

COVID-19

A Dual-Center Observational Review of Hospital-Based Palliative Care in Patients Dying With COVID-19



Jennifer Turner, BSc, MBBS, MRCP, Luke Eliot Hodgson, MD, MSc, BSc, MRCP, FFICM, EDIC, Todd Leckie, BMBS, MSc, MRCP, Lisa Eade, RGN, and Suzanne Ford-Dunn, BM, MSc, MRCP

ST5 Geriatric Medicine (J.T.), Worthing Hospital, Western Sussex Hospitals NHS Foundation Trust, Worthing; Intensive Care Department (L.E.H.), Worthing Hospital Western Sussex Hospitals NHS Foundation Trust, Worthing; Faculty of Health & Medical Sciences (L.E.H.), University of Surrey, Guildford; ST3 Anaesthetics (T.L.), Intensive Care Department, Worthing Hospital, Western Sussex Hospitals NHS Foundation Trust, Worthing; Palliative Care (L.E.), St Richards Hospital, Western Sussex Hospitals NHS Foundation Trust, Chichester; Palliative Medicine (S.F.-D.), Worthing Hospital, Western Sussex Hospitals NHS Foundation Trust, Worthing; and St Barnabas House Hospice (S.F.-D.), Worthing, UK

Abstract

The current coronavirus disease 2019 (COVID-19) pandemic has put significant strain on all aspects of health care delivery, including palliative care services. Given the high mortality from this disease, particularly in the more vulnerable members of society, it is important to examine how best to deliver a high standard of end-of-life care during this crisis. This case series collected data from two acute hospitals examining the management of patients diagnosed with COVID-19 who subsequently died (n = 36) and compared this with national and local end-of-life audit data for all other deaths. Our results demonstrated a shorter dying phase (38.25 hours vs. 74 hours) and higher rates of syringe driver use (72% vs. 33% in local audits), although with similar average medication doses. Of note was the significant heterogeneity in the phenotype of deterioration in the dying phase, two distinct patterns emerged, with one group demonstrating severe illness with a short interval between symptom onset and death and another group presenting with a more protracted deterioration. This brief report suggests a spectrum of mode of dying. Overall, the cohort reflects previously described experiences, with increased frailty (median Clinical Frailty Scale score of 5) and extensive comorbidity burden. This brief report provides clinicians with a contemporaneous overview of our experience, knowledge, and pattern recognition when caring for people with COVID-19 and highlights the value of proactive identification of patients and risk of deterioration and palliation. J Pain Symptom Manage 2020;60:e75–e78. © 2020 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words

Palliative care, COVID-19, frailty, symptom management, end-of-life care

Key Message

This retrospective review of end-of-life care of patients dying with coronavirus disease 2019 suggests a shorter duration of dying phase compared with deaths of other causes and high symptom burden. These findings may help refine pathways and guidance to ensure high-quality care for those dying with coronavirus disease 2019.

Introduction

The coronavirus disease 2019 (COVID-19) pandemic has created significant challenges across delivery of all aspects of health care globally. Although data exist regarding effective triage of people during humanitarian crises,¹ this is the first time that developed health care systems have been placed under sustained and at times overwhelming pressure. Emerging

Address correspondence to: Suzanne Ford-Dunn, BM, MSc, MRCP, Western Sussex Hospitals NHS Foundation Trust, Worthing Hospital, Lyndhurst Road, Worthing BN11 2DH, UK. E-mail: suzanne.ford-dunn@nhs.net

Accepted for publication: April 28, 2020.

data have described the active management and outcomes of patients with COVID-19;^{2–4} however at present, there is little information to help inform the management of those patients recognized as dying. The surge in people requiring care means services are stretched and finite resources must be allocated efficiently. Understanding the dying process in patients with COVID-19 in an environment that presents additional challenges of potentially limited resource and comprehensive infection control precautions is crucial to deliver high standards of care.

This observational study aimed to present a case series from audit data collected from Western Sussex National Health Service Foundation Trust, an acute hospital trust on the South coast of England, specifically looking at the palliative care patients with COVID-19 received in a ward setting. The trust is based across two acute hospital sites in Worthing and Chichester and serves a population of 450,000 people, with a large proportion of older individuals and those living with frailty. We envisaged using the data to review the challenges faced during this pandemic and examine whether any patterns are arising, including unanticipated ones, to inform future care pathways. Even within an overburdened health system with finite resources, integrating palliative care is essential^{5,6} when looking at delivering the wider COVID-19 service, so that clinicians are able to provide the best standards of care to all our population.

Methods and Results

We conducted a retrospective audit of patients who died outside critical care with a positive reverse transcription-polymerase chain reaction nasopharyngeal swab for severe acute respiratory syndrome coronavirus 2 between March 15 and April 11, 2020. Data were extracted from medical and nursing notes (admission notes, electronic prescribing system, and electronic records) by clinicians. Clinical frailty was assessed by the admitting doctor using the validated Rockwood Clinical Frailty Scale (CFS),⁷ which is an assessment based on recent functional ability and has been a routine part of the admission clerking in our trust since 2015. Use of the T34 McKinley Syringe Driver pumps (Caesarea Medical Electronics Ltd, Caesarea, Israel) to administer medication was recorded, along with drug and dose used. These syringe drivers are commonly used in the U.K. to continuously administer essential symptom control medications subcutaneously for patients at the end of life to provide good control of symptoms such as breathlessness and respiratory secretions. The work was registered with the clinical effectiveness team of the hospital.

During the dates mentioned previously, 36 deaths in patients with COVID-19 were recorded. The median age was 81 (range 48–96) years. Most (75%) were admitted from their own homes. The CFS (scale from 1 to 9)⁷ median score was 5 (range 3–7). All the patients had significant pre-existing comorbidities, with an average of four per patient. Of these patients, 13 were diabetic, 14 had ischemic heart disease, 12 were hypertensive, and eight had chronic obstructive pulmonary disease.

Of the notes available ($n = 30$), the median time from symptom onset to death was nine days (range 2–30). Full notes were available for 30 patients, and in these, the average time spent in the dying phase, from recognition of dying to death, was 38.25 hours. About 72% of the patients had a syringe driver delivering medication at the time of death. In the last 24 hours before death, 86% had received opioids, 81% benzodiazepines, and 44% hyoscine butylbromide. With regard to doses, the total mean opioid dose (subcutaneous morphine equivalent) during the final 24 hours was 15.96 mg and for midazolam 13.3 mg.

After our clinical experience having observed patients with apparently different trajectories of illness and dying, we were able to group patients with full notes ($n = 30$) based on severity of symptoms at presentation and the duration of illness. In those patients, we were able to suggest different phenotypes of dying from COVID-19 based on how the patient first presented to hospital—either those quickly identified as being very unwell or those in whom symptoms were less obvious or severe. These groups of patients are summarized in [Table 1](#).

Discussion

From our case series-observed experience to date, dying from COVID-19 differs in a number of ways from the usual end-of-life patterns. The U.K. National Hospital End-of-Life Audit in 2018 looking at hospital deaths of all causes revealed that the average time from first recognition of dying to death was 74 hours, and this was 69 hours for our trust.⁸ From our COVID-19 case review, we observed a shorter average dying phase of 38.25 hours. Only four of our patients were recognized as dying for longer than 74 hours.

Different phenotypes of dying emerge ([Table 1](#)) broadly. We have observed one cohort, Group 1 ($n = 11$), that develop a severe disease during the course of several days, have a short admission, are recognized as being very unwell at presentation, and progress to a short terminal phase, less than 48 hours, although typically even less than this. These patients had a wide range of ages and frailty scores although

Table 1
Phenotypes of Dying From COVID-19

Phenotype of Dying	Average Illness Duration (Days)	Average Length of Dying Phase (Hours)	Average Age	Median Clinical Frailty Score	Median Number of Comorbidities
Group 1 (<i>n</i> = 11) Fulminant COVID	5.17	11.95	70.7	4	4
Group 2 (<i>n</i> = 14) Longer illness and slower deaths	11.15	68.8	83.9	6	5
Group 3 (<i>n</i> = 5) Long illness, stability, and rapid death	16.6	9.6	83.4	3	5

COVID-19 = coronavirus disease 2019.

they tended to be younger and less frail on average. All however did have significant comorbidities. The second cohort, Group 2 (*n* = 14), either had less severe symptoms at presentation or presented atypically and had a longer duration of illness and dying phase. These patients were all older than 75 years, and the majority were either moderately or severely frail, with none scoring less than five on their CFS. It could be that this frail group did not experience severe COVID-19 but instead that they were already extremely vulnerable and had limited abilities to overcome any illness, which is a feature common to those we see dying of other causes with frailty. The duration of the dying phase in this cohort is similar to what we usually see in palliative care. A smaller number (Group 3; *n* = 5) did not fit either of these groups; they too were elderly with multiple comorbidities but not necessarily frail before admission. They had a long duration of illness and length of hospital stay but a very rapid deterioration and dying phase. It could be that in this group the dying phase was simply not recognized as such for some time or that there was a superimposed illness in an already vulnerable and deconditioned individual.

All the ward deaths were in patients not considered for escalation of care to critical care because of a combination of frailty and comorbidities, which mirrors the wider mortality risk,⁹ the comorbidities of hypertension, ischemic heart disease, diabetes, and chronic obstructive pulmonary disease, which have been described in the literature as significant factors in determining risk of death,¹⁰ featured heavily in our cohort.

Compared with previous end-of-life audits of all deaths at our trust (2016 and 2018), we observed higher numbers of patients given medication continuously via syringe driver at the end of life—72% compared with 33% previously. Recognized COVID-19 symptoms, such as cough, dyspnea, and anxiety,¹⁰ as well as agitation and delirium are typically very distressing and therefore may well necessitate a higher

proportion of patients being managed with syringe drivers to ease the symptom burden appropriately. Mean doses used however were comparable between this cohort and those seen in previous audits and are consistent with data published from other centers.¹¹ This suggests that although more patients appear to require these medications, their symptoms are controllable to the same extent as patients dying from other causes.

Conclusions

This dual-center case series of clinical practice reports on our experience of ward-based inpatients dying from COVID-19 has revealed clinically important findings for other clinicians to be aware of. The symptom burden may be higher than we typically see, as demonstrated by higher requirement for syringe drivers. It is therefore important to recognize this, so patients diagnosed as dying can have access to early use of appropriate treatments to allow for a comfortable and dignified death. We perhaps need to acknowledge that in those with any symptoms requiring medication, there will be little benefit in delaying the introduction of a syringe driver once identified as dying. The recognition of the emerging phenotypes of dying, especially among vulnerable, comorbid, and frail patients deemed not likely to benefit from critical care, will help clinicians in terms of modifying expectations and discussing prognosis with their families.

Disclosures and Acknowledgments

The authors acknowledge the ongoing dedicated work of all their clinical colleagues, including the hospital palliative care team, intensive care staff, and elderly care teams. They thank Richard Brooks for his assistance in carrying out the literature search. The authors declare no conflicts of interest.

References

1. Arya A, Buchman S, Gagnon B, Downar J. Pandemic palliative care: beyond ventilators and saving lives. *Can Med Assoc J* 2020;192:E400–E404.
2. Grasselli G, Zangrillo A, Zanella A, et al. Baseline characteristics and outcomes of 1591 patients infected with SARS-CoV-2 admitted to ICUs of the Lombardy region, Italy. *JAMA* 2020;323:1574–1581.
3. Guan WJ, Ni ZY, Hu Y, et al. Clinical characteristics of coronavirus disease 2019 in China. *N Engl J Med* 2020;382:1708–1720.
4. Wu Z, McGoogan JM. Characteristics of and important lessons from the coronavirus disease 2019 (COVID-19) outbreak in China: summary of a report of 72 314 cases from the Chinese Center for Disease Control and Prevention. *JAMA* 2020. <https://doi.org/10.1001/jama.2020.2648>.
5. WHA67 R. 19. Strengthening of palliative care as a component of comprehensive care throughout the life course. Geneva: Sixty Seventh World Health Assembly, 2014:24.
6. Knaul FM, Farmer PE, Bhadelia A, Berman P, Horton R. Closing the divide: the Harvard Global Equity Initiative—Lancet Commission on global access to pain control and palliative care. *Lancet* 2015;386:722–724.
7. Rockwood K, Song X, MacKnight C, et al. A global clinical measure of fitness and frailty in elderly people. *CMAJ* 2005;173:489–495.
8. HQIP. NHS Benchmarking Network, National Audit of Care at the End of Life: First round of audit (2018/19) report: England and Wales [internet]. 2019. Available from www.nhsbenchmarking.nhs.uk/nacel. Accessed May 15, 2020.
9. Tanja FS, Nancy P, Keller N, Claudia G. Conservative management of Covid-19 patients—emergency palliative care in action. *J Pain Symptom Manage* 2020. <https://doi.org/10.1016/j.jpainsymman.2020.03.030>.
10. Bajwah S, Wilcock A, Towers R, et al. Managing the supportive care needs of those affected by COVID-19. *Eur Respir J* 2020;55:2000815.
11. Lovell N, Maddocks M, Etkind SN, et al. Characteristics, symptom management and outcomes of 101 patients with COVID-19 referred for hospital palliative care. *J Pain Symptom Manage* 2020. <https://doi.org/10.1016/j.jpainsymman.2020.04.015>.