

Integration of Telemedicine for Home-Based End-of-Life Care in Advanced Cancer Patients during Nationwide Lockdown: A Case Series

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Abstract

Dignified death is a basic human right that has been widely overlooked in countries like India. During nationwide lockdown, it is extremely challenging to provide quality end-of-life care (EOLC) to all patients with a poor system for dignified death. Telemedicine, whose feasibility for community-based EOLC in rural settings has already been established, was a useful tool for us to overcome these barriers. Adding a widely used smartphone-based application for video calls along with voice calls and text messages made the process more dynamic and convenient. Here, we share our experience with three patients with advanced malignancy in providing EOLC during COVID-19 lockdown. A well-planned study for the utility of this service for a larger cancer patient population from different sociocultural and demographic backgrounds is warranted in the future.

Keywords: Death, dignity, telemedicine

INTRODUCTION

Dying with dignity is a right to every human being.^[1] During a pandemic and nationwide lockdown, it is extremely challenging to provide a quality end-of-life care (EOLC) to all patients.^[2] Due to the overwhelming medical system, we need to adapt to new technologies for achieving goals of care. Telemedicine is a potential answer to this problem.^[3] It not only enables us to connect to a dying patient at a remote place but also helps in shared decision-making,^[4] advanced care planning, to guide the caregivers for managing the symptoms,^[5] and providing psychological support to the bereaved family members.^[6]

India already has a poor system to provide good quality of death.^[7] It has a limited number of palliative care units (PCU) and hospices for the EOLC services. Nationwide lockdown since March 24, 2020, had made the barriers to access these services more challenging for the patients. Hereby, we explore the scope of telemedicine with audio-visual technology in our patients with advanced cancer. Here, we share our experience with three patients, where we used a smartphone-based application (WhatsApp) for the process of providing EOLC.

CASES REPORTS

Case 1

A 68-year-old male patient, resident of Bihar, with a diagnosis of metastatic carcinoma lung, was under follow-up of palliative medicine department for best supportive care for the past 5 months. He was taken to his native place before lockdown in view of his terminal disease. He was taking tablet morphine 15 mg 4th hourly for the dyspnea and pain. His elder son (primary caregiver) availed our telemedicine service with the complaint of dyspnea. Over a video call, we assessed his symptoms. He was found to have dyspnea at rest and agitation

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due to labored breathing. We advised them to gradually increase the oral morphine dose with intermittent video calls to ensure the safety of the patient. He became comfortable with tablet morphine 25 mg 4th hourly and tablet haloperidol 0.5 mg. We also advised to use a small fan to blow air near his face. While assessing the needs of the caregivers, we found that his son was feeling guilty for being unable to take him to a hospital due to lockdown. We reassured him about availability for our help and empathetically explained that whatever is happening is not his fault. The goals of care were discussed with the family members. Futility of mechanical ventilation in view of his progressive lung cancer was explained to them. This was helpful to manage the anxiety of the caregivers. He passed away peacefully after 1 day.

Case 2

A 45-year-old patient, resident of Uttar Pradesh, a diagnosed case of cholangiocarcinoma with multiple liver metastases was having best supportive care for the past 3 months under our follow-up. She was sent to her home 2 weeks back in view of her terminal illness and severe liver dysfunction. Her husband availed our telemedicine service with the complaints of gurgling sound at throat. We made a video conferencing call involving her son, residing at Mumbai. We identified the gurgling sound as death rattle. We discussed the goals of care with her family. She was comfortable and pain free with fentanyl patch 50 µg/h. Her family members were well aware about the disease prognosis and maintained previous agreement over the comfort care at home. We explained and reassured them about the terminal event. She passed away peacefully after 3 h.

Case 3

A 52-year-old female patient, resident of Himachal Pradesh, a case of metastatic gallbladder carcinoma, with multiple liver metastases was under best supportive care for the past 2 months. She was admitted twice in the past 2 weeks at our PCU for recurrent ascitic fluid tapping and malignant bowel obstruction. She was on fentanyl 75 µg/h patch. Advanced care planning was done for her in consensus with primary physicians and family members. She was advised to be taken to her native place in view of extremely poor physical status and terminal illness. Her daughter called us with a complaint of discomfort and restlessness. She was assessed over a video call, and no gross abdominal distension was noted. This ruled out any obvious need for ascitic fluid tapping and emergency hospital visit. We advised tablet haloperidol 0.5 mg through Ryle's tube. Her daughter could herself appreciate it as a terminal event and asked for her comfort only. With two doses of haloperidol, she became calm and comfortable. She passed away on the same evening with adequate comfort.

All the families were called back after 24 h by our team for bereavement service. We assessed the satisfaction level of the caregivers on a 4-point Likert scale: very satisfied,^[4] satisfied,^[3] partially satisfied,^[2] and unsatisfied.^[1] The primary caregiver of the second case was very satisfied, while the rest of the

caregivers were satisfied with the telemedicine guidance at the last moment. All of them were of the same opinion that the video calls were quite helpful to them to have a physician virtually by their side at the last moment.

DISCUSSION

EOLC is a right to every dying patient.^[1] Higginson *et al.*^[8] (2007) found in their systematic review that the preferred place to die for an advanced cancer patient is at home. All of our three patients had advanced care planning during their follow-up and preferred to have their last days at home instead of hospital. Thus, they were sent back to their native places in view of terminal illness. However, palliative care physicians need to continue the support to the patients and caregivers whenever they need during a crisis moment. Silveira and Forman^[9] identified some important factors to provide a quality EOLC as per the perspectives of caregivers. Some of these are a continuous care process involving primary care physicians to assist in decision-making, flexible scheduling to assist the patients in emergencies, and a coordinated care system to respond to a patient's changing needs quickly. The ongoing lockdown is very likely to restrict the patient's access to the primary care team in emergency hours. This barrier may significantly compromise the aforementioned components of quality EOLC.

Telemedicine was a useful tool for us to overcome these barriers. Tieman *et al.*^[10] have already established the feasibility of the use of telemedicine for community-based EOLC in rural settings. Adding a widely used smartphone-based application for video calls along with conventional phone calls and text messages made the process more dynamic and convenient. It allows us to examine and assess the patient effectively.^[11] Thus, we were able to rule out the need for ascitic tapping, identify death rattles, and terminal delirium effectively in our patients.

During the process of EOLC, it is extremely challenging to give psychosocial support to the caregivers. The pandemic itself causes the disintegration of the family members. The near and loved ones residing at a distant place cannot join the family for the last rituals. Reuniting them over a video call can greatly help to manage their grief.^[12,13] In addition, these conference calls make the otherwise difficult communication about advanced care planning easier.^[12] In two of our patients, we managed to involve patients' children in our conversations addressing their guilt of not saying goodbye at the final moment and not being able to come to hospital. Addressing these issues in caregivers is important to prevent the progression of an anticipatory grief to a complex one.^[12]

The major limitation of this process was a continuous monitoring of the patients during EOLC. The utility of mobile e-applications^[14] continuously recording patient's vitals can help to track the changes of patient's condition more dynamically and on a long-term basis. Second, all our patients, fortunately, had a timely advanced care planning in place already. However, in patients without set goals for

care, the utility of telemedicine for EOLC scenario at our setup is yet to be explored. Engaging physicians from other specialties involved in the care of the patient should also be considered during the teleconsultations to improve shared decision-making and patient's satisfaction.

CONCLUSION

Despite some major limitations, telemedicine service with an audio-visual facility seems to be an effective mode of providing EOLC to advanced cancer patients. This is particularly important for the patients who cannot commute to the hospices either due to their terminal illness or due to strict restrictions on movement during the lockdown period. We were able to manage physical symptoms and major psychosocial needs of patients and caregivers. A well-planned study for the utility of this service for a larger cancer patient population from different sociocultural and demographic backgrounds is warranted in the future for a generalized application.

Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent forms. In the form the patient(s) has/have given his/her/their consent for his/her/their images and other clinical information to be reported in the journal. The patients understand that their names and initials will not be published and due efforts will be made to conceal their identity, but anonymity cannot be guaranteed.

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Conflicts of interest

There are no conflicts of interest.

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