

## Review

# Access to Palliative Care in Low- and Middle-Income Countries during Coronavirus Disease-2019 Pandemic and Post-Pandemic Era: A Kenyan Experience

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The coronavirus disease-2019 (COVID-19) pandemic emphasized the role of palliative care as an essential service to patients and families affected by life-threatening illnesses. Challenges encountered included: patients were not able to access services due to lockdown or restricted movement, limited or no home-based care and visits, opioid analgesic supplies were depleted, high frequency of uncontrolled symptoms and psychosocial distress, limited patient-caregiver-clinician communication, reduced family interactions due to fear of infecting the already sick family members, few training opportunities for health care workers (HCW) and HCW distress and burn-out. To address these challenges, the following strategies were employed; utilization of digital technologies to match resources, innovation in provision of PC including adapting etiquette for patient care using digital technology, advocating policy changes, education, use of technology such as video calls among family members support for HCW.

**Keywords**

COVID-19; Palliative care; Low- and middle-income countries; Pandemic; Post-pandemic; Health care workers (HCW).

**INTRODUCTION**

Severe acute respiratory syndrome coronavirus 2 (SARS-CoV2) (coronavirus disease-2019 (COVID-19)) pandemic originated in Wuhan, Hubei Province of the People's Republic of China in December 2019 and has since overwhelmed health care systems across the world.<sup>1,2</sup> Palliative care as a holistic approach is an essential component of universal health care, especially during a pandemic.<sup>3</sup> Optimal management of distressing symptoms, clinical uncertainties, complex decision making, and strengthening care provided by family caregivers thereby improving patients' quality of life are key attributes of palliative care practice that are much needed in this difficult period.<sup>4</sup> Further, community PC can facilitate provision of home-based quality care to patients with cancer and those with complications of COVID-19 who can be cared for within the community.<sup>5</sup> As of August 2022, Africa had reported 8,780,536 cumulative cases in 47 countries with 173,243 deaths reported (World Health Organization (WHO) COVID reports). Most countries in Low- and Middle-Income Countries

(LMICs) have no, or minimal resources allocated to deal with this COVID-19 type of pandemic.<sup>6</sup> Even prior to the pandemic, LMIC had few healthcare providers (HCW) trained in palliative care.<sup>7</sup>

The pandemic significantly depleted an already poorly resourced PC service. In a study conducted in a tertiary referral hospital in Kenya it was realized that though the COVID-19 pandemic posed a threat to the lives of individuals across the globe, additional challenges were inherent due to provider shortages; scarcity of medical facilities and supplies; and mistrust of healthcare workers among patient populations.<sup>8</sup> This personalized need and demand were overlooked and curtailed. At the peak of the pandemic, scarce resources such as ventilators, intensive care unit (ICU) beds, dialysis machines, and human capacity were not available for all patients who were in need.<sup>9</sup>

Kenya Hospices and Palliative Care Association (KEHPCA) conducted a survey in April 2020 which focused on the im-

fact of the COVID-19 pandemic on palliative care service delivery. Purposive sampling was undertaken, 16 palliative care facilities (hospices, palliative care units in public, private and faith-based institutions) from different counties participated in the survey. The results of the survey suggested that palliative care practitioners had genuine concerns both for themselves and for their patients. A survey conducted by KEHPCA in 2020 indicated that the pandemic had caused devastating collateral damage to the limited palliative care programs for patients with life-threatening illnesses in Kenya.<sup>10</sup> COVID-19 pandemic resulted in a negative impact on supply chains with acute

shortages in the healthcare systems resulting in depletion of medical supplies and importation delays. According to there has been limited and improper use of personal protective equipment in Africa due to the paucity of skills to do so. There is limited published research on the PC needs of individuals affected by life-threatening illnesses including those suffering from severe COVID-19.<sup>11</sup>

The same study showed that most facilities had scaled down the provision of palliative care services to patients as indicated in Table 1. There was a 36% reduction in the provision of

**Table 1. Challenges and Strategies used to Improve Access to Palliative Care during COVID-19 in Kenya**

Palliative Care Need	Challenges	Strategies	Comments
Care during the COVID-19 pandemic-isolation	-Pandemic led to lockdown, curfews, limited health care capacities, fear of contracting COVID-19 virus by the patients, families, care givers and health care workers (HCW) -Patients were afraid that they may die alone (with no family member with them).	-Education for patients and families -Physical distancing-Provision of resources such as PPEs to enable palliative care HCW to see patients and their family-Provision of information on COVID-19 (in brochures, leaflets, posters, online training). -Making emergency kits available to patients -Moral support through video call facility by family members	-Advocacy for Policy changes
Home based care and visits	-Limited centers continuing with home based care due to fear of contracting COVID-19 virus -Patients and families were afraid of the potential of infection transmitted by the HCW.	-Provision of PPEs to home based care providers -Patient and family education on PPE and importance of continuing with care -Provision of care by phone/digitally	-Increase of awareness, and advocacy requires all stakeholders to participate -Innovation and use of technology to reach out to patients
Optimal pain management	-Inaccessibility to opioids and limited stock. -Poor knowledge and skills on prescription of opioids -Limited capacity of opioid prescribers -Improving screening of pain and symptoms -Optimize symptom management	-Decentralization of opioid handling and storage to primary, secondary and tertiary health care -Training HCW on opioid prescription -Allow trained nurses and other health care providers such as physician assistants to prescribe opioids -Routine use of simple screening tools such as simple 0-10 pain severity scales. Example Edmonton Symptom Assessment Scale (ESAS) -Appropriate use of medications and non-pharmacological measures	-Policy changes and updates to allow decentralization is important -Tele mentoring programs to train health care providers on the various aspects of opioids prescription -Laws and policies need to be updated to allow this strategy to be implemented
Symptoms management	-Symptoms assessment and management	-Thorough individualized symptom assessment. Use of tools such as ESAS which is easy to use by the patient, caregiver and the clinician -Evidence based treatments	
Consultations with patients and families	Lock downs, curfews, isolation	-Telemedicine: using online models e.g. smart phones, zoom, Skype for consultation, prescriptions, patient and family education	The usual etiquette need to be followed e.g. introduction of the clinician, listening to the patient, screening symptoms and maintenance of confidentiality
Patient psychosocial needs	-Anxiety, depression, worsening psychiatric disorders, eventual post-traumatic stress disorder	-Counseling, reassurance, social worker's assessment, continuity of other care such as cancer treatment, physical symptoms management	-Multidisciplinary team approach is key in delivering psychosocial support to patients and families
Spiritual needs	-Spiritual team were unable to reach to patients and vice versa -There is fear of contracting COVID-19 in case there is this kind of consult	-Spiritual support should be provided digitally -Recorded spiritual citations to be used by the patients are recommended.	-This will need commitment from the concerned spiritual and religious team and supervisors
Patients and family education	-It was difficult to hold family meetings/conferences in the wake of limited visitations to the hospital and clinics	-Family conferences can be held online, can also be done with a few family members especially the recognized next of kin who can update other family members/ stakeholders	-There is a need to be maintenance of patient confidentiality and protection of privacy
Hunger and nutritional well-being	-Patients and families were unable to source for food due to lockdowns and loss of jobs	-Food rations should be provided to patients and families who are unable to work or source for food	-Concerted efforts by local, national and international Government and NGO agencies is recommended
<b>Patient-Caregiver-Clinician Communication</b>			
Interrupted specialized treatment	-Limited access to specialized treatment and centers -Concern among patients on specialized treatment that they were unable to complete their treatment and that all funds prioritized COVID-19	-Networking with clinicians/doctors in rural areas who can continue specialized treatment under the instructions of the specialist who are responsible for the prescription -Intravenous medications can be, where applicable, converted to oral medications	-The rural clinicians will need on job training on the most important aspects of treatment This can be done through online models -Indemnity need to be extended, however, this will not entail negating accountability and responsibility by the specialist and the local clinician

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Ethical issues and dilemmas	-Allocation of limited resources e.g., ventilators, hospital beds, dialysis machines	-Guidelines should be developed for triage ethical issues -Use of Triage Committees to make decision rather than the treating doctor will prevent the emotional and moral distress and take away the burden of decision making from the treating doctor	-Triage guidelines and committees should be nationally recommended and recognized
End-of-life care (EoLC)	-Site of care for provision of EoLC-patients wanted to die at home, in their rural areas but are confined in towns due to lockdown -Lack of necessary medications as mentioned above	-Patient and family education and reassurance -Advocacy supportive letters by the doctors and hospitals to allow transition of patients as per their preferences -Need to ensure availability of necessary medicines such as opioids for quality care at end-of-life (EoL)	-An understanding by the authorities on respecting the patient's advance directives/last wishes is important
Bereavement, grief support and burial rites	-Due to limited physical meetings, this support was not being provided in full -Burial rites were shelved as per the government regulations. The importance of this cannot be downplayed as there is a belief of ancestors/living dead influencing the living and negatively if the rites are not followed to the letter	-Bereavement support (anticipatory/postmortem) can be done by provision of access to digital technology for HCW, and patients/families. -Building systems for psychosocial support to patients/families, as well as palliative care clinicians and volunteers, and developing bereavement support programs -Burials at sites of patient /family preferences should be allowed with attendance of family members if regulations are followed such as physical distancing and wearing of masks. Families need to be assured and informed of the same	-The government and other authorities have a duty to educate the public of the fact that the limitations are temporary

inpatient palliative care services, this was attributed to a government directive to decongest health facilities and patients' request for discharge to continue with care at home. They were concerned about getting infected, infecting their patients because of a lack of appropriate personal protective equipment, and not having enough information on COVID-19. Restricted movement and physical people interactions posed a great risk for poor mental health among individuals affected by life-threatening illnesses as most are not able to access health care, or visit their relatives and friends.<sup>12</sup> Some of the unique challenges for palliative care provision in LMIC in the wake of COVID-19 were: depletion of essential medicines supplies, limited communication of HCW with patients and family members due to lockdowns and curfews, this was a significant predicament for patients and families as well as HCW as the African society's survival is greatly dependent on socialization and communal interactions).<sup>13</sup> In addition, there was non-affordability of basic medications and medical necessities due to job losses and worsening poverty due to the pandemic. Caregivers had to work to provide for their families and risked exposing their relatives with life-threatening illnesses to COVID-19. Caregivers were also burdened by extra responsibilities such as childcare and home schooling and attending to their ailing relatives.

**Limited or No Home-Based Care and Visits**

In LMIC, palliative care is not widely available. KEHPCA estimates that only 15% of adults and 5% of children in need of palliative care in Kenya have access. Home-based care was the commonest mode of delivery of palliative care in Africa before the pandemic as it was also a cost-effective way of provision of care to the cancer patients who needed them the most.<sup>14</sup> However, restricted travel, limited financial capacity among palliative care patients and physical distancing affected delivery of some critical palliative care services including day care services, family conferencing, legal aid clinic among others. The survey by KEHPCA indicates that the majority of palliative care providers had reduced provision of home-based care with 24% were providing these services at very restricted capacity. Some of the reasons attributed to this were due to the fear among palliative care providers of transmitting the vi-

rus to their vulnerable patients at home and the limited supply of personal protective equipment (PPE) to palliative care providers.

**Pain and Psychosocial Distress Management and Essential Palliative Care Medicines Accessibility**

Most individuals affected by life-threatening illnesses in LMIC usually seek treatment late when their disease has already advanced and most of them present with severe pain or other distressing symptoms. Opioid analgesics are the mainstay for treating moderate to severe pain, and morphine is the drug of choice for pain and dyspnea. Access to opioids in LMIC is limited by several reasons including restrictive laws and regulations, limited knowledge among HCW and high prices.<sup>15</sup> Another major challenge is that opioids must be prescribed by registered doctors in Kenya. Many primary healthcare facilities do not have doctors but are run by nurses or clinical officers. Patients are forced to travel long distances to access essential medicines and sometimes the doctors are unavailable at the time when the prescription is needed.<sup>16</sup> The pandemic isolation has further made access more difficult.

**Patient-Caregiver-Clinician Communication**

One of the critical roles of a palliative care clinician is to facilitate patient-caregiver-clinician communication. This includes a discussion of the disease, possible treatment, optimal reduction of suffering due to the severe symptoms, end-of-life care, and proper allocation of resources for the bereavement of the most distressed caregivers. Additionally, the deterioration of health due to the disease and the complications due to the impact of the pandemic further highlighted the need to answer the ethical questions including the utilization of already stretched health resources such as hospitalization, treatments such as the use of antivirals, ventilators which were in limited supply. Patient-clinician communication was largely conducted during their ambulatory and home visits either individually or as a part of a family conference.

**Lack of Specialized Treatment**

In Kenya, major cities namely Nairobi and Mombasa were on lock

down to limit movement of people in and out as they had high numbers of people infected with COVID-19. Specialized treatment like radiotherapy, targeted therapy and immunotherapy for cancer treatment are only available in Nairobi at Kenyatta National Hospital within the public system. As such, patients had to travel to Nairobi for specialized treatment some of them coming from areas that are about 300-500 kilometers away. The number of patients attending specialized clinics in Nairobi greatly reduced with many patients developing disease-related complications due to missed treatment. Similarly, delayed importations resulting in shortages of chemotherapy, HIV medications, and other essential medications to treat life-threatening illnesses were reported.

### Healthcare Provider Distress and Burn-Out

The pandemic had devastating effects among HCW providing palliative care. The limited access to patients and caregivers, lack of resources to take of patients, unmet training needs, increase in mortality, lack of PPE, fear of personal health as result of COVID-19, and limited access to education and training in palliative care resulted in severe distress and accompanying burnout.

### STRATEGIES TO PROVIDE PALLIATIVE CARE DURING AND POST-CORONAVIRUS DISEASE-2019 PANDEMIC

Downar and Seccareccia, have identified four critical elements to ensure provision of palliative care services during the pandemic: equipment, staffing, location of care and systems redesign.<sup>16</sup> We will now examine how Kenya as an example of a LMIC utilized these four critical elements to sustain palliative care service delivery in the face of the COVID pandemic.

#### Innovative Use of Digital Technology

Digital technologies have been embraced by many countries to strength health care delivery, they have played a key role in LMIC due to the growing number of mobile communications and inaccessible health care facilities.<sup>17</sup> There has been a rapid increase in use of digital health innovations to strengthen health care system delivery in LMICs.<sup>18</sup> This is as a result of weak and poorly coordinated health care systems; hence the use of technologies is needed to fill the existing gaps.<sup>19</sup> Accordingly, it is believed that LMICs will be the epicenter for digital health innovations. Palliative care providers took advantage of these innovations to promote access to palliative care services during the pandemic. This included telemedicine and using courier services to deliver medical and non-medical supplies, communication with their patients *via* phone calls, short messages, pictures and video calls.<sup>20</sup> The need for digital platforms for improving palliative care education in Kenya had already been identified earlier in 2017 by Mushani et al<sup>21</sup> when they stated that there is a need to leverage on the power of digital health to training and build the capacity of HCW online, conduct tele-consultation and set up help lines to facilitate communication during pandemic.

Digital technology was also utilized more frequently to address the reduced education to HCW regards to palliative care education and care. Platforms like Zoom, WhatsApp, Skype, and

others to train and capacity build health care workers were used. Programs such as Extension of Community Health Outcomes-Palliative Care in Africa program (ECHO-PACA) can be further adapted by various regional centers to provide access to quality care education to the primary care providers and thereby improve the capacity to meet the palliative care needs during and after the pandemic. The goal of the ECHO-PACA is to make the primary care providers have the skills of a specialist palliative care provider. This will facilitate to virtually train further personnel at the primary care areas to meet the demand due to the pandemic.<sup>22</sup> The African Palliative Care Association (APCA), the umbrella organization for coordinating palliative care services in Africa conducted several webinars to sensitize both palliative care and other health care providers on provision of palliative care services during the COVID-19 pandemic.

Use of these innovative technologies also posed challenges including compromised patient privacy and confidentiality since in some instances they had to share devices to communicate with HCW. This was mitigated in a way by use of hospital sanctioned gadgets and systems for tele consults and also by ensuring education to patients and families regarding the inherent risks and the steps to reduce the same.

#### Healthcare Worker Distress and Burn-Out

Burnout was often under diagnosed and undertreated in HCW taking care of cancer patients in LMIC, and an unmet need as a consequence of a pandemic.<sup>23</sup> It affected HCW taking care of cancer patients without COVID-19 more than those taking care of COVID-19.<sup>24</sup> HCW distress and burn out were reduced by education, psycho-social support and enhanced communication.<sup>25</sup> Education not only focused on optimal provision of palliative care during pandemic, but also regarded proper use of PPE, healthy self-care behaviors including exercise. Relaxation and proper sleep and avoiding maladaptive behavior, enhancing communication between patients, caregivers, colleagues. New skills were needed to work at home using digital technology.<sup>26</sup>

#### Identification of Palliative Care Systems Needs

Incorporating palliative care services in all critically ill patients' management plans and protocols is needed by LMICs including essential medicines and training for HCW.<sup>13</sup> Most LMICs have strong community-based structures during the COVID-19 however pandemic related movement restrictions and patient fears of healthcare facilities limited service provision.<sup>27</sup> Table 1 outlines the challenges and the strategies used to mitigate them.

Inaccessibility to essential medicines and limited stock of these medicines in the regional and primary care centers was a critical challenge to provision of optimal pain and symptoms control in these regions even before the pandemic. There has been also lack of trained prescribers and HCW providing PC. Governments in LMIC need to prioritize palliative care and allocate adequate resources to reduce suffering to promote access to palliative care. The pandemic has negatively affected the financial earning of families and their access to healthcare.<sup>28</sup> Palliative care services need

to be fully integrated into the Universal Health Coverage (UHC) package to ensure all patients and families in need of palliative care have access regardless of their ability to pay. Table 1 describes a recommended approach to enhancement of palliative care services in LMIC countries based on the Kenyan pandemic experience.

## CONCLUSION

The COVID-19 pandemic further heightened the need to provide timely palliative care to improve quality of life of patients and families affected by life-threatening illnesses in LMIC countries. The authors propose the following strategies to promote access to palliative care during pandemics including: utilization of digital technology, enhanced training of palliative care providers, adoption of efficient systems to reach out to patients and promote access to essential medicines, and advocate policy changes to improve population health. Further research on effectiveness of strategies to facilitate the provision of palliative care in LMIC countries are urgently needed.

## CONFLICTS OF INTEREST

The authors declare that they have no conflicts of interest.

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