ScientificScholar®
Knowledge is power
Publisher of Scientific Journals

https://ijmsweb.com

Indian Journal of Medical Sciences

Narrative Review

Adaptations to palliative home care in India in a COVID pandemic: An experiential narrative

Sunil Rameshchandra Dhiliwal[1], Ashish Gulia[2], Naveen Salins[3]

[1]Department of Palliative Medicine, ACI-Cumballa Hill Hospital, [2]Department of Bone and Soft Tissue, Tata Memorial Hospital, Mumbai, Maharashtra, [3]Department of Palliative Medicine and Supportive Care, Kasturba Medical College, Manipal Academy of Higher Education, Manipal, Karnataka, India.

***Corresponding author:**
Sunil Rameshchandra Dhiliwal, Department of Palliative Medicine, ACI-Cumballa Hill Hospital, Mumbai, Maharashtra, India.

dr.sunil.dhiliwal@gmail.com

Received : 05 January 2021
Accepted : 04 February 2021
Published : 29 May 2021

DOI
10.25259/IJMS_13_2021

Quick Response Code:

ABSTRACT

India is in the midst of a fierce pandemic with a rapid surge of cases and the health-care system in a quandary. Care of patients with life-limiting illness needing palliative care has been compromised due to limitations in palliative care access and a paradigm shift in the hospital toward care of COVID. Therefore, it is imperative to augment the home-based services so that patients continue to remain at home with their care needs met so that their access to hospitals is restricted for acute and complex needs. To overcome practical aspects of home-based care service delivery, several adaptations were needed. An urban standalone home-based palliative care service provider made adaptations to personal protection, personal protection equipment, and team self-care that facilitated an effective service delivery and satisfaction.

Keywords: Palliative, Home care, COVID-19, Pandemic, Life-limiting illness needing palliative care

INTRODUCTION

On March 11, 2020, the COVID reached the epidemiological criteria to be declared as a pandemic.[1] Since then there is a rapid surge of COVID cases in India, and in early September, there were more than 4 million cases and 70,000 deaths. Patients with cancer and end-stage organ impairment are more susceptible to COVID infections.[2] In India, cancer treatment guidelines were adapted to the COVID situation,[3] supra-major surgeries were avoided and cancer-directed treatment in a metastatic setting was limited or stopped.[4] Moreover, palliative care in these patients is significantly compromised due to challenges in palliative care access and delivery.[5] Flexibility and ability to adapt to a crisis situation is a fundamental attribute of dealing with a pandemic and home care is not an exception.[6] These adaptations to palliative care was quintessential to ensure comfort of these vulnerable population.[7] Moreover, these adaptations were based on sound ethical principles.[8]

Elderly and frail at home were hard hit due to pandemic as they experienced significant access issues both in person and virtually.[9] Palliative care services in the community were further constrained due to lack of Personal Protective Equipment (PPE), poor understanding of rapidly changing COVID guidance, and anxiety associated with the risk of contracting the infection.[10] Moreover, patients with poor performance status and disability were made more vulnerable due to limitation of access.[11] They were more at risk of an adverse outcomes and increased mortality.[12] Home care and ambulatory clinics can facilitate reduction of unwanted patient movement and decreases hospital resource utilization in a pandemic situation.[13]

Telemedicine is proposed as an alternative to home visits in a palliative care setting.[14,15] However, it may not be able to provide a comprehensive care in presence of acute needs or end of life setting.[16] Therefore, it is paramount to maintain the continuity of care for patients needing palliative care and at the same time adapt to the requirements with infection control measures as the highest priority.[17] In this article, a narrative account of the adaptations made to palliative home care by a standalone urban home care service in India is discussed.

EXPERIENTIAL NARRATIVE OF ADAPTATIONS TO PALLIATIVE HOME CARE

The extremely restrictive lockdown measures imposed by the government following WHO declaration of pandemic was a nightmare to the already distressed and vulnerable patients and their families accessing palliative care. Our service was used to a particular style of home care delivery and we were least prepared to the suddenness and a rapidly evolving health scenarios, curfew on people movement, chaos, and stigmatization of illness. We did not comprehend the seriousness until we started to get flurry of panic telephone calls from patients and their families. Patients were running out of their medications, family physicians stopped consulting, and the local hospitals became hyper selective in choosing their patients. Majority of patients with cancer had their cancer treatment interrupted and those on palliative intent chemotherapy stopped receiving any treatment. Although our home care team was equally petrified and clueless on how to respond to this volatile health situation, I think our resolve and resilience inspired and reminded us our duty to provide.

Our palliative home care service is situated in a busy metropolitan city of Mumbai, India. It is a standalone urban service by a group of motivated family physicians with generalist palliative care training. It is a multi-disciplinary team with a diverse network of health-care professionals providing a holistic care. It liaises with the specialist hospital-based palliative care services for complex needs and in-patient admissions.

Between April and July 2020, we conducted 1128 palliative home visits. One-third of them required only nursing services and others required a combination of medical, nursing, and physiotherapy services. Around 500 procedures were done at home, with varying degrees of complexities such as pleurocentesis, paracentesis, nasogastric tube placement, urinary catheterization, wound dressing, and others. Moreover, an important responsibility of the team was to ensure uninterrupted access of essential symptom control medications at home. The silver lining in this daunting experience was that none of the health-care providers in the team got infected with COVID.

The team faced multitude of challenges during this process. However, this crisis provided us with a unique opportunity to find novel solutions that could have a long-lasting impact on our team practice. We have discussed some of our challenges and adaptations below.

Using a standard, PPE for every visit for each patient presents with a significant cost. These are not provided free by the Government at a community setting for home-based care. Donning and doffing PPEs at each home is time consuming and limits the number of patients consulted at home. Moreover, wearing a PPE has a stigmatization effect in a housing complex with a close neighborhood. Therefore, we had to make certain adaptations. We used a light-weight full-sleeve transparent raincoat with trousers, which was easy to don and doff, reusable and sanitized. Moreover, it eliminated the stigma and mitigated the PPE disposal problems.

Access to genuine N95 masks were challenging due to the high demands, and it became prohibitively expensive. The team was very mindful of transferability of these costs to the patients. Therefore, the team did a bulk purchase from the company and had a strategy for a safe reuse of the masks. The prolonged usage of traditional powdered latex gloves used to cause skin reactions in the form of pigmentation and pruritus. Similar issues were seen with prolonged use of hand sanitizer. Therefore, a non-powdered nitryl gloves with a disposable plastic gloves mitigated these issues. Adaptations made with both masks and gloves had a significant cost-saving benefit during a private home care consultation.

Due to barricading during the lockdown, accessing patient home with a home care car was becoming increasingly challenging. Moreover, the health-care providers had to travel long distances from the barricade point to homes carrying the home care bag and kit. Therefore, the team decide to use bikes fitted with essential service boards that facilitated easier navigation and increased the number of overall consultations completed in a day.

The team had challenges in accessing water and food during the community visits as shops and hotels were shut due to restrictive measures. Moreover, eating at others home or at a joint meant breach of PPE placing the healthcare worker in jeopardy. Therefore, a smart food boxes were prepared that had a readily edible safe high calorie diet and juices that can be consumed in few minutes. The team also received self-care kits that comprised of immune booster vitamins and sanitization needs. These strategies enhanced the satisfaction of clients receiving the home care and the team providing it.

The challenges faced and mitigation strategies deployed enabled us to reflect on our pre-COVID era practices and we feel that there was a great deal of learning from these experiences. It helped us to reflect on our infection control practices, use of technology in care delivery, cost effectiveness

of the intervention, staff management in a crisis, and optimal utilization of resources. These adaptations might have a long-term impact on our practices beyond the COVID-era.

DISCUSSION

Palliative care providers in a pandemic have a huge responsibility of maintaining continuity of care by rapidly and flexibly responding to the palliative care needs in the community, training non-specialists, deploying volunteers to provide psychosocial and bereavement care, and using technology to communicate with patients and carers.[18] In a pandemic situation, it is not possible for the hospitals to sustain a rapid surge of patients arriving to the emergency room or need for hospitalization.[19] Therefore, it is imperative to provide majority of care for patients needing palliative care at home and triage a select few to the hospital.[20] Providing a home-based care to around 1000 patients in a city of 20 million population might be an inadequate response. However, the model demonstrated by a small urban home care service can set an example for replication and scaling in a manifold magnitude by the Government and bigger health-care players.

Adaptation is a new vogue term in this pandemic. Everyone and everything in the health and non-health-care sector is rapidly and continually adapting to the new reality, which is fast becoming a new normal. There are numerous guidelines for clinical service adaptations by various specialty professional bodies and similar recommendations are made for palliative care practice in India by the Indian Association of Palliative Care.[21] However, majority of these recommendations pertained to clinical aspects of patient management, especially in a hospital setting. Recommendations or adaptations to address practical challenges in community palliative care delivery are seldom addressed, especially in the Indian sociocultural context. Therefore, a narrative account like these could provide an impetus to explore this gap in knowledge through a larger prospective research.

CONCLUSION

Provision of home-based palliative care was fronted with unique service delivery challenges due to pandemic situation and restrictive governmental measures. To facilitate continuity of care in the community, practical service adaptation strategies relating to personal protection, personal protection equipment, travel logistics, and self-care were deployed. These unique adaptations facilitated an effective delivery of palliative home care service that enhanced both client and health-care provider satisfaction.

Declaration of patient consent

Patient's consent not required as patients identity is not disclosed or compromised.

Financial support and sponsorship

Nil.

Conflicts of interest

Dr Ashish Gulia is the editor of this journal.

REFERENCES

1. Cucinotta D, Vanelli M. WHO declares COVID-19 a pandemic. Acta Biomed 2020;91:157-60.
2. Liang W, Guan W, Chen R, Wang W, Li J, Xu K, *et al*. Cancer patients in SARS-CoV-2 infection: A nationwide analysis in China. Lancet Oncol 2020;21:335-7.
3. Gulia A, Arora RS, Panda PK, Raja A, Tiwari A, Bakhshi S, *et al*. Adapting management of sarcomas in COVID-19: An evidence-based review. Indian J Orthop 2020;2020:1-13.
4. Gulia A, Tiwari A, Arora RS, Gupta S, Raja A. Sarcoma care practice in India during COVID pandemic: A nationwide survey. Indian J Orthop 2020;54 Suppl 2:1-8.
5. Singhai P, Rao KS, Rao SR, Salins N. Palliative care for advanced cancer patients in the COVID-19 pandemic: Challenges and adaptations. Cancer Res Stat Treatment 2020;3:127.
6. Porzio G, Aielli F, Verna L, Aloisi P, Guadalupi F, Cannita K, *et al*. Home care for cancer patients after an earthquake: The experience of the "L'Aquila per la Vita" Home Care Unit. J Pain Symptom Manag 2011;42:e1-4.
7. Rao KS, Singhai P, Salins N, Rao SR. The pathway to comfort: Role of palliative care for serious COVID-19 illness. Indian J Med Sci 2020;72:95.
8. Gulia A, Salins N. Ethics-based decision-making in a COVID-19 pandemic crisis. Indian J Med Sci 2020;72:39-40.
9. Kunz R, Minder M. COVID-19 pandemic: Palliative care for elderly and frail patients at home and in residential and nursing homes. Swiss Med Wkly 2020;150:w20235.
10. Costantini M, Sleeman KE, Peruselli C, Higginson IJ. Response and role of palliative care during the COVID-19 pandemic: A national telephone survey of hospices in Italy. Palliat Med 2020;2020:269216320920780.
11. Tseng TG, Wu HL, Ku HC, Tai CJ. The impact of the COVID-19 pandemic on disabled and hospice home care patients. J Gerontol A Biol Sci Med Sci 2020;75:e128-9.
12. Fallon A, Dukelow T, Kennelly SP, O'Neill D. COVID-19 in nursing homes. QJM 2020;113:391-2.
13. Naco M, Ciocca A, Giupponi A, Brambillasca P, Lussana F, Pisano M, *et al*. At the epicenter of the COVID-19 pandemic and humanitarian crises in Italy: Changing perspectives on preparation and mitigation. NEJM Catal Innov Care Deliv 2020. doi: 10.1056/CAT.20.0080.
14. Funderskov KF, Danbjørg DB, Jess M, Munk L, Zwisler AD, Dieperink KB. Telemedicine in specialised palliative care: Healthcare professionals' and their perspectives on video consultations a qualitative study. J Clin Nurs 2019;28:3966-76.
15. Funderskov KF, Raunkiær M, Danbjørg DB, Zwisler AD, Munk L, Jess M, *et al*. Experiences with video consultations in specialized palliative home-care: Qualitative study of patient and relative perspectives. J Med Intern Res 2019;21:e10208.

16. Ritchey KC, Foy A, McArdel E, Gruenewald DA. Reinventing palliative care delivery in the Era of COVID-19: How telemedicine can support end of life care. Am J Hosp Palliat Med 2020;37:992-7.
17. Porzio G, Cortellini A, Bruera E, Verna L, Ravoni G, Peris F, *et al*. Home care for cancer patients during COVID-19 pandemic: the "double triage" protocol. J Pain Symptom Manage 2020;60:e5-7.
18. Etkind SN, Bone AE, Lovell N, Cripps RL, Harding R, Higginson IJ, *et al*. The role and response of palliative care and hospice services in epidemics and pandemics: A rapid review to inform practice during the COVID-19 pandemic. J Pain Symptom Manage 2020;60:e31-40.
19. Arya A, Buchman S, Gagnon B, Downar J. Pandemic palliative care: Beyond ventilators and saving lives. CMAJ 2020;192:E400-4.
20. Sharma R. Providing palliative home care during COVID-19 pandemic lockdown in India. Indian J Palliat Care 2020;26:56.
21. Damani A, Ghoshal A, Rao K, Singhai P, Rayala S, Rao S, *et al*. Palliative care in coronavirus disease 2019 pandemic: Position statement of the Indian association of palliative care. Indian J Palliat Care 2020;26:3.

How to cite this article: Dhiliwal SR, Gulia A, Salins N. Adaptations to palliative home care in India in a COVID pandemic: An experiential narrative. Indian J Med Sci 2021;73(1):48-51.

NEWS

44th ICON Virtual Conference

5-6th, 12-13th, 19-20th June 2021

Organized by Mumbai Oncocare Centers

Dr Ashish Joshi Program Director Dr Kshitij Joshi	Dr Vashishth Maniar Program Director Dr Pritam Kalaskar
Org Secretary	Org Secretary
96876-19991	drkshitijjoshi@mocindia.co.in

Conference Managers : Kavina Creations

iconconferences@gmail.com 9819025850