173-8. bLin MH, Moh SL, Kuo YC, Wu PY, Lin CL, Tsai MH, *et al.* Art therapy for terminal cancer patients in a hospice palliative care unit in Taiwan. *Palliat Support Care* 2012;10:51-7.
- Wallace CL, Wladkowski SP, Gibson A, White P. Grief during the COVID-19 pandemic: Considerations for palliative care providers. *J Pain Symptom Manag* 2020. pii: S0885-3924 (20) 30207-4.
- Reidy L, Baily ME, Doody O. Family Caregivers' Perceptions of an Irish Palliative Day-Care Unit: A Qualitative Descriptive Study; 2018.
- Lawton J. *The Dying Process: Patients' Experiences of Palliative Care*. London: Psychology Press; 2000.
- Adams JG, Walls RM. Supporting the health care workforce during the COVID-19 global epidemic. *JAMA* 2020;323:1439-40.
- Feder S, Akgün KM, Schulman-Green D. Palliative care strategies offer guidance to clinicians and comfort for COVID-19 patient and families. *Heart Lung* 2020. pii: S0147-9563 (20) 30111-4.
- Singhai P, Rao KS, Rao SR, Salins N. Palliative care for advanced cancer patients in the COVID-19 pandemic: Challenges and adaptations. *Cancer Res Stat Treat* 2020;3:127.
- Emanuel EJ, Persad G, Upshur R, Thome B, Parker M, Glickman A, *et al.* Fair allocation of scarce medical resources in the time of Covid-19. *N Engl J Med* 2020;382:2049-55.
- Dharmawardene M, Givens J, Wachholtz A, Makowski S, Tjia J. A systematic review and meta-analysis of meditative interventions for informal caregivers and health professionals. *BMJ Support Palliat Care* 2016;6:160-9.