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Original Article

COVID-19 Palliative and End-of-Life Care Plan: Development and Audit of Outcomes

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ABSTRACT

Objectives: Palliative care (PC) referral in serious and critical COVID-19 improves decision-making, health resource utilisation, end-of-life symptom management and family support. In this study, we explored developing a systematic decision-making matrix for PC referral in COVID-19 and audited its outcomes.

Materials and Methods: A team of interdisciplinary experts developed a hospital COVID-19 PC plan. PC referral and outcomes of PC referral in hospitalised COVID-19 patients were audited.

Results: Out of 1575 inpatients, 1066 (67.7%) had mild and 509 (32.3%) had serious and critical COVID-19 illness. Among 50 (3.1%) referred to PC, 5 (0.4%) had mild and 45 (8.8%) had serious and critical COVID-19 illness. Out of 45 serious and critical COVID-19 patients referred to PC, 38 (84%) received end-of-life care (EOLC), 4 (9%) self-discharged against medical advice and 3 (7%) recovered. Forty-seven (94%) were referred for goals-of-care discussion. About 78% received opioids, 70% benzodiazepines and 42% haloperidol for symptom management. Among 45 serious and critical COVID-19 patients referred to PC, foregoing life-sustaining treatment was documented in 43 (96%) but implemented only in 23 (53%). Out of 38 who received EOLC, ICU was the place of death in 31 (82%) and ward in 7 (18%).

Conclusion: Despite interdisciplinary experts developing a hospital COVID-19 PC, low referral of serious and critical COVID-19 patients to PC was observed. PC referral enabled access to management of end-of-life symptoms and facilitated limitation of life-sustaining treatment in some COVID-19 patients with serious illness. Educating critical care physicians about the scope of PC in the COVID-19 setting might improve PC referral.

Keywords: COVID-19, End-of-life care, Palliative care, Referral, Serious and critical COVID-19 illness

What was already known?

• Integration of critical care and palliative care (PC) during humanitarian crisis alleviates serious health-related suffering of patients and their families

What were the new findings?

- PC referral enabled access to the management of end-of-life symptoms and facilitated limitation of life-sustaining treatment in some patients with serious and critical COVID-19 illness.
- However, discussing limitation of treatment was challenging considering the reversible nature of the illness leading to low referral rates.

What was their significance?

- PC services in acute illness are often under-utilized even where such services are fully available
- There is a need to educate critical care physicians regarding scope of PC in serious and critical COVID-19 illness.

INTRODUCTION

The COVID-19 pandemic has resulted in a global humanitarian crisis and has resulted in unprecedented damage to human lives and the world economy.^[1] The average

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global case fatality rate is 2.5%.^[2-4] About 5–15% of them need intensive care unit (ICU) care, and 2.3% require mechanical ventilation.^[5] Healthcare systems have struggled to cope with the rising number of seriously ill COVID-19 patients, and India was no exception. India has 2.3 critical care beds per 100,000 population, of which <50% are equipped with ventilators.^[6] Most of these ICU beds are inequitably concentrated in few parts of the country.^[7] The rising demand for ICU beds exceeding supply, prompted triaging, rationing and allocating beds to those with a possible chance of survival.^[8] For those not eligible or not responding to the intensive care therapy, palliative care (PC) might offer the much-needed succour. Therefore, a multifaceted PC strategy incorporated into the pandemic response becomes an ethical and moral responsibility of every healthcare system.^[9]

A higher COVID-19-associated morbidity and mortality was observed in the elderly and those with multiple comorbidities.^[4] Among those needing mechanical ventilation, the mortality rate was as high as 86%.^[10,11] The rapid deterioration in this cohort provided little time for decision-making.^[12] Excessive focus on illness management impeded effective communication between patients, family caregivers and healthcare providers.^[12] Isolation during end-of-life increased patient as well as caregiver distress.^[13] Therefore, a prompt assessment and management of physical and psycho-socio-spiritual issues were imperative to ensure optimal comfort to the patient and their families.^[14] Incorporating a multifaceted strategy for integrating PC into acute care facilitated better symptom management, goals of care discussions and emotional support.^[15] More than 50% of patients admitted to our hospital needed ICU care. Rising demand for ICU beds and poor ICU outcomes in serious COVID-19 patients prompted the clinical and administrative stakeholders to pursue PC for these patients. We adopted a proactive ICU-PC approach and created a COVID-19 palliative and end-of-life care plan (COPE-CP). The aim of this paper is to discuss the development of the COPE-CP and audit the outcomes of PC referral during the first wave of COVID-19 pandemic.

MATERIALS AND METHODS

Phase 1: Development of the COPE-CP

The hospital formed a focus group to explore PC provision in serious and critical COVID-19 patients. All patients with dyspnoea, hypoxia or over 50% lung involvement on imaging were considered to have severe disease, and those with respiratory failure, shock and multiorgan dysfunction were considered to have critical disease. The focus group had representatives from critical care, emergency medicine, internal medicine, infectious disease and PC.

The focus group conducted a rapid review of the literature examining PC provision internationally in people with serious COVID-19. The review findings showed that COVID-19 PC response internationally focused on (a) infrastructure and

capacity to provide PC in a critical care setting,^[16] (b) a triage system for early identification of those patients needing PC,^[17] (c) effective symptom management protocols for dyspnoea, anxiety, delirium and others,^[14,18] (d) communication framework to enable shared decision-making,^[19] (e) psychosocio-spiritual support to the patients and their families,^[12] (f) hospital end-of-life-care policy^[15] and (g) grief and bereavement support services for the families,^[12,18]

The findings of the rapid review informed the development of the initial construct of COPE-CP. It consisted of (a) a screening checklist for early identification of the PC patients in the ICU, (b) a checklist for referral to PC and (c) a PC provision checklist that comprised symptom management algorithms, a framework for recognising and communicating a medically futile situation and documentation and implementation of forgoing life-sustaining treatment (FLST), psycho-sociospiritual support, after death care and bereavement support.

Developing a screening checklist for PC referral in the ICU

[Table 1] provides the screening checklist for PC referral. The screening checklist included triggers for early PC referral in a critical care setting. It was adapted from the published national and international expert recommendations and findings of the rapid review. The triggers were adapted to meet the local exigencies and guided by the ethical principles of justice, beneficence and equity.^[20] Although elderly patients are at high risk for serious COVID-19 illness,^[21] aging is a heterogeneous process. Triaging based on age alone is not ethically justifiable. We incorporated frailty as assessed by Clinical Frailty Score with a cutoff score of \geq 7 (severely frail) and presence of comorbidities as indicators of poor outcome and mortality along with age.^[22,23] In addition to the above three criteria, either physiological scores like the sequential organ failure assessment score of ≥13 or physician prediction of poor outcome were additional indicators required for referral to PC.[24] Higher mortalities have been recorded in patients with end-stage organ impairment and advanced malignancy, and these were included as independent indicators for PC referral.^[25] The criteria for end-stage organ impairment were adapted from the specific clinical indicators for the advanced disease of the Gold Standards Framework for palliative and end-of-life care (EOLC).^[26] The checklist enabled the ICU physicians to identify patients who would benefit from PC and aided the decision-making for PC referral.

Developing a PC referral checklist

Checklist for initiating PC referral is provided in [Table 2]. In crisis situations, fragmented information sharing through incomplete documentation and asynchronous communication practices during transitions of care impact patient safety and quality of care.^[27,28] Seamless interaction through a continuous joint collaboration between healthcare teams is essential for quality care.^[28] To ensure appropriate and complete transfer of information, we initiated a process of written documentation of clinical consensus regarding

Table 1: Screening checklist for PC referral.				
Name: Hospital Number:		Date: Time:		
Item	Criteria	Present		
1	Age≥65			
2	Clinical frailty scale score≥7 (Appendix 1)			
3	One or more comorbidities			
4	Expected to need ventilator support with physician prediction of low probability of meaningful survival			
5	Sequential organ failure assessment score≥13 (Appendix 1)			
6	End-stage organ impairment			
7	(Appendix 1) Malignancy			
	OR			
	Recurrence/relapsed haematological malignancy			
	AND Palliative intent cancer-directed therapy OR			
	Not on any disease-directed therapy			
	Criteria for PC referral	PC referral initiated		
А	Item 1+Item 2+Item 3+Item 4			
В	Item 1+Item 2+Item 3+Item 5			
С	Item 6			
D	Item 7			
Signatur Name: Seal:	re of the treating physician:			
PC: Pall	iative care			

prognosis and care plans. In addition, we conducted meetings between PC physicians and the ICU physicians telephonically every day to discuss the referrals. We discussed expected

every day to discuss the referrals. We discussed expected clinical trajectory, anticipated treatment outcomes, clarity of goals and congruence of goals. This collaborative decisionmaking ensured that all ICU and PC teams were aligned to the prognosis and treatment goals. ICU physicians were encouraged to document futility for patients nearing the end of life. It was followed by family meetings, which were conducted jointly by the ICU and the PC team. It facilitated early and effective goals of care discussions.

Lack of policies, legal and legislative clarity and ambiguities in terminology and social acceptance complicate the process of limiting treatment at end of life in India.^[29] However, our hospital is one among the few centres in India with an EOLC policy termed BLUE MAPLE[•]. It follows a 4-step process:

1. Endorsement of futility by two treating consultants

Table 2: Referral checklist for PC.				
Name: Hospital No:		Date: Time:		
S. No.	Criteria	Present		
1.	Patient meets criteria for severe COVID-19 illness.			
2.	Patient meets criteria either A, B, C or D in the COVID-19 PC screening checklist for PC			
3.	referral (Appendix 1) There is consensus among the treating team about the clinical futility, discontinuation/			
4.	non-escalation of medical interventions Endorsement of medical futility by the treating teams			
5.	Communication with the family			
6.	PC referral initiated			
Signatur Name: Seal:	e of the treating physician:			
PC: Palli	ative care			

- 2. Medical Futility Discussion with patients and their families
- 3. Documenting patient and family directives regarding limiting treatment
- 4. Ratification of the decision to limit treatment by three members of the End-of-Life Care Review Team.

The procedural guidelines as outlined in the BLUE MAPLE policy were followed while providing EOLC.

Developing a checklist for PC providers

The checklist followed by the PC team during referral from ICU is provided in [Table 3].

It enabled the PC team to implement the COPE-Care Plan. Patients triaged for EOLC were either transferred to the sevenbedded COVID-19 PC ward when expected survival was days to weeks or managed in the ICU if they were imminently dying. As families could not be at the patient bedside during the final hours, we established a pathway for communication between patient and families through videoconferencing, where the families could see and converse with their loved ones. They were also given twice-daily updates telephonically. Besides, families were screened for complicated grief, spiritual and existential distress and emotional trauma. Palliative medicine team provided grief counselling and psychosocial support telephonically, and referrals to mental health professionals were initiated when indicated. After death care protocols were explained to the family, and they were provided with information regarding funeral preparations based on their religious affiliation. All patients referred to PC received bereavement calls within 2-4 weeks of the death of their loved ones. The palliative medicine team conducted consults through videoconferencing to minimise breach in infection control measures and to preserve scarce resources like personal protective equipment.

Developing a consensus on COPE-CP

Given the lack of country-specific guidelines for incorporating PC in serious COVID-19 pandemic response, we adopted a three-step modified Delphi technique to obtain a consensus around the domains included in the COPE-CP.^[30] The statements for the first round of Delphi were developed from the existing literature and modified by inputs from a team of PC experts. The constructs of the care plan went through a continuous iterative process of modification based on information provided

Table 3: Checklist for PC providers.				
Name: Hospital No:		Date: Time:		
S. No.	Criteria			
1.	Endorsement of futility form completed by treating team			
2.	Family meeting was conducted			
3.	Documentation of futility discussions during family meeting (Hierarchy of surrogate decision-making – spouse, adult children, parents, siblings and for children both parents			
	have to decide)			
4.	Documentation for limiting treatment at end of life			
5.	Ratification of the decision to limit treatment at end of life is completed			
6.	Family decision conveyed to the treating team (Document name of the liaicon physician)			
7.	Anticipatory prescription for symptom			
8.	Comfort measures initiated (stop unnecessary			
9.	investigations, decrease monitoring of vitals) Pathway for patient-caregiver interaction			
10.	initiated (telephone/video conference) Shifting patient to COVID-19 PC ward			
	initiated when expected survival is days to weeks.			
	Continue care in ICU if imminently dying			
11.	Hourly monitoring of symptoms for titrating of medications			
12.	Pathway for twice-daily updates to family initiated			
13.	After death care procedures explained			
14.	Date of death documented in palliative medicine database			
15.	Bereavement call after 2 weeks by the palliative medicine team			
Signature Name: Seal:	e of PC physician:			
PC: Pallia	ative care			

by the expert panel until expert group consensus was obtained. This process took place between April and July 2020 and consisted of two rounds of email questionnaire and one round of teleconference through Microsoft team's proprietary business communication platform. The final expert interaction enabled clarification of individual viewpoints and aided the development of the clinical pathway. The expert panel consisted of 16 members and included stakeholders from the department of critical care medicine, emergency medicine, general medicine, infectious diseases, palliative medicine, hospital administration and hospital clinical ethics committee members. The final COPE-CP is illustrated in [Figure 1].

Phase 2: Audit of COPE-CP outcomes

A retrospective cohort analysis of inpatients with COVID-19 referred to a specialist PC unit (SPCU) from 1 April 2020, to 31 October 2020 was conducted. The medical records of inpatients over 18 years, with a confirmed COVID-19 status through reverse transcription-polymerase chain reaction (RT-PCR) nasopharyngeal swab and referred to the SPCU were audited. This study was conducted in a university teaching hospital in India, which served as a designated COVID-19 referral centre during the pandemic. The data from the medical case records were extracted into a pre-designed pro forma. Data were extracted from the hospital electronic medical records and physical records after ethics approval. All direct identifiers were removed, and the data were anonymised. The study was approved by the Institutional Ethics Committee of Kasturba Medical College and Kasturba Hospital (IEC: 678/2020) and it was registered with the Clinical Trials Registry of India (CTRI/2020/11/029398).

RESULTS

The demographics, illness variables and outcomes of COVID-19 PC cohort are outlined in [Table 4].

Out of 1575 inpatients, 1066 (67.7%) had mild to moderate and 509 (32.3%) had serious and critical COVID-19 illness. Fifty (3.1%) were referred to PC, 5 (0.4%) had mild and 45 (8.8%) serious and critical COVID-19 illness. All patients with mild COVID-19 illness recovered. Among 45 serious and critical COVID-19 illness referred to PC, 38 (84%) received EOLC, 4 (9%) self-discharged against medical advice and 3 (7%) recovered.

Among 50 patients referred to PC, 32 (64%) were men. The median age of those referred was 68 (interquartile range [IQR] 65–73). The median age of women was higher than men, at 74 years. The cost of hospital admission and treatment was borne by the government insurance schemes in 72%, 16% had private insurance, while 12% paid out of pocket.

Forty-two patients (84%) had ≥ 2 comorbidities, with an average of 3 (range 1–6) comorbidities. The common comorbidities were type 2 diabetes mellitus (54%), hypertension (64%) and ischaemic heart disease (48%).

Forty-five patients (90%) referred to PC had severe to critical COVID-19 illness. Thirty-five had critical



Figure 1: COVID-19 palliative and end-of-life care plan.

COVID-19 illness (respiratory failure, septic shock and/ or multiple organ dysfunction), 10 had severe COVID-19 illness (dyspnoea, respiratory frequency \geq 30/min, blood oxygen saturation \leq 93% and/or lung infiltrates >50% of the lung field within 24–48 h) and 5 (10%) of the PC referrals had mild disease (non-pneumonia).^[31] All the mild COVID-19 illness patients were the elderly with multiple comorbidities. These were anticipatory referrals and all of them recovered.

All 50 patients had received COVID-19-specific management in the form of intravenous steroid, anticoagulation therapy and remdesivir before PC referral. Forty-nine patients (98%) were on IV antibiotics, 28 patients (56%) were on invasive mechanical ventilation, 14 patients (28%) on non-invasive ventilation and 5 patients (10%) on high-flow nasal cannula. Thirteen patients (26%) were receiving dialysis, while 30 patients (60%) were on multiple inotropes.

The most common reason documented for referral was for goals of care conversation (GoC) 47 (94%), with 3 (7%)

S. No.		COVID-19 PC cohort 2020
1.	Total number of patients referred to PC	N=50
2.	Median age in years (IQR)	68 (65-73)
3.	Gender (male: female) (%)	32:18 (64:36)
4.	Comorbidities (%) ≥2	42 (84%)
5.	Severity of COVID-19 (%)	N=50
	Severe and critical COVID-19 illness	45 (90%)
	Mild COVID-19 illness	5 (10%)
6.	Reason for referral	N=50
	Goals of care conversation	47 (94%)
	Symptom management	3 (7%)
7.	Outcomes in patients with serious and	
	critical COVID-19 illness	N=45
	Death	38 (84%)
	Recovered	3 (7%)
	Discharged against medical advice	4 (9%)
8.	FLST (forgoing life-sustaining	
	treatment) in patients with serious and	
	critical COVID-19 illness	N=45
	Documented	43 (96%)
	Not documented	2 (4%)
	Documented and implemented	23 (53%)
	Documented and not implemented	20 (47%)
	FLST (forgoing life-sustaining	
	treatment) in patients with mild	
	COVID-19 illness	N=5
	Documented	2 (40%)
	Not documented	3 (60%)
9.	Place of death in patients with serious	
	and critical COVID-19 illness	N=38
	ICU	31 (82%)
	Ward	7 (18%)

Table 4: Demographics, illness variables and outcomes of

referred specifically for symptom control. Symptom management was initiated in 48 patients (96%). Thirty-nine patients (78%) received opioids, 35 (70%) received a combination of opioid and benzodiazepine for EOLC symptom management and 15 (42.85%) received haloperidol for delirium.

Palliative medicine team conducted family meeting for GoC in all patients. Although foregoing life-sustaining treatment was documented in 43 (96%) patients with serious and critical COVID-19 illness, it was implemented in only 23 (53%). The average number of family meetings conducted per patient was 4 (IQR 3–4).

Of the 45 patients with serious and critical COVID-19 illness referred to PC, 38 patients (84%) died, 3 (7%) patients recovered and were discharged home and families of 4 patients (9%) self-discharged their patients against medical advice. All four discharged against medical advice

had a prolonged ICU stay. Although they had critical illness, they were considered not infective as repeat COVID-19 RT-PCR after 2 weeks of initial COVID-19 test was negative. In 31 patients (82%), ICU was the place of death, while 7 (18%) patients were shifted to the ward before death.

Due to the governmental regulations, families were denied access to be with the patient physically. However, communication channels between patients and their next of kin were kept open through video calls. Psychosocial support was offered to all family members through tele-counselling. Bereavement calls were made to all the family members of the deceased.

DISCUSSION

In 2018, the World Health Organisation, in its policy paper, advocated the integration of critical care and PC into responses to humanitarian emergencies and crises.^[32] Experience with communicable diseases with high rates of mortality such as Ebola and tetanus has demonstrated how PC units, with their collaborative approach and competencies in patient-centred whole-person care, can alleviate the serious health-related suffering of patients and their families.^[33] During the humanitarian crisis precipitated by the COVID-19 pandemic,^[34] the PC team at our hospital expanded their scope beyond cancer and chronic illness.

An integrated approach involves both transfer of patient information and building of relationships across specialties and healthcare systems.^[35] All stakeholders involved in the care of COVID-19 patients were also involved in development and implementation of the COPE-CP. Studies in oncology have shown a collaborative approach, shared responsibility and network extension aid integration.[36] The establishment of an ICU focused subspecialty PC services in our hospital enabled integration of PC into the ICU and emergency medicine department (EMD). The ICU physicians had to ascertain medical futility in an acute illness like COVID-19 with an uncertain trajectory. Moreover, discussing limitation of treatment with the patients and families was challenging considering the reversible nature of COVID-19 illness. It probably led to low referral rates. However, the interdisciplinary team managed patients concurrently, with the majority of the patients receiving COVID-19-specific treatment (100%) along with symptom control (96%).

The hospital has a methodised action plan for EOLC (BLUE MAPLE), with structure and processes in place, since 2019. In 2019 and 2020, our PC team has provided EOLC to over 275 patients in the ICU and EMD. We were able to transfer the learning from this experience into the pandemic response. Evidence indicates that for most of the patient dying in the ICU, symptoms are unrelieved and unaddressed.^[37] This was evident in our study as only three patients were referred to PC for symptom control, while the PC team initiated symptom management in 96% of the patients after the consult.

Over and above the three traditional illness trajectories seen in people with chronic progressive illness, a fourth trajectory proposed by some researchers includes sudden onset of acute illness in individuals leading to death or disability.^[38] Critical and informed decisions regarding care had to be made within a short time. When the deterioration is sudden, the trajectory and treatment uncertain, these conversations can be challenging.^[12] The government disease containment norms prevented bedside visitation, and some family members were either quarantined or unable to travel.^[39] The PC team had to adapt rapidly to the changing needs, using available communication technology to conduct these conversations. In 96% of the patients referred to PC, the team was able to conduct family meetings and document goals of care.

One of the significant outcomes of our study was the documentation of FLST. We were able to successfully implement FLST in 45 (90%) patients referred to PC. However, it was implemented in less than half of the patients. The right to life is a fundamental right ensconced in the Indian Constitution (Article 21) and encompasses the right to die with dignity.^[40] There are provisions in the Indian Law to limit life-sustaining treatment from a terminally or critically ill patient if there is no hope of recovery or cure. However, it is poorly understood and interpreted^[41,42] causing lacklustre implementation of EOLC in India. In our study, PC referral enabled discussion and facilitated implementation of FLST in some patients.

The COPE-CP incorporated the core principles of teambased healthcare. It defined shared goals, providing clarity of roles, fostered mutual trust and established channels for effective communication between the members of interdisciplinary team.^[43] Rotation in PC is part of postgraduate medical and allied health sciences curricula in our institute. The existing training programs were used a portal to disseminate knowledge and training of the COPE-CP among junior doctors. The EOLC policy, awareness and integration of PC into general healthcare and the availability of medications helped us develop and implement the COPE-CP within a short time. The institutional leadership that fully and unequivocally embraced and supported the development and implementation of the COPE-CP was an essential factor in its successful implementation.

Limitations of the study

The data for the study were collected retrospectively from the medical records. Incomplete documentation could have impacted data retrieval. No validated scales were used to define the presence of symptoms or assess their intensity. We did not use any formal outcome measures to measure the impact of EOLC discussions on the quality of life and quality of dying. Additional research is required to understand the PC needs of hospitalised COVID-19 patients and the efficacy of PC interventions. A more extensive study might enable identification of differences in the length of stay in critically ill patients when referred to PC.

Future implications

Despite a hospital COVID-19 PC policy, there were fewer PC referrals. Proactive triaging and identification of critically ill patients for PC might prevent futile interventions. Moreover, there is a need to educate critical care physicians regarding scope of PC in serious and critical COVID-19 illness. Many received CPR despite FLST discussion and document. There is a need for excellent interteam communication to overcome this. Early referral might overcome some of these barriers and give PC team an opportunity to implement good EOLC practices. Further research is needed to understand the barriers and facilitators of COPE-CP implementation in our setting. The learning from this experience has the potential to change policy and practice in our hospital as well as in our country where acceptance and delivery of EOLC are clothed in ambiguity.

CONCLUSION

This study has highlighted development of a PC plan for patients with serious and critical COVID-19 illness. Despite interdisciplinary experts developing a hospital COVID-19 PC, low referral of serious and critical COVID-19 patients to PC was observed. PC referral enabled access to management of end-of-life symptoms and facilitated limitation of lifesustaining treatment in some patients with serious and critical COVID-19 illness. PC services in acute illness are often under-utilised even where such services are fully available.

Ethics approval and consent to participate

The study was approved by the Institutional Ethics Committee of the hospital (IEC: 678/2020) and it was registered with the Clinical Trials Registry of India (CTRI/2020/11/029398). The consent to audit files was obtained from the administration of the hospital.

Authors' Contributions

All authors have contributed toward design, conduct, analysis and manuscript writing.

Data and material availability

The data for this study can be accessed on request through the Research Cell of the hospital.

Declaration of patient consent

Institutional Review Board (IRB) permission obtained for the study.

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

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