

Homecare and the COVID-19 Pandemic – Experience at an Urban Specialist Cancer Palliative Center

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Abstract

Background: With the COVID-19 pandemic wreaking havoc globally, the extremely vulnerable subset of cancer palliative care patients has to go through the worst nightmare. Difficulty in accessing medical care in the event of increased symptom burden, obstacles in reaching hospitals at time of emergencies or end of life, limited access to medication, social distancing causing isolation, leading to psychosocial burden, lack of bereavement support, are few of the issues we identified. Palliative home care is an important tool to allay the anxieties and address the fears of cancer patients and caregivers, by ensuring continuity of care and providing the much needed handholding in these difficult times. This article aims to highlight the home-based care strategy and experience of the Cipla Palliative Care and Training Center during the COVID-19 lockdown. **Materials and Methods:** We have utilized the data of documentation of the process of designing the protocol, the data entered by the team on unique data management software that is used at the palliative care center to record all palliative care interventions and reflections of the team on their experience of home visits during this period. **Results:** Continuity of care through home visits will ensure better management of patients in terms of physical symptoms, psychosocial support, allaying fears, and anxieties, as well as the ultimate goal of an improved quality of life. Physical symptoms (24%), morphine drop off (19%), psychosocial support (15%), end of life care (33%), and procedures (9%) were the major indications of visits. **Conclusion:** The COVID-19 pandemic has increased the need for support, thus reiterating the importance of continuity of care. With abundant precautions and protocols in place, home care through visits is possible. With the lockdown and restrictions now entering their fourth phase, we need to be ready now more than ever to adapt to changing times and evolving definitions of the “New Normal.”

Keywords: Continuity of care, COVID-19, home care, palliative care

INTRODUCTION

Access to palliative care in itself is frugal, in the best of times. With the COVID-19 pandemic wreaking havoc worldwide, the need for palliative care has risen exponentially, and the availability remains the same, creating a major demand-supply rift. The World Health Organization (WHO) has issued guidance on how to maintain essential health services during the pandemic, highlighting immunization, maternal care, emergency care, and chronic diseases among others, but there was no mention of palliative care.^[1]

Cancer palliative care patients especially are facing several challenges in terms of difficulty in accessing medical care in event of increased symptom burden, any clinical emergencies, or end of life. Also access to medication, social distancing causing isolation, leading to psychosocial burden, lack of bereavement support which has never been a problem in the

Indian context due to the close knit family and community structure are the other problems, to name a few.

Several research studies have highlighted that patients preferred place of receiving palliative care is in their own homes^[2] when this is a safe environment for patients and care givers. Home care services, therefore, play an important role in supporting patients and family members to manage their pain, symptoms, and prepare them for the end of life issues.

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This paper aims to highlight the home-based care strategy and experience of the Cipla Palliative Care and Training Center (CPC) during the COVID-19 lockdown. CPC is located in Pune, Warje, and is a 55 bedded in-patient facility offering home care services as well as outpatient support in hospitals to cancer patients requiring palliative care. It started in 1997 and has since reached out to over 17,500 patients.

METHODS

Through this paper, we would like to share our experience of initiating home care for our palliative care patients during the COVID-19 lockdown. The specific aims of this paper are

- To present the home-care protocol that was developed and highlight the process by which it was developed
- To share the data on the implementation of the protocol and the families who were visited on home care during the lockdown period
- To describe the challenges faced by the team in delivering home-based care during this period.

The data for these articles are based on the documentation of the process of designing the protocol; the data entered by the team on unique data management software that is used at the palliative care center to record all palliative care interventions; and documenting the reflections of the team on their experience of visiting homes during this period.

The roadmap: Defining the home care protocols

Initially when the lockdown was announced in Pune on March 21, home care services were suspended as we felt it was necessary to avoid community exposure, to both our staff, as well as the patients that we would be visiting, since cancer patients fall into the category of vulnerable patients. Considering the lockdown to be a short-term occurrence, we devised ways to keep in touch with our patients through telephonic and video consultations, and liaised with local general practitioners for any urgent clinical needs or end of life management.

However, as it became clearer that the lockdown would get extended further, and through our telephonic and video consultations, we realized that patients and caregivers were getting increasingly distressed, with lack of social support, isolation, growing symptom burden, exhaustion of medication, and anxieties regarding both their primary disease and COVID-19.

The team at CPC, including clinical staff (doctors, nurses, and social workers), the administrative team, and the research team brainstormed regarding the need for home visits, anticipate the challenges for the same, and how they could be overcome. This process culminated in defining the protocols and homecare services resuming on April 14, 2020.

The key aspects of the home care protocol developed included:

- It was based on a review of existing guidelines both nationally by government and internationally by the WHO

- The entire team clinical and nonclinical including the drivers of the vehicles were involved in the process of the development of the protocols
- There were numerous individual, small group, and larger group meetings with all staff including support staff at the center to understand their fears, concerns, and family reactions to them working at the palliative care center at this time
- The guidelines were also shared with the experts in the field of palliative care for their suggestions and inputs before finalization
- There was a mechanism built into the protocol to be dynamic and responsive to the daily changing situation as there were daily briefing and de-briefing meetings with the team involved in home care
- There was a clear focus on infection control measures that were put in place to safeguard the staff, the families who were visited and the in-patients who were admitted at the center.

The key features of the homecare protocol that were developed are highlighted in Table 1.

In addition, special permissions needed to be applied/obtained from competent authorities for all members of the homecare team to move in the city for rendering homecare services. It was decided to have 2 homecare teams comprising of a doctor and nurse in each time.

The algorithm for visits was developed into a flow chart as depicted in Diagram 1 below.

As illustrated in this diagram, above factors such as family involvement, local general practitioner relationship, transport availability to reach CPC were also taken into consideration while deciding about the critical cases requiring a visit.

Translating the protocols into action Presentation of data

In the period under review from March 24, 2020 to May 15, 2020, all our home care patients registered ($n = 280$ patients) were contacted over the phone and a total of 699 calls were

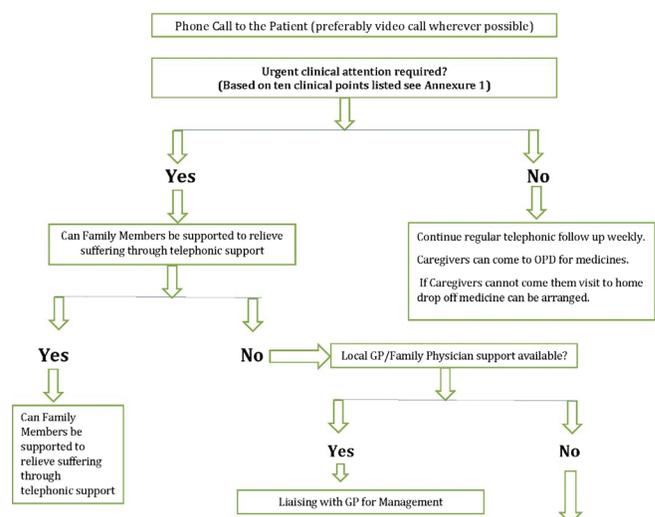


Diagram 1: Flow chart of the homecare protocol

Table 1: Some salient features of our home care guideline during COVID

Issue	Strategies we used	What helped
Previsit protocol: Defining the most critical cases		
Prioritizing visits to be made	Developing an algorithm to define critical cases that was developed into a flow chart illustrated below [Diagram 1] Telephonic preferably video call screening of all the patients (and members residing with patient) identified for home care visits conducted based on the criteria listed in the pre-visit screening checklist	Clear management guideline that home care to be delivered only to the most critical Senior medical leads vetting the cases to be visited to check criticality the prior day Video/phone call with patient caregiver prior to visit explained possible consequences of the visit. Caregivers took onus to ensure home care team could enter premises
Checking visit preparedness	A daily briefing call with a team of technical consultants at CPC will be done, led by the home care team doctors. Screening details will be presented and discussed during this call by the home care team Visit preparedness checklist [Annexure 1] for homecare visit will be checked for the items to be carried during the home visit and verified by the home care doctors Vehicle for home visit will be sanitized in the morning of the home visit Challenges for infection prevention control measures will be discussed	The preparedness of the team from infection control point of view was actively discussed during this call Staff anxieties, fears, and apprehensions were reduced by the daily briefing and debriefing calls with senior team members Daily updates/changes in hotspot areas also discussed
Visit protocol		
Conducting the home visit	The home care team will wear the N 95/3-ply surgical mask and gloves for every homecare visit and follow the donning and doffing sequence (in aerosol generating procedures) as per CDC Guidelines	During the visit, the family was educated on using cloth mask, nutrition, hand hygiene, cleaning and disinfection at home by Lysol, avoiding visitors, respiratory etiquettes etc.
Conducting special procedures	In case if any specialized procedures such as catheterization, bladder wash, wound dressings is to be carried, then double gloves, gown, goggles and N-95 mask will be used	The home care team was equipped with 3 PPE Kits with all the PPE material that include cap, goggle, 3-ply surgical mask, N-95 mask, gown, gloves, shoe cover as per the quantity defined in the PPE Kit list In addition, the Kit included 2 Z-kits, hand sanitizers, hand wash liquid, tissue papers and 2 yellow biomedical waste collection bags
Postvisit protocol		
-	A report will be shared by the home care team that will include the clinical history, evaluation, treatment, procedure done if any, medications dispensed, infection control practices followed, and challenges faced during the visit if any	The daily debriefing session post home visits conducted based on the debriefing checklist helped to learn, understand challenges, so that, necessary amendments could be made in subsequent visits
Addressing staff concerns: Safety of the team		
Anxiety of staff about exposure to the virus when they go out to the community	Daily briefing and debriefing session for all staff including drivers Frequent training and refreshers on handwashing, use of masks, PPE kits Protocols for staff when they return from home care-bathing, clothes	Commitment and motivation of the team. Teams were quick to learn the new rules and follow them carefully
Staff self-care	Forums for staff to discuss impact on them personally, family reactions; activities for the staff conducted by our social work and physiotherapy departments, team building exercises, games and relaxation activities available at the center, one to one counseling sessions available, entertainment programs by the staff, for the staff, daily group discussions	Active participation of staff and honesty to discuss issues The most vulnerable members were allowed to decline participation
Staff deployment team	Creation of two teams to minimize contact. It was ensured that the teams were mutually exclusive and did not come in contact with each other	Sufficient staff to enable creation of 2 working teams

CPC: Cipla palliative care, PPE: Personal protective equipment

made to them. This ranged from a minimum of one call to the family in the month to a maximum of six calls to a family in the month. Families requiring extended support, diet consultation, physiotherapy advice received additional calls. The month-wise distribution of calls is outlined in Figure 1.

In the month of March, all the patients were contacted over the phone, over is soon became increasing important with our home care protocols in place that a video call would be more effective wherever possible. Hence, in the month of April out of the 395 calls, 78 of them (20%) were done as a video call and between

May 1 and May 16, 70 were video calls (33%) out of the total of 214 calls. This illustrates the increasing trend in adapting for a video call by patients though this also depends on the availability of smart phones and internet connectivity [Figure 2].

From the month of April, the team also triaged the patients as per symptom burden, distress calls received, end of life patients, and resumed home care services. Basis the algorithm devised, patients were assigned one of three categories, namely high, medium, or low. The algorithm developed as illustrated in Diagram 1 was used to identify patients who were classified as “Critical.” Patients in the medium category included those whose visits could be planned at a later date and those classified as “Low risk” were patients who could be managed over video calls.

Based on this triaging system, out of the 280 patients on home care, there were 31 patients classified as critical, 145 patients who were at medium risk and 104 patients who were classified as low risk as illustrated in Figure 3.

All these 31 patients who were classified as critical were visited during the period between April 14 and May 16, and in addition, a few patients ($n = 15$) patients who had been classified as medium were also visited as they required medications/morphine and caregivers were unable to reach the center to collect these. A total of 46 visits were thus made.

The distribution of visits across Pune city based on the municipal corporation classification of “red,” “orange” and “green” zones is depicted in Figure 4 below,^[3] red being the

zone with maximum number of COVID patients, and having the maximum restrictions.

As illustrated below, the CPC team conducted 12 visits in the red zone, 9 in the orange, and 8 in the green zone. In addition, 17 visits were done outside the limits of the Pune Municipal Corporation, i.e., Pimpri-Chinchwad area which was also in the red zone.^[1]

Of the 46 patients visited during this period, the support offered included: addressing physical symptoms, providing psychosocial support, end of life care, in case of morphine drop offs, or needing any procedures or wound dressing. The type of services provided is illustrated in the chart below. Although the services provided may not have been exclusive, and few patients may have used more than one service, we have tried to highlight the major ones we identified.

RESULTS AND DISCUSSION

The concept of continuity of care is ever so important during the current COVID crisis, where isolation, lack of access to medical care, anxieties, and apprehensions are rampant. The American Academy of Family Physicians defines continuity of care as “the process by which the patient and his/her physician-led care team are cooperatively involved in ongoing health care management toward the shared goal of high-quality,

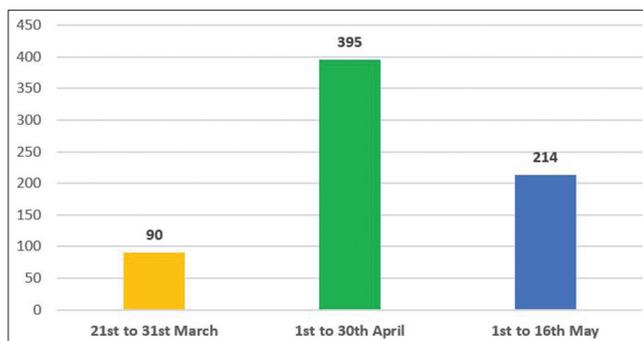


Figure 1: Month-wise distribution of calls done to patients on home care

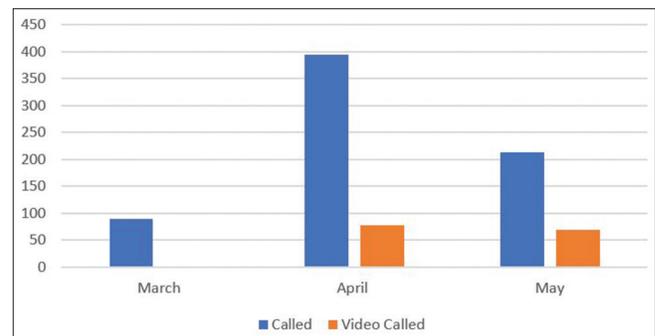


Figure 2: Month-wise distribution of calls and video calls

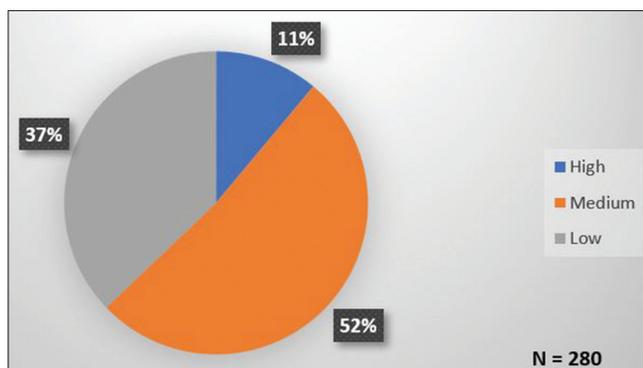


Figure 3: Criticality profile of patients

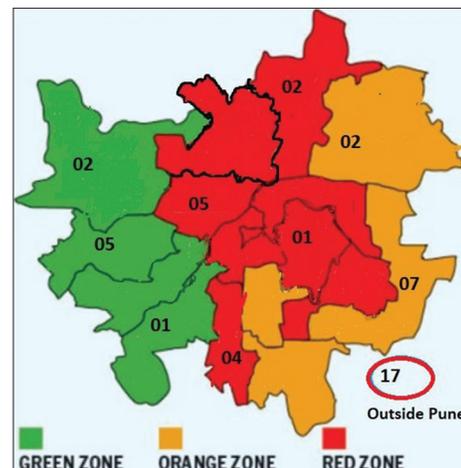


Figure 4: Division of Pune into color-coded zones

cost-effective medical care.^[4] Continued care ensures constant connect of the patient with the healthcare system, thus reducing patient anxieties, improving patient satisfaction, improving quality of life, and as some reports mention, even reducing mortality.^[5] With Pune being one of the districts worst hit by the pandemic, there were severe travel restrictions, limiting access to home care for several of our patients [Figure 4]. We tried to ensure continuity of care through phone calls and video calls [Figures 1 and 2].

Restarting home visits was a policy decision that we made, based on the criticality of patients assessed through phone calls and video calls made, as per our algorithm [Diagram 1] and the number of stressed calls we received. However, keeping in mind, the travel restrictions, reduced number of staff, and the need for judicious use of protective equipment, we triaged the patients into high, medium, and low criticality [Figure 3].

Aggravated physical symptoms such as pain, vomiting, bleeding, and delirium were one of the major indication for our visits. Palliative care is ongoing and responsive care.^[6,7] Symptoms dynamically change due to changes in the disease status, adverse effects of curative treatment, debilitated condition, and comorbidities. Out of the total, 24% visits were for managing physical symptoms [Figure 5].

Cancer patients and their families are extremely vulnerable^[8] due to the physical symptoms of the disease, the morbidity of treatment, financial setback due to the cost of treatment, uncertainty regarding the future, and threat to identity of the patient. The entire family loses all sense of normalcy in daily life. To add to it, the pandemic situation has led to further isolation,^[9] limited resources, and added uncertainty. The psychological burden patients and their families have are evident by the fact that 66.6% ($n = 466$ out of 699) calls and 15% visits [Figure 5] were for counselling/psychosocial support. These seven patients required a visit as the issues faced could not be addressed through calls.

The calls made by our team also helped us to identify other issues the families may be facing such as nonavailability/poor accessibility of ration, difficulty in accessing medication, and difficulty in reaching local physicians. This prompted us to help with dry rationing, thus improving quality of life of patients and caregivers by all means possible.

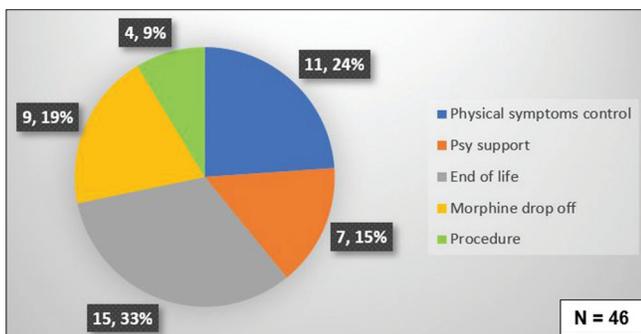


Figure 5: Different Indications for which visits were planned

Although medical stores and hospitals were not shut down, after speaking with the patients, we realized that accessibility of medical stores was a problem due to transport restrictions. Opioids are not available everywhere. Also getting a fresh prescription for opioids was a major problem, due to which several patients were defaulting morphine doses. Thus, we started with dropping off morphine to patients who needed it most, these visits comprising 19% of the total [Figure 5].

End of life is a difficult situation to handle even in normal conditions.^[10] With the current COVID crisis, every step at the end of life is a challenge. The family will have to manage the end of life symptoms on their own, which is quite distressing. The local physician may not be easily available/accessible. Emergency shifting to the hospital may be difficult due to all the restrictions. One of our patients' families faced isolation from the community as death had occurred during the time of COVID and the community suspected the cause of death to be COVID. Bereavement has to be done in isolation, and the close-knit society, which is the hallmark of Indian culture, that makes loss bearable, is no longer available, due to the COVID crisis. About 33% of our visits were for end of life care [Figure 5], where our team went out into the community and empowered the family for the outcome, apart from managing the symptoms. They were counseled in detail regarding what to expect and what to do in the given circumstances. We liaised with the local physicians and ensured that the family will have all the support needed whenever possible. A total of 40 bereavement calls were also made by the team in this period which included patients who expired during the lockdown and those who had expired before the lockdown in the month of March.

CONCLUSION

The current situation, though challenging presented us with an opportunity to work beyond our current scope while reaching out to our patient pool. Optimum resource allocation, utilization, and planning form the pillars that ensured coverage in these testing times. We realized that during lockdown, the need for support is higher; hence services should not be discontinued. With abundant precautions and protocols in place, home care through visits is possible. All team members including drivers need to be taken into confidence. With the lockdown and restrictions now entering their fourth phase, we need to be ready now more than ever to adapt to changing times and evolving definitions of the "New Normal."

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Nil.

Conflicts of interest

There are no conflicts of interest.

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Annexure 1: Visit preparedness checklist

Preparation parameters	Yes/no (remarks)
Pre-designed kit ready with following	
PPEs - Gloves, N 95 masks	
Screening forms	
Alcohol based hand rub solution	
Liquid hand wash solution	
Tissue papers	
Biomedical waste collection bag and container	
Extra masks for the family	
Permission for visit/pass obtained	
Vehicle disinfected appropriately	
Home care team and driver body temperature screening done	
Team briefing carried out before the start of the visit	