

Palliative Care Interventions from a Social Work Perspective and the Challenges Faced by Patients and Caregivers during COVID-19

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Abstract

Aim: The aim of this article is to describe the range of challenges faced by both patients and caregivers during the lockdown due to the COVID-19 pandemic. It also seeks to describe the nature of interventions provided by the social work team to address these challenges. In addition, it aims to highlight the lessons that can be learnt in supporting families on palliative care in such unique disaster situations. **Methods:** This exploratory study uses a qualitative approach and analyses the perceptions of patients, their caregivers, and the staff in providing care. Out of 30 patients worked with during the lockdown period, a total of nine families were selected that had received services during this time. The challenges faced and the interventions provided were analyzed using Framework analysis. We then used this framework to develop the themes that have been presented in the article. **Results:** The analysis indicates that the range of challenges faced by patients included physical distress due lack of availability of medicines and nursing care; emotional distress due to the interruption of cancer treatment; financial and social distress about loss of incomes, isolation; and spiritual distress due to the uncertainty of last rites as well as fulfilment of last wishes. The concerns outlined by caregivers included: living with guilt due to the inability to ease their relative's distress; the stress of constant care giving; lack of information about available services and confidence to ask for help from others as well as the dealing with the grief of a dying relative. These families were supported through telephone calls and home visits for critical patients with the social work team providing active listening, reassurance, empathy, and networking to assist patients and families at this time. **Conclusion:** Palliative care is an essential component, especially in a disaster-related situation such as the COVID pandemic as patients and caregivers are left more vulnerable at this time. Telephonic and video calls play an important role in supporting patients and caregivers and in the most critical cases. However, it is also important to find the ways to provide direct home-based support to patients and families at this time so that they feel less alone, cope better, and experience meaningful support to build their resilience.

Keywords: Challenges, COVID 19, palliative care, response interventions, social work

INTRODUCTION

A disaster situation such as the COVID-19 crisis highlights the specific challenges faced by patients and their caregivers on palliative care. An analysis of 95 peer-reviewed and gray literature documents reveal a scarcity of data on palliative care needs and interventions provided in crises, challenges of care provision, particularly due to inadequate pain relief resources and guidelines, a lack of consensus on the ethics of providing or limiting palliative care as part of humanitarian healthcare response, and the importance of contextually appropriate care.^[1] This article aims to address some of these gaps.

Context

The Cipla Palliative Care and Training Centre (CPC), Pune, Maharashtra, offers in-patient, out-patient, and home care to people living with cancer and opting for palliative care services.

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It is staffed by a multidisciplinary team of doctors, including pain specialists, physiotherapists, dieticians, nurses, and social workers. During this lockdown period, the inpatient care and home-care services for critical patients continued while the outpatient clinics in external hospitals were suspended. The social work team consists of seven members who were involved in supporting patients and families during this time.

Aim of this paper

As COVID-19 has thrown up special challenges, especially in face-to-face contact and communication with patients and families. This article aims to:

Describe the challenges faced by patients and caregivers at this time

In regular times patients and caregivers face numerous challenges.^[2,3] However, in situations such as the COVID lockdown, these challenges may be exacerbated. This study, therefore, aims to understand the specific challenges faced by the patients and caregivers due to the pandemic.

Outline the interventions possible by the social work team

The COVID situation has changed the communication pattern of the social work team from being face to face to largely on the phone. This article aims to outline the support provided to families during this time and the reflections of the social work team in providing this support.

METHODOLOGY

The case notes of all the thirty families that the social work team intervened ($n = 30$) from the announcement of lockdown on the March 22 to May 15 were reviewed. From these nine families were chosen who were (a) at various stages in their cancer trajectory (b) of different ages (from 17 to 68 years) and (c) were either in-patient or on home care receiving palliative care. The data from these nine families were analyzed using the Framework approach,^[4] and the key findings are presented in this article.

Findings

The findings have been divided into three categories: challenges faced by patients during the lockdown period; stress faced by caregivers during this period, and finally, the types of support and interventions provided to families.

Challenges faced by patients during this time of COVID

The key challenges faced by the patients during this time included:

Unavailability of medicines

Patients living with cancer already go through a lot of anxiety and stress. The uncertainty of the availability of medicines made them more anxious. Patients had several limitations to travel to CPC or any other hospital as there were lot of formalities to be completed in terms of obtaining a police pass for travel as well as arranging transport. Patients living in more rural areas were even more disadvantaged. For example, one patient on home care has been stable on morphine for almost

1 year, but his morphine supply was now running low. As he was staying far away from CPC, it was not possible from him or his relative to travel due to lockdown. In addition, when we were able to locate an oncologist closer to the patient who could provide morphine, there was reluctance from the oncologists side to do as he had not previously intervened with the patient.

Fear of treatment being incomplete

Patients expressed a lot of worries about the delay to their treatment due to the postponement to all elective procedures/ treatment during the lockdown period. The hospitals which were declared as COVID-19 hospitals were not very keen to admit cancer patients so as not to put them at risk due to their comprised immunity. Patients were anxious that this postponement in their treatment may result in them experiencing increased level of pain and that they would suffer with some other side effects.

Inadequate nursing care

Patients also complained about a lack of nursing care that was available as either they were living alone or family members were unable to provide this level of care. Also, dressing material was not easily available during lock down period which resulted on the lack of wound management in people staying at home. Patients especially with cervical cancer and oral cancer faced problems of getting diapers and dressing materials which resulted in incomplete dressings. Patients expressed that their wounds were resulting in a foul smell and also that they had started developing bedsores.

Worries about other family members

Patients who were admitted in the in-patient facility at CPC were worried about their family members who were staying in containment zones. They were worried about family members being infected by COVID. As the lockdown progressed, patients were increasingly worried about the uncertainty of employment for their in family members. As relative visits to CPC were also restricted due to lockdown, this resulted in increased irritability among patients.

Sense of isolation

Patients also spoke about how alone they were feeling even at home. One patient spoke about how as he had a cough and mild fever which he considered to be normal during his cancer treatment, several members from the community stopped visiting him as they feared he was suffering from COVID.

Caregivers in some cases were also reluctant to go near their patient and do the dressing as they were worried that their patient was suffering from COVID. This made the patient feel left-alone and he spoke to the social worker that this is terrible life he is living where in his own family is not supporting him at the end-of-life.

Unable to complete last wishes

Patients who are close to the end of life expressed their frustration at being unable to fulfil their last wishes. Patients wished to stay with family during last moments of life and

Table 1: Types of support availed by all families during the lock down period

Total number of patients supported	n=30
Food coupon	3
Financial help	3
Ambulance	4
Transportation	4
Medical equipment	4
EOLC wish	4
Connect with local GP	5
Dressing material	6
Medicines	6
Grocery	8
NGO networking	8
Caregivers counselled	30
Patients counselled	30
Telephonic calls	120

Some families received multiple types of support. GP: General practitioner, EOLC: End of life care, NGO: Nongovernmental organization

this seemed to not be possible due to travel restriction and social isolation norms. One patient was anxious that as he was nearing end-of-life, he wanted to make his will to divide his assets equally among the daughters-but this was not possible due to unavailability of services.

Stress faced by caregivers at this time

The key stressors identified by caregivers at this time included:

Helplessness and guilt caused by the inability to care for patient properly

Few patients had travelled from their hometown to CPC to avail services. Once the lockdown started, the patients were unable to receive help from the relatives. This resulted in helplessness and guilt from the caregivers of not providing care to patient. Also several caregivers spoke about their uncertain employment situation during this time which diverted their attention from caring for their relative. For some caregivers, this financial strain hampered their ability to meet the basic needs of the patients like arranging ambulance travel or nutritious food to meet the patients diet, getting dressing material, which resulted in more guilt among them.

Lack of information with caregivers, lack of confidence to ask for help

Caregivers expressed that they were anxious that they were unable to find clear information about COVID and its impact on daily life. Many expressed a fear of having to ask for help from the police or IO8 ambulance services to travel to Pune. Caregivers also shared their lack of confidence to travel alone to receive the medicine for patients from CPC and felt frustrated that they were unable to arrange medicines from any facility closer to them.

Caregivers own physical health deterioration

Caregivers spoke about the issues with their own health as they cared for their patient. One of the caregiver had been

complaining of the rash on her skin but was not able to visit doctor and also was unwilling to do the regular investigation. She shared she did not want to put additional financial stress on the family.

Worries about death certificate

Caregivers whose patients were at the end of life shared additional worries. The caregiver whose patient was in the in-patient facility of CPC shared they would prefer not to get a discharge even though it was the wish of their patient to spend their final days at home. This was because they feared that if their relative died at home, then the local physician may refuse to visit their home which may result in inability to get the death certificate.

Frustration about incomplete last rituals and no proper ending/grief

Caregivers whose patients died during this time spoke about their loss and additional grief at their relative not being able to have a proper funeral. This was because some family members and members from the community refused to attend the last rituals of patient or some key relatives such as a daughter was unavailable to travel from Delhi to Pune due to lockdown. The caregiver felt helpless and frustrated as nobody was willing to support him during this time making them feel more isolated and guilty that their patient did not have a proper ending in life.

Interventions from the social work team perspective

As highlighted in the previous sections, patients and caregivers faced several challenges and stress points during the COVID lockdown. During the period of the COVID lockdown that continues till the time of writing (end March to 1st week of May 2020), the social work team actively intervened with 30 families affected by cancer through phone calls, video chats and liaising with the CPC home care team that were visiting patients in critical conditions to ensure continuity of care.

The team supported the caregivers and patients and made them comfortable through phone calls, one-on-one session and started home care visits. CPC also designed guidelines to follow during the lockdown that focused on hand hygiene, caregiving at home and at the canteen. The social work team was instrumental in explaining and dialoguing with the patients and caregivers to implement these guidelines and understanding any barriers they faced.

The kinds of support provided to patients and families are outlined in Table 1. This support included:

Counselling patients on the disease progression

The social work team members are generally used to breaking news face to face. However in these circumstances as it was not possible, counselling had to be done over the phone. Example: patient A was aware about the diagnosis but was unaware about the progression and prognosis. Due to lockdown it was difficult to reach CPC. The patient was very anxious about the symptoms related to disease progression and complained that the pain was also very severe. The social worker intervened and

with a regular calls tried to relieve her anxiety. For individual counselling initially the family was not comfortable but with regular intervention the social worker convinced them about the need of counselling and making the patient aware about her progression. The family agreed and the social worker spoke to the patient reported feeling less anxious. Later the family also supported the patient by talking to her about the prognosis.

End of life wishes

A key task for the palliative social work team is to assist in helping patients identify their wishes in their final months to help improve their quality of life. This was hampered due to the lockdown situation. For example: one patient at the end of life care wished to meet her children. Due to lockdown it was difficult for CPC to allow children to enter in premises. Also, the children were facing difficulties to reach centre as they were unable to obtain an e pass. Initially the social worker intervened to do the video call with the children, but that didn't suffice the purpose and patient was not happy with the call. She continuously emphasized on meeting them physically and talking to them face to face. With the advice of the multidisciplinary team, the social workers could take the decision to call the children to the Centre. With all the precautions (wearing PPE kit) we took the patient at the gate and the meeting happened with the patient and their children. It was very emotional moment for all those who were present there. She was very satisfied after meeting her children and passed away peacefully after 2 days at the centre.

Nongovernmental organization networking

The task of nongovernmental organization (NGO) networking was intensified during the COVID period as several NGOs were not operational themselves. The social work team therefore had to identify these NGOs that were able to support patients at this time. For example, one patient who was not from Pune and had visited CPC for palliative care service faced financial issues and was not able to meet basic needs. CPC networked with few organisations and provided the patient with grocery and financial support. Also, they were provided with medical essentials from NGO as well as CPC.

Connect with local general practitioner

The social work team realised the importance of having a strong network of general practitioners (GPs) who were locally available to patients in any emergency situation. For example, a patient who wished to spend his last days with his family had to travel to his home town. There the GP was not so convinced about the need to visit the patient. The family was therefore not sure of getting the death certificate if the patient passed away at home. CPC team, after several calls with the concerned GP could convince him to visit the patient if required, bringing much reassurance to the caregiver and the patient. In another case, the social work team actively followed up with the GP to visit the home of a patient who had died to give the family a death certificate.

In summary, the specific nature of support provided by the social work included:

Support to patients and caregivers who were staying at the in-patient facility of CPC

One-on-one sessions with patients helped them to vent out their feelings and helped in releasing their stress. Sessions and activities helped caregivers to be motivated and support patient with intense care. These sessions included group activities maintaining social distancing but involved communication and aimed to leave the caregiver feeling energised and relaxed.

Support to patients and caregivers who were being discharged from the Centre to go back home

The CPC team was continuously engaged in coordinating services for patients who wanted to go back home. This included arranging ambulance services, arranging for rations to start off the family provisions when they get back home and preparing both the patient and caregiver for care at home. The social work team called families once they reached back home to follow up on any of their concerns.

Support to patients and caregivers who were at home

Coordinating and liaising with different organisation focused on providing basic needs like grocery and financial help to patients. This resulted in building the confidence among patients and caregivers and the feeling of being supported. Additional support included coordinating with relatives to support during last rituals and arranging transport for family to come to take medicine.

Also support in getting e-pass from the police. Continuous follow up during end of life care and bereavement support helped caregivers to grieve. Home care visits helped in wound management and resulted in managing the smell which had hampered the comfort of family members staying with patient.

The social work team received positive feedback from several of these families through their verbal and written feedback. The key aspects in this feedback to the team was that they felt the CPC team had helped them cope better in this crisis situation; helping fulfill last wishes; making them feel less alone and giving them hope making it possible to cope with the situation.

DISCUSSION

This analysis highlights the additional stress and challenges faced by patients and families who are receiving palliative care. This group is generally most neglected during a crisis situation as their needs are considered low priority.^[5] However the stress and challenges shared by patients and caregivers reveal how the lack of services to this group impacts their physical, social and emotional health.^[6] It demonstrates that in the absence of any services for palliative care during a crisis, patient and caregiver needs would go unaddressed-leaving patients in pain and caregivers in guilt, affecting their grieving process significantly.

The social work team at CPC has also reflected on the importance of keeping in contact with families and patients

over the telephone, to be available for them, listen to their worries and plan together with them to reduce their suffering.^[7] The team learnt that it is essential to strengthen the networking among different palliative care organizations as well as with local GPs, so that patients on palliative care can access services more locally. Bereavement support should also be strengthened in such lockdown situation. In addition, a group of volunteers should be trained to support the families who face the problem conducting the last rituals for the patient.

CONCLUSION

A crisis situation such as the COVID pandemic has illustrated the scope of palliative care services to integrate the physical, emotional, and social aspects of care and highlighted the importance of the interrelationship of all these dimensions. As we slowly will move back to new normalcy in life, it would be important to ensure that we continue to focus on identifying and responding to patients on palliative care who are struggling to meet their basic needs; ensure our plans of care for patients and families are designed based on their inputs and suggestions; and that continue to offer regular

telephonic support in addition to face-to-face support to patients and families.

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Conflicts of interest

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