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Cross-sectional Study of Palliative Care to Hospitalised Patients with COVID-19

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Abstract

Aims

To describe the characteristics, symptoms and outcomes for patients with COVID-19 referred to a hospital-based specialist palliative care service and to describe communication and visiting practices.

Methods

A descriptive cross-sectional retrospective study, which is a part of the ANTICIPATE study project.

Results

50 patients were referred; 49 included in analysis. 38 patients died. 27 patients were male; median age was 81 years. On referral, median Charlson Comorbidity Index was 6; median Australia-modified Karnofsky Performance Status score was 20%. Median number of days from referral to death was 2. Common baseline symptoms (*n*) were dyspnoea (35), agitation (23), and pain (13). Opioids (100%), benzodiazepines (97.1%) and neuroleptics (61.8%) were most commonly used medications to achieve symptom control. 13/19 patients with serial data had a decrease in Palliative Care Problem Severity Score. 26 patients received a family visit before death; 8 had virtual forms of contact. 9 patients had family present at time of death.

Conclusion

The short interval from referral to Specialist Palliative Care and death indicates the need for prompt service response. Data on visiting highlights challenges of providing psychosocial support.

Introduction

Ireland's preparations for management of COVID-19 began in January 2020 with the activation of the National Public Health Emergency Team for COVID-19. The scale of the challenge was recognised to be unprecedented and necessitated a multi-agency response. Reconfiguration was undertaken across the healthcare system, including our own hospital. Recognising the role of palliative care, the hospital-based specialist palliative care (SPC) team were supported to adopt new ways of working. Team members were trained in use of Personal Protective Equipment (PPE) and additional staff were deployed to the service. While visiting restrictions were introduced, it was agreed that exceptions would be permitted for end-of-life care.

Etkind et al. commented in their review that the provision of holistic care in a pandemic can be compromised.[1] The evidence base which largely guided the response of palliative care at the start of the pandemic amounted to a sparse ten articles. Since then, there has been a proliferation of material, however, observational data on hospital-based SPC provision remains limited.[2-5] Similarly, despite emerging evidence of the impact of visitor restrictions on the experience of loss, the predominant focus of literature has been on residential care settings[6,7] and data on visiting for hospitalised patients is lacking.[8]

In our hospital by end-June, 530 patients received in-patient treatment. This paper presents data on a cross-sectional study of patients who received SPC and reflects the experience of management during the pandemic's first wave.

Our objective was to describe the characteristics, symptoms and outcomes for patients with COVID-19 referred to a hospital-based SPC service and to describe communication and visiting practices.

Methods

The study was set in an urban academic hospital in Ireland which has 580 in-patient beds, serves a local catchment population of 295,000 and provides tertiary and quaternary services.
Ethical approval was granted by the Institutional Review Board, Mater Misericordiae University Hospital, Dublin, Ireland (Ref # 1/378/2141).

This is a retrospective cross-sectional study. It is a part of the ANTICIPATE study which aims to determine characteristics and longer-term outcomes of COVID-19 patients.[8] All patients diagnosed with COVID-19 and referred for SPC consultation between 1st March 2020-30th June 2020 were eligible for inclusion. The number of cases with COVID-19 who were referred determined sample size.

Data on patients were extracted from healthcare records and from the Palliative Care Service Patient Register (which includes data on Palliative Care Outcomes Collaborative measures)[9] . Data extraction between 1st June 2020- 30th July 2020. Extracted data were anonymised and inputted into Microsoft Excel®.

Quantitative data were analysed using descriptive statistics. Data are presented as mean (standard deviation; SD) in case of normally distributed variables and as median (interquartile range= IQR) in case of non-normally distributed variables. Qualitative data were analysed using content analysis.

Results

Population characteristics:

In total, 50 patients were diagnosed with COVID-19 and referred to SPC; 49 were included in analysis as one person died before SPC review.

Over half of the patients were male (n=27) and the population was elderly with a median age of 81 years [73-86]. Median Charlson Comorbidity Index[10] score was 6 [5-8]. The majority lived at home before admission (n=38). Patients had a reduced performance status and were heavily dependent. Median Australia-modified Karnofsky Performance Score (AKPS) was 20 [10-20], and median Resource Utilisation Groups- Activities of Daily Living (RUG-ADL) score was 18 [16-18]. Population characteristics are summarised in Table 1.

Table 1: Baseline participant characteristics.

Baseline characteristic (N=49)	*n* or median [IQR]
Gender	
Female	22
Male	27
Age	81 [73-86]
Ethnicity	
White Irish	48
Any other white background	1
Other	0
Charlson Comorbidity Index	6 [5-8]
Hypertension	23
Congestive heart failure	16
Dementia	15
Chronic pulmonary disease	14
Diabetes	11
Advanced/metastatic cancer	10
Renal failure	10
Stroke/neurological disorder	6
Peripheral vascular disorder	5
Liver disease	3
Usual place of residence	
Home	38
Long term residential care (nursing home)	8
Assisted living	3

Previously seen by specialist palliative care services	
No	40
Yes	9
Place of care on referral to Specialist Palliative Care (SPC)	
Ward	49
High Dependency Unit	0
Intensive Therapy Unit	0
PCOC Phase of illness on first review (N=48)	
Dying	20
Deteriorating	15
Unstable	10
Stable	3
Australia-modified KPS (AKPS)	20 [10-20]
Resource Utilisation Groups – Activities of Daily Living (RUG-ADL)	18 [16-18]
Palliative Care Problem Severity Score (PCPSS)	6.5 [5-9]

Specialist palliative care provision

A median of 11 days [4.5-18] elapsed between admission and referral. Referrals were received for two patients prior to their development of COVID-19; all others were referred to SPC following infection. In-person consultation was provided to 44 patients; four were reviewed remotely and phone call advice was provided for one patient who died before being seen. Referrals were responded to promptly; 44 were seen within 24 hours of referral. A total of 223 consultation visits were made- 124 visits were in-person and 99 were remote. The median number of visits was 3 [1-6]. (Table 2).

Table 2: Specialist palliative care provision.

Specialist palliative care provision (N=48)	*n*
Reason for referral to specialist palliative care	
End of life care	36
Symptom control	8
Care planning	5
Symptoms	
Breathlessness	35
Agitation	23
Pain	13
Airway Secretions	11
Drowsiness	7
Delirium	7
Nausea	6
Fatigue	4
Cough	2

Symptom relieving drugs given by subcutaneous infusion in last 24 hours of life (n=34)	
Two medications:	
Morphine +midazolam	3
Morphine + levomepromazine	1
Fentanyl + midazolam	2
Three medications:	
Morphine + midazolam + buscopan	3
Morphine + midazolam + glycopyrronium	1
Morphine + midazolam + levomepromazine	6
Fentanyl + midazolam + levomepromazine	3
Fentanyl + midazolam + buscopan	1
Fentanyl + midazolam + glycopyrronium	1
Fentanyl + midazolam + cyclizine	1
Alfentanil + midazolam + levomepromazine	1
Four medications:	
Morphine + midazolam + buscopan + levomepromazine	2
Morphine + midazolam + levomepromazine + glycopyrronium	4
Fentanyl + midazolam + buscopan + cyclizine	1
Fentanyl + midazolam + buscopan + levomepromazine	3
Oxycodone + midazolam + cyclizine + haloperidol	1
	1
Outcome	
Death	38
Discharged home	7
Discharged back to team	2
Discharged to rehabilitation service	1
Discharged to hospice	1

Palliative Care Outcomes Collaborative (PCOC) Scores were completed on at least one occasion in 48 patients. 19 patients had serial data collection using proxy reporting of the PCOC measures. The PCOC phase of illness on first review was most commonly recorded as ‘dying’ (n=20); 15 patients were ‘deteriorating’; 10 were ‘unstable’; and only 3 were ‘stable’.

Of the patients referred, 39 (78%) died within the study period. The duration of SPC involvement for those patients who died was short; median number of days was 2 [1-4.5]. There was a longer duration of involvement for patients who survived; median number of days was 15 [6.75-25.5]. The outcomes for the patients who survived were: two improved such that they no longer had SPC needs, resulting in their discharge from SPC review while hospitalised; seven were discharged home; one was transferred to a rehabilitation service, and one was transferred to a hospice.

Patients experienced a range of symptoms, with dyspnoea (n=35), agitation (n=23), pain (n=13) and airway secretions (n=11) most common. Symptom burden was high with a median Palliative Care Problem Severity Score of 6.5 [5-9]. A continuous subcutaneous infusion of medications was required for symptom relief in 34 of the patients who died. The three most commonly used medications used in the subcutaneous infusions were opioids, benzodiazepines and neuroleptics, for 100%, 97.1% and 61.8% of patients, respectively. Doses were low to moderate; the median dose of morphine equivalent infusion in the last day of life was 20mg/24 hours [12-30mg/24 hours].The most commonly used opioid was morphine sulphate (n= 20), although fentanyl/ alfentanil were used in just over one-third of patients because of the presence of renal failure (n= 13). (Table 3)

Table 3: Subcutaneous infusion medications dosage in last 24 hours of life. *

Medication subcutaneous dose mg /24 hours	**Mean**	**Standard Deviation**	**Median**	**Q1**	**Q3**	**IQR**
Morphine equivalent, all doses (n=34)	20.96	9.98	20	11.86	30	18.13
Morphine sulphate (n=20)	17.75	7.37	17.5	10	20	10
Fentanyl (n=12)	520.83	197.33	600	325	675	350
Hyoscine butylbromide (n=10)	100	25.3	120	75	120	45
Glycopyrronium bromide (n=5)	2.16	0.48	2.4	1.8	2.4	0.6
Levomepromazine (n=20)	22.5	15.10	15.63	12.5	25	12.5
Midazolam (n=33)	17.58	12.07	15	10	22.5	12.5
Cyclizine (n=3)	108.33	31.18	100	NA	NA	NA

* Alfentanil (n=1), dose= 3mg SC/24h; oxycodone (n=1) , dose = 10mg SC/24h; haloperidol (n=1), dose = 1mg SC/24h

Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) orders

No advance care plans were in place for any participants prior to contracting COVID-19. A DNACPR order was agreed during hospitalisation for 46 of the 49 patients. The median number of days between admission and instatement was 4 [2-18]. SPC referral most commonly followed agreement of a DNACPR order, and a median of 5 [2-11] days elapsed between instatement of the order and referral. The median number of days between instatement of DNACPR order and death was 11 [4-19 days].

Family visiting and bereavement support

Of the 38 patients who died and were reviewed by SPC, 25 received a family visit prior to death. Visiting was offered to 10 families, who were unable or declined for a variety of reasons. (Table 4).

The median number of days between visit and death was 2 [1-4]. Median number of visits was 2 [1-3]. Visitor identity was documented in 20 out of the 26 patients who received a visit. Only five individuals had visits that included members of their own generation; 15 visits were from members of a younger generation only. The most common reason affecting families where no-one was able to visit was the presence of underlying health conditions (n= 4). At the time of death, nine had family present. After death, 19 had family members visit; while 17 of those families had visited before death, for two of those families this was their first visit.

Virtual video-based contact was facilitated for eight patients who could not manage this independently; recorded voice messages were played for three patients and a phone call was facilitated for two patients who could not manage this independently.

Medical Social Work (MSW) offered bereavement support follow-up to 37 families; one family had declined input prior to death and in accordance with their wishes, they were not contacted. In 36 cases, contact was by phone; in one case it was in the form of a written letter of condolence with bereavement support information provided (Table 4).

Table 4: Family visiting and bereavement support.

Characteristic	n
Reasons for family not visiting prior to death (n=12)	
Own health reasons	4
Fear of COVID-19	2
Experiencing symptoms of COVID-19	1
Status as a COVID-19 contact	1
Patient died before family arrived	1
No immediate family in Ireland	1
No reason documented	2
Bereavement follow up (n=38)	
Phone call not answered, bereavement information posted	4
Phone call answered; required posting of bereavement information only	13
Phone call answered; declined/ did not require posting of bereavement information	6
Phone call answered; practical supports provided and bereavement information posted	5
Phone call answered; additional period of bereavement support (counselling) provided	5
Phone call answered; referral to community bereavement support groups made	2
Written letter of condolence and bereavement support information	1
Family declined Medical Social Worker contact prior to death	1

Discussion

To date, there has been no data published on SPC provision for patients with COVID-19 in Ireland. This study demonstrates effective integration of SPC in our hospital's response. 65 hospitalised patients died as a result of SARS-CoV-2 infection during the first wave, 39 were referred to SPC representing 60% of decedents. SPC input was focused on end-of-life care provision for the majority. However, in one-quarter of cases input was requested for symptom management and care planning illustrating the potential contribution of SPC across the trajectory of serious SARS-CoV-2 illness.

Similar to other observational studies of SPC provision, referrals were for older patients with co-morbidities. All patients received a trial of interventional therapy before referral. The majority of patients were gravely unwell underscoring the need for SPC to be able to respond rapidly to referrals of patients with COVID-19. Although alternatives were used in order to prevent exposure and transmission of virus, in-person consultation was provided for 44 patients. The ability of patients to communicate was impaired and the SPC team experience was that in-person consultation was often needed to accurately assess symptoms and provide psychosocial support.

Symptom burden and management of patients is similar to previous studies.[3,11] A decrease in Palliative Care Problem Severity Score in most patients provides confirmation that symptoms in patients with COVID-19 can be managed with low to moderate doses[12] of opioids and other medications included in the World Health Organization Model List of Essential Medications.[13] Renal failure was present in approximately one-third, and subcutaneous fentanyl or alfentanil were preferentially used for these individuals. This data on medication use and dosage may be used in pandemic planning.

No patient had an advance directive in place, despite the presence of comorbidity. A study of DNACPR orders in our institution has confirmed that the pandemic has prompted more widespread decision-making for patients with and without COVID-19. [14] It has been observed that the nature of COVID-19 is changing how people die, and that frail older people and/ or their families may have to make quick decisions under stressful circumstances.[15] While guidelines recommend that advance care planning discussions are carried out in a sensitive, timely and iterative manner by skilled professionals who are familiar with the individual, the data reveals the scale and pace of decision-making that took place.

Guidance from a European Respiratory Society International Taskforce recommends that loved ones should be supported to visit dying patients with COVID-19.[16] Almost 70% of patients who died, received a visit, demonstrating that it is possible to facilitate visiting. The smaller number of visitors from members of the same generation as the dying individual, likely reflects the awareness of the increased risks associated with becoming infected with SARS-CoV-2 at an older age.

During the first wave, visiting remained constrained in comparison to usual practice. Only 24% of patients had a family member present at time of death, this is comparable to the study by Heath et al. where 19% of patients had a family member present at end of life.[17] This reflects the practice of shorter visits so that families were unable to maintain bedside vigils. A learning curve was evident in our use of technology, and only modest levels of virtual contact were facilitated. In common with others, we found that we needed to gain experience in making adjustments for virtual communication and develop skills in building rapport.[18-20]

Study strengths include the fact that it represents the first documentation of SPC provision to patients with COVID-19 in Ireland. Selection bias was minimised by the inclusion of all patients referred to SPC and complete follow-up. The study included a high number of patients who died from COVID-19 in the hospital, enhancing the generalisability of findings.

It has been noted that well-designed observational studies have an important role in understanding emerging pandemics.[21] This examination of SPC provision has generated clinical insights and hypotheses to support further research; however it has also highlighted the need to accelerate efforts to structure SPC infrastructure so that national clinical data is shared and organisations act as an interconnected learning system. Ultimately, effective palliative care responses are dependent on research that yields quality data and actionable information.

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Declaration of Conflicts of Interest:
There are no conflicts of interest to declare.

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