

Palliative Care During COVID-19: Data and Visits From Loved Ones

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Abstract

Objectives: A vital component of the coronavirus response is care of the dying COVID-19 patient. We document the demographics, symptoms experienced, medications required, effectiveness observed, and challenges to high-quality holistic palliative care in 31 patients. This will aid colleagues in primary and secondary care settings anticipate common symptoms and formulate management plans. **Methods:** A retrospective survey was conducted of patients referred to the hospital palliative care service in a tertiary hospital, south east of England between March 21 and April 26, 2020. Patients included had a confirmed laboratory diagnosis of COVID-19 via reverse transcription polymerase chain reaction nasopharyngeal swab for SARS-Cov-2 or radiological evidence of COVID-19. **Results:** The thirty-one patients included were predominantly male (77%), elderly (median [interquartile range]: 84 [76-89]), and had multiple (4 [3-5]) comorbidities. Referral was made in the last 2 [1-3] days of life. Common symptoms were breathlessness (84%) and delirium (77%). Fifty-eight percent of patients received at least 1 “as required” dose of an opioid or midazolam in the 24 hours before death. Sixty percent of patients needed a continuous subcutaneous infusion and the median morphine dose was 10 mg S/C per 24 hours and midazolam 10 mg S/C per 24 hours. Nineteen percent of our cohort had a loved one or relative present when dying. **Conclusion:** We provide additional data to the internationally reported pool examining death arising from infection with SARS-CoV-19. The majority of patients had symptoms controlled with low doses of morphine and midazolam, and death was rapid. The impact of low visitation during dying needs exploring.

Keywords

family management, bereavement, holistic care, COVID-19, SARS-CoV-2, symptom management, palliative medicine

Introduction

Globally, the case fatality rate of COVID-19 is 1% to 3% with over 425 000 deaths reported to date,^{1,2} with older age, male sex, and the presence of comorbidities associated with an increased risk of death.^{3,4} Current COVID-19 clinical research is focused on acute and intensive care.⁵ However, for many patients, care will not be escalated to an intensive care setting and an understanding of the symptom control needs, and end-of-life care challenges of this group are important.⁶

Some of these challenges include: providing palliative care when resources are focussed on intensive care provision, an increased demand for palliative care input that outstrips resource, recognition of deterioration and dying in a new disease, and a lack of familiarity with managing COVID-19 symptoms. Redeployment of staff and changes in health care infrastructure also provide additional pressures in symptom management and delivering care for the dying patient.⁷

We describe data from 31 patients referred to the hospital palliative care team in a large teaching hospital in South East England who died from COVID-19. This report increases the

number of reported palliative care cases of patients who have died in the United Kingdom and United States.⁸⁻¹⁰ We also describe the symptoms, management, and effectiveness of treatment for this patient cohort and report on communication with families, visitation at the end of life, and presence of treatment escalation plans (TEPs).

We anticipate this information will help community teams, care homes, hospices, and hospitals to anticipate common symptoms associated with dying from COVID-19 and help inform management plans.

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Table 1. Most Prevalent Comorbidities in 31 Patients Diagnosed With COVID-19 Referred to a Hospital Palliative Care Team.

Comorbidity	N (% of sample) or median [IQR]
Hypertension	11 (35)
Atrial fibrillation	11 (35)
Chronic kidney disease	10 (32)
Lung disease	9 (29)
Dementia	9 (26)
Type 2 diabetes	8 (26)
Cerebrovascular disease	8 (26)
Cancer	7 (23)
Ischemic heart disease	5 (16)
Hematological malignancy	5 (16)
Total number	4 [(3-5)]

Abbreviation: IQR, interquartile range.

Methods

We conducted a retrospective survey of patients who died under the care of a tertiary hospital palliative care team between March 21 and April 26, 2020. The survey was registered as a local quality improvement project as per hospital policy. All patients included had a confirmed laboratory diagnosis of COVID-19 via reverse transcription polymerase chain reaction (RT-PCR) nasopharyngeal swab for SARS-Cov-2 and/or radiological evidence of coronavirus infection (commonly a plain chest radiograph reported as “classic” or “probable” COVID-19 by a radiologist).

Data was extracted from the hospital electronic patient record by a clinician team. Anonymized data were uploaded and analyzed in Microsoft Excel 2010.

Results

Of the 31 patients, 90% (n = 28) were diagnosed with a positive RT-PCR nasopharyngeal swab for SARS-Cov-2 and 10% (n = 3) were diagnosed by either radiological and/or clinical suspicion of COVID-19 infection. This cohort represented 30% of the total patients referred to the hospital palliative care team and 49% of the total COVID-19 deaths at the hospital in this timeframe.

Seventy-seven percent were men, median age 84 (Interquartile range [IQR] 76-89), with an average of 4[3-5] comorbidities (Table 1). The majority (81%) were seen in a ward-based setting, with a significant minority (19%) seen on respiratory HDU, and none were referred from ICU.

The median time between admission and referral was 4 [2-8] days, and between referral and death was 2 [1-3] days. Eighty-four percent were White British, which is reflective of our local population. The most common reason for referral was for advice regarding care at the end of life (87%) and/or symptom management (71%). At the time of referral, the median Australian Karnofsky Performance Scale (AKPS) was 20 [10-20]—“Totally bedfast and requiring extensive nursing care by professionals and/or family.” Most patients were either in the dying (58%) or deteriorating (23%) phase of illness.¹¹

Symptoms experienced most frequently were breathlessness (84%) and agitation/delirium (77%). The median number of consultations by the palliative care team was 2 [2-3]. All had subcutaneous anticipatory medications prescribed for symptom management. One hundred percent had an opioid either morphine or oxycodone and a benzodiazepine (midazolam) prescribed. In addition, 90% had medication for delirium with haloperidol being first line and an additional 32% having levomepromazine prescribed second line. Ninety-four percent were prescribed an antisecretory medication (hyoscine butylbromide) and 61% an antiemetic.

Fifty-eight percent of patients received at least 1 “as required” dose of an opioid or midazolam in the 24 hours before death. Ten percent were administered “as required” doses of haloperidol and 13% of hyoscine butylbromide. Levomepromazine or antiemetics were not administered. Where the patient had received an “as required” medication, there was documentation of efficacy in 50%.

Sixty-eight percent of patients had medications administered subcutaneously using a continuous infusion via a syringe driver. The most frequent combination of medication administered was an opioid (morphine, oxycodone, or alfentanil) and a benzodiazepine (midazolam). The median total oral morphine equivalent dose in the last 24 hours of life (sum of syringe driver and “as required” doses converted to oral equivalent) was 20 mg [IQR 14-38 mg]. The median total dose of benzodiazepine (midazolam) was 10 mg [4-15 mg]. This equates to 20 mg diazepam PO/24 hours.¹²

In all but 1 patient, there was documentation of communication with next of kin explaining the high risk of death. There was documented evidence that all next of kin were informed following the death of their loved one. Seventy-four percent had a documented discussion with next of kin with regard to visiting while dying; however, only 19% of our cohort had a loved one or relative present when dying.

All patients had a documented “Do Not Attempt Cardiopulmonary Resuscitation” decision. There was evidence of a TEP for the patient in 90%.

Discussion

This article provides additional data to the internationally reported pool examining death arising from SARS-CoV-19. Limitations include the small sample size from one center and the racial and ethnic homogeneity of our patients due to our local population demographics.

In our hospital, two-thirds of those diagnosed with COVID-19 have recovered benefitting from good nursing care, hydration, and ventilatory support. Given a one-third mortality, it is important to hope for the best and plan for the worst.

The majority of referrals were for advice regarding best supportive care at the end of life in those recognized to be dying. This was supported by the average AKPS of 20 on first review and a median of 2 days between referral and death, suggesting appropriate and timely referral.

The hospital palliative care team introduced a COVID-19 medication “power plan” (suggested list of medications with doses, to manage common COVID-19 symptoms) to support staff in timely prescribing of anticipatory medications. The nursing workforce in the team increased through redeployment allowing increased numbers of nursing staff to work out of hours supported by 7-day consultant palliative physician working.

Our data demonstrated the most frequent symptoms of COVID-19 infection in our patient cohort were breathlessness (84%) and delirium (77%). Although highly prevalent, 42% did not utilize any as required medications in the last 24 hours of life and 32% did not require a continuous infusion via a syringe driver. For the 68% of patients who required a continuous subcutaneous infusion of medication, doses were low with a median equivalent to 10mg morphine SC/24 hours and midazolam 10mg/24 hours. Morphine was the opioid of choice in 71%, oxycodone in 19%, and alfentanil in 10%. Both renal and hepatic failure are a recognized consequence of SARS-CoV-2 infection. However, rapidity of dying means opioid accumulation and toxicity is less likely in a short space of time.

Despite a high prevalence of breathlessness and delirium, low doses of medications used, combined with one-third of patients not requiring symptom control medications in the last 24 hours of life, suggest managing the dying COVID-19 patient does not require complex interventions. This is helpful when planning for further waves of infection as PPE equipment, staff redeployment, and pandemic nursing ratios make it more difficult to administer “as required” medications as well as sourcing appropriate numbers of syringe drivers.

Despite good symptom control, it was recognized patients were often too unwell to participate in communication either normally or through novel methods including video chat via tablet, although it was supported in some cases. Do Not Attempt Cardiopulmonary Resuscitation decisions and TEPs were documented in 100% and 90% of cases; this was an important achievement by staff as the use TEPs was introduced during the pandemic.

In our survey, 81% of patients did not have a family member or loved one present during the dying phase, despite a policy of allowing 1 person to be present. It was noted this was most frequently due to those close to the patient were themselves vulnerable and frightened of infection and/or had been advised to shield.

Those close to the patient provide important information when delivering individualized care to those dying, especially when the patient is too unwell to do so themselves. Eliciting key information in a more formal way for staff was both challenging and rewarding in ensuring holistic patient care at the end of life. Staff are more likely to avoid moral injury if they judge that patients have died comfortably.

Consequences of low visitation may include increased and more complex bereavement needs of loved ones. Further consideration of the effects of this is required, as this is a relatively

unexplored aspect of the COVID crisis. Plans to meet these needs in primary care and social care settings should be considered in future coronavirus planning.

Conclusion

We provide additional data to the internationally reported pool examining death arising from infection with SARS-CoV-19. The majority of patients had symptoms controlled with low doses of morphine and midazolam, and death was rapid. The impact of low visitation during dying needs exploring and could include increased bereavement needs for loved ones. We note documentation of efficacy of interventions and individualized care for patients dying of COVID-19 during the pandemic is important in our national planning for bereavement support.


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Supplemental Material

Supplemental material for this article is available online.

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