THE STATE OF PALLIATIVE CARE DURING COVID-19

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Abstract

The novel coronavirus infectious disease (COVID-19) took the global population at shock by its rapid contagious nature, producing havoc in nations and the wealthiest healthcare systems. The outbreak resulted in drastic changes in daily regular social functioning and increased the number of patients in need of medical attention. The physical symptoms and the social isolation caused by the pandemic placed many patients and their families in need of compassionate care that could best be delivered by the palliative care approach.

Delivering palliative care to COVID-19 infected patients is an integral part of any comprehensive care in mass casualty events. It addresses patients' suffering by providing comfort medicine helping isolated patients connect with their family members, and paving the way for advanced care planning. Nevertheless, patients, families, health care system, and health professionals face a vast array of social, psychological, physical, economic, and existential challenges. The palliative care workforce is working at full capacity to respond to the increased demand and to secure the needed resources to attend to the psychosocial and medical needs of infected COVID-19 patients. This manuscript will summarize the challenges faced by patients, families, healthcare professionals during this pandemic and the action plan developed in response to it. A list of recommendations related to best palliative care practice will be presented as well.

Keywords: COVID-19, Palliative care, Supportive care, Quality of Life, Pandemic, Challenges.

The State of Palliative Care during COVID-19

The novel coronavirus disease (COVID-19) was first reported to the World Health Organization in December 2019 from Wuhan, China, for causing an unknown type of pneumonia and respiratory failure. By January 2020, COVID-19 had alarmed multiple countries all over the world and overwhelmed the most resourceful health care facilities, causing a shortage in medical supplies through the severe illness and death it caused.[1] On March 11, 2020, devastated by the quick global spread and severity, the WHO declared COVID-19 a pandemic.

COVID-19 affected all layers of the population, particularly the most vulnerable, those with existing comorbidities like diabetes, hypertension, and cancer. It was understood that the primary means of transmission is through respiratory droplets transported through sneezing, coughing, and

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from close human to human contact.[2] Thus, measures of physical distancing, strict hand washing, disinfecting surfaces, wearing protective face masks, withholding all types of gathering like schools and gyms, and self-isolation (sometimes forced) were recommended by the Center for Disease Control & Prevention.[3]

Palliative Care and COVID-19 in Lebanon

Lebanon is relatively a small Middle Eastern country with a population of around 5.8 million, in addition to 1.5 million refugees from neighboring countries.[4] Its population is one of the fastest growing in older adults in the Arab region with a life expectancy of 80 years.[5]

Given its aging population and emergence of chronic illnesses, palliative care practice started to emerge around a decade ago. The Lebanese Ministry of Public Health recognized palliative medicine as a specialty in 2013.[6] Palliative care aims to enhance the quality of life of individuals facing serious illnesses by attending to their physical, psychosocial and spiritual needs. It offers a support system to the patients and their families and helps them live their life as comfortable as possible until the last days.[1]

However, palliative care is still an underrepresented specialty in Lebanon and the Arab region.[6] The main challenges in its advancement are the lack of clear governmental policies, minimal or no reimbursement of palliative care services, misconceptions about what palliative care means by patients, families, and physicians, lack of advanced care planning, shortage in the availability and accessibility to opioids, and the insufficient number of trained health team members.[7] Death is a taboo and providing aggressive care interventions until the last days of life is a common practice.[8]

Role of Palliative Care during the Pandemic

Palliative care is an integral part of any com--prehensive health care even during COVID-19 pandemic.[9] Palliation attends to the physical, psychological, spiritual, and existential needs of patients and their families alongside life-saving interventions in humanitarian crises.[10] Compassionate care sensitive to the patients' dignity and comfort is highly needed during the pandemic where suffering, pain, grief, and social isolation are recurrent due to the multifaceted impact of the global outbreak.[9]

COVID-19 has affected the social interactions and daily functioning of all individuals tremendously. The infectious and contagious nature of the virus has led people to live and operate differently and has left severely ill patients alone during their last days of life. The quarantine and physical isolation reinforced in hospital settings have restricted human contact to prevent contamination. Thus, the psychological suffering related to anxiety, depression, loneliness, insomnia, and stigma has compounded the physical illness and pressed a sense of fear, vulnerability, and isolation among patients, health care workers, and families.[11]

Through its multidisciplinary approach, the role of palliative care extends beyond symptom relief caused directly by the infection, to include advocacy of family support, and open space for the occurrence of difficult conversations between patients and health care providers regarding preferences in the plan of care.[12] COVID-19 infected patients with multiple co-existing disorders and a frail health profile may be in a state where mechanical ventilators or other invasive procedures would rather prolong their suffering than improve it. Thus, health care providers are in a crucial position to clearly communicate options of care to patients and their caregivers to guarantee an informed decision and best quality of life. Tough conversations that allow patients and families to reflect on personal values and preferences are essential aspects of palliative care that aim to preserve the patient's autonomy and cultural values. This is particularly important because family connections and involvement in decision making are core values and an integral part of the Lebanese culture serving a significant pillar of support at times of crisis.[13] Strategies like, rapid training of all medical staff to be sensitive to the palliative care needs of patients with COVID-19 like pain, breathlessness, sedation, connecting families with their infected loved ones virtually, supporting families during the bereavement period, and supporting the health care providers who are front liners are at the heart of palliative care.[14] Overall, the challenges in the

COVID-19 pandemic can be broken down into that of the patients, their families, and the health care system and professionals.

Challenges Faced by Patients and Their Families

A recent report regarding a survey conducted at Hospices and Palliative Care Units (PCU) in Kenya concerning COVID-19 showed that among the main challenges faced by palliative care patients and their families are socio-economic and COVD-19 related fears, such as social isolation, lack of educative knowledge regarding COVID-19, and shortage of medications including opioids.[15] Limited face to face interaction measures between patients and their families were imposed, depriving patients of much needed social support. Many patients feared to die alone or to die before being able to see their family members. Some were concerned about the economic impact and social restrictions imposed by this pandemic and consequently the fear their of losing their caregivers' jobs and the inability to manage expenses. Moreover, patients were afraid of the physical symptoms and the suffering associated with COVID-19. Patients were also aware that those with coexisting medical conditions were more vulnerable, so they felt more at risk and unsafe.

A report published in Italy described a similar challenges.[16] It is known that family support in a Mediterranean country is highly important. However, palliative care patients in Italy remained alone all day, except for the support provided by the health care professionals.[16] To partially overcome these issues, the hospital adopted the virtual communication method between patients and their relatives.[16] Family members were pleased to be in contact with their elders, while some of the older adults stated that "I recognize the actual situation is regulated by law, but no technology can provide the same effects experienced by my presence" or "It could be the last time I see him/her".[16]

Another study showed that advanced cancer patients in the PCU have also faced many challenges, mainly fear of scaling down cancer- related services with a shortage in clinicians, placing them at high risk for symptom deterioration.[15,17] Nevertheless, cancer-directed therapies are being continued as planned in many centers. However, in conditions where the risk of COVID-19 outweighs the expected cancer-related outcome, shared decision making while discussing the potential risks and benefits of planned treatment, empowers patients and their family members to prioritize their preferences.[17] The Bio-psycho-socio-spiritual approaches of palliative care have been proposed as the best dimension that improves the Quality of Life (QoL) of cancer patients and their families.[17]

Challenges Faced by Health Care Professionals and Health Care System

Shared decision-making between clinicians and patients is a common and essential process in planning for the end of life.[18] However, during a pandemic, patient autonomy to choose life-prolonging measures or place of death is restricted because of public health directives and resource availability.[18] Consequently, patients may not be offered mechanical ventilation even if they desire it. Additionally, COVID-19 patients may need to be confined to a space that is not of their choosing. These situations will likely cause distress to patients, their family members, and the health care providers.[18]

As such, the Kenya report outlined some of the difficulties faced by the health care providers in PCUs where physicians have reported a lack in finances which in turn resulted to an undersupply of personal protective equipment (PPEs). Hence, this placed health care professionals in fear of contracting the virus and passing it on to other patients.[15] Likewise, one of the main challenges reported in Italy during COVID-19 outbreak was the lack of sufficient PPE required to preserve patients' and health care workers safety.[16] While health care workers acknowledge the increased risk of infection in their work, they also bear concerns regarding transmitting the virus to their families, especially if they have an elderly, immunocompromised, or seriously ill member in the household.[19]

Another challenge reported by several studies was the scarcity of trained staff of PCUs to deliver care to patients with palliative care needs and infected

with COVID19.[15,17] A shortage of workforce and staff availability were also reported in health care institutions.[17,18] Thus, limited availability of trained health professionals compounded by restricted visitations of family caregivers in PCUs adds another burden to the challenge of providing appropriate psychosocial support to the patients and their families.[17]

Moreover, a review of the role and response of PCUs during the COVID-19 pandemic conducted in many countries, showed that psychologists play an important role.[20] Since palliative care teams cannot provide direct care to all patients who are dying, pandemic planning should include engagement of all inter-professional health care teams who have training and experience in end of life care.[18] Measures to improve connectedness between staff were also adopted to reduce anxiety and to minimize the adverse mental health effects, such as distress about risks of contracting the disease and dealing with grief.[19,20] Some PCU staff members were also trained to provide emotional support to patients, and grief and bereavement support to family members.[18] All of these different scenarios can overwhelm the staff in inpatient hospital PCUs.

The COVID-19 pandemic has dramatically affected the healthcare systems in hospital-based palliative care.[17] Although palliative care has recently been given much attention and has experienced a growth in the vast arena of the health care system, the palliative care workforce's growth has yet to meet demand.[21] Many palliative care interdisciplinary teams work at or near capacity, and at present, a massive increase in the palliative care consultations is sure to push most palliative care teams to the point of exhaustion.[21]

Due to this overload, regular outpatient services in PCUs have been suspended following strict health guidelines. As a result, many patients who require palliative care may not be able to receive it.[17] An interdisciplinary team is integral to palliative care service delivery, and with the non-urgent outpatient palliative care being shut down, access to allied health professionals becomes a privilege.[17] Only patients with unmanageable symptoms and those requiring urgent end of life care are admitted to inpatient PCUs, leaving a vast majority of patients with mild symptoms with unattended needs.[17] As a result of this downturn, some of the cancer treatment centers have stopped receiving new patients to limit their load to patients who were already on treatment.[15] Others have suspended all palliative care services due to the shortage of staff and lack of PPE.[15]

Experience of Palliative and Supportive Care Program at the American University of Beirut-Medical Center, Lebanon during COVID-19 pandemic

The palliative and support care program at the American University of Beirut-Medical Center (AUBMC) comprises a multidisciplinary team including physicians, nurses, psychologist, social worker, and pharmacist to address the needs of Palliative Care patients. Some of the services provided by the palliative care team at AUBMC incorporate the following: management of symptoms, providing assistance with planning and decision making, offering counseling services, and planning discharge. The programs provided by the palliative care program at AUBMC include inpatient consultation services, outpatient clinics, outreach, and bereavement programs.

Throughout the COVID-19 pandemic lockdown, the palliative care program at AUBMC took several measures to meet the demands of both the palliative care patients and their families. The outpatient palliative care clinic adopted the virtual clinic visits to reduce the risk of exposing patients and staff to the infection. All types of meetings, such as the interdisciplinary meetings between health care teams where treatment plans are usually discussed, and the encounters with families to discuss the treatment options and goals of care, were conducted through virtual platforms. During this period, the bereavement and the outreach programs remained active through carrying out telephone call services. The psychologist and the social worker were present at almost all times, ready to address the psychosocial needs of the patients and their family members in the inpatient and outpatient settings.

Suggested key points and Recommendations related to Palliative Care services during Pandemic

In 2008, the US Task Force on mass casualty critical care published a framework for mass casualty events that comprised the following: stuff, staff, space, and systems that were adapted later on to the palliative care context. With COVID-19 pandemic, four additional dimensions were recently added on this framework: sedation, separation, communication, and equity. Altogether these eight dimensions constitute a palliative care pandemic plan for the management of COVID-19.[18]

1- Stuff: Stockpiling essential medications, PPEs, and equipment to deliver basic palliative care needs.

2- Staff: Identifying and mobilizing all PCU staff, debriefing staff on how to provide symptom management of acute respiratory illnesses, as well as how to give emotional support for both patients and their relatives.

3- Space: Identifying additional beds and areas in the PCUs that can be used during the pandemic.

4- System: Adopting a triage system to determine which patients require specialist palliative care consultation and can be seen virtually.

5- Sedation: Prepare to use palliative sedation for symptoms that are refractory to common medications.

6- Separation: Enabling virtual communication by video calling to connect patients to family members.

7- Communication: Health care professionals to reassess treatment plans with high-risk patients such as, advanced cancer.

8- Equity: Paying careful attention to marginalized patients.

Palliative care constitute a key element of any response to a humanitarian crisis. A multidimensional approach based on stuff, staff, space, systems, sedation, separation, communication and equity can serve as a guide to plan and ensure that the palliative care needs of the patients and their caregivers are being addressed.[18,20]

Conclusion

Like all other specialties, palliative care services experienced changes due to the challenges that arose from the pandemic. Skills training workshops and virtual meetings are being developed and implemented to ensure that the patients' palliative care needs are being met. During this critical period, people have been seeking more palliative care services. However, the clinical outcomes of the changes in palliative care services delivery need to be further researched to ensure effectiveness.

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