


Palliative Care and Neurology Needs in Patients With and Without COVID-19

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Abstract

Background: The COVID-19 pandemic led to increased neurology and palliative care needs. We compare the characteristics of COVID-19 positive vs negative patients who received consultation by neurology and palliative care services during the 2020 COVID-19 surge in New York City to see how the groups differ in their consultation needs and to identify opportunities to improve care. **Methods:** This retrospective analysis was performed within a multi-center hospital system in New York City, USA over a 2-month period (15 March to 15 May, 2020) which represented the peak of the first COVID-19 wave. Hospitalized patients who received a consultation from neurology and palliative care services were included. The patients were classified according to COVID-19 status (positive or negative based on PCR testing). Data abstracted from chart review included demographic data, details of neurology and palliative care consultations, duration of admission, ICU admission, intubation, code status, and death. **Results:** The study included 70 patients who tested positive for COVID-19 and 39 patients who tested negative for a total of 109 patients. Compared to the patients who tested negative for COVID-19, the patients who tested positive for COVID-19 were more likely to have palliative care consultation for management of goals of care (70 [100%] vs 33 [84.6%], $P = .003$) and less likely for management of symptoms (2 [2.9%] vs 7 [17.9%], $P = .02$). **Conclusion:** The findings emphasize the need for collaboration between palliative care and neurology, which was heightened during the COVID-19 pandemic. There was a particular need for communication surrounding goals of care.

Keywords

neurology, covid, pandemic, coronavirus, neuropalliative care, inpatient

Introduction

The coronavirus disease 2019 (COVID-19) pandemic spread rapidly, accompanied by high rates of death and suffering.¹ The pandemic significantly affected patients with underlying neurological conditions, both directly through neurological complications, and indirectly through consequences on healthcare delivery (for example delayed care due to fear of infection, limited access to outpatient and elective services, and the need for preserved critical care capacity).^{2,3} Many such patients are at higher risk of severe COVID-19, in turn putting them at higher risk of morbidity and mortality from the infection. In some cases (eg dementia and stroke), there are shared risk factors for severe COVID-19, such as advanced age, cardiovascular disease, hypertension, and diabetes.^{4,5} Others may be vulnerable to rapid respiratory decline due to pre-existing neuromuscular conditions such as amyotrophic lateral sclerosis or myasthenia gravis.⁶

Additionally, an estimated 36–62.7% of patients hospitalized with COVID-19 suffer from neurological complications of the virus.^{7,8} The most common of these complications include myalgias (44.8%), headaches (37.7%), and encephalopathy

(31.8%).^{7,9} Less common complications include stroke, movement disorders, and seizures (1.6%, .8%, and .8% respectively).⁷ In addition to substantial morbidity and mortality, these patients with pre-existing or COVID-19-related neurologic conditions may be faced with complex medical decision-making surrounding tracheostomy, artificial nutrition, and other invasive life-sustaining treatments.

The severity of illness and complex medical decision making experienced by patients with COVID-19, particularly those with neurologic conditions, results in high levels of palliative care needs. Palliative care focuses on relieving

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suffering and achieving the best possible quality of life as well as helping patients and families make informed decisions about their care.¹⁰ Therefore, palliative care teams, including that in our health system, expanded due to escalating need during the COVID-19 pandemic.¹¹⁻¹⁴

Despite the increased palliative care and neurology needs during the pandemic, it is unknown how patients with COVID-19 with palliative care and neurology co-consultation differ in terms of their demographics, illness, and consultation needs. We therefore aim to compare the characteristics of COVID-19 positive vs negative patients with palliative care and neurology consultations during the 2020 COVID-19 surge in New York City to identify ways to improve care and collaboration, particularly in times of crisis.

Methods

We used administrative data from the Mount Sinai Health System to retrospectively identify a cohort of patients hospitalized between March 15, 2020 and May 15, 2020. This study period was chosen because it spanned the peak of the first COVID-19 wave in New York City.¹⁵ The Mount Sinai Health System is an eight-hospital, 3926-bed health system¹⁶ that was at the epicenter of the New York City COVID-19 pandemic in spring 2020. We included patients who had consultations from both palliative care and neurology during the same hospital admission and had been tested for COVID-19 infection. We excluded patients who were admitted at 3 of the 8 hospitals (Mount Sinai Beth Israel, Mount Sinai South Nassau, and New York Eye and Ear Infirmary of Mount Sinai) as these hospitals did not use the same electronic medical record at the time of the study period. We also excluded patients who were not tested for COVID-19 infection during their admission.

Patients were classified according to COVID-19 status (positive or negative) based on the results of a polymerase chain reaction (PCR) test during the admission. Additional information abstracted from the charts included demographic data, presence of underlying neurological condition, details of neurology and palliative care consultations (reason for consultation, number of days from admission to consultation, number of notes from the consulting service), duration of admission, duration of ICU admission if applicable, whether or not endotracheal intubation, percutaneous tracheostomy, percutaneous endoscopic gastrostomy, rapid response team activation, cardiac arrest team activation, or palliative extubation was performed, code status at time of discharge, days from admission to change in code status if applicable, and whether the patient died during the admission.

Statistical Analysis

Statistical analysis was performed in R.¹⁷ Chi-squared tests and unpaired t-tests were conducted to compare COVID-19 positive and COVID-19 negative groups for categorical and continuous variables, respectively. A *P*-value of less than .05 was used to indicate statistical significance.

Standard Protocol Approvals, Registrations, and Patient Consents

This study was approved by the Mount Sinai Institutional Review Board (study number 20-01583). It was determined that written informed consent by participants was not required due to the retrospective nature of this study and lack of identifiable personal health information being used.

Data Availability

Anonymized data not published within this article will be made available by request from any qualified investigator.

Results

Between March 15 and May 15, 2020, we identified 116 qualifying inpatient admissions during which the patients were seen by both palliative care and neurology. One patient had 2 admissions during the study period which met the inclusion criteria. Data from both admissions were included in the study. We excluded patients who were seen by neurology working on an internal medicine service due to redeployment (*n* = 3). We excluded patients who were not tested for COVID-19 (*n* = 4). We included 109 admissions in the final analysis (Table 1).

There were no significant differences in baseline demographic and clinical characteristics of the patients in the COVID-19 positive and negative groups (Table 1). The most common pre-existing neurological condition was cerebrovascular disease (11 [15.7%] in the COVID-19 positive group vs 4 [10.3%] in the COVID-19 negative group, *P* = .62), followed by dementia (6 [8.6%] vs 5 [12.8%], *P* = .71), and seizure disorder (6 [8.6%] vs 1 [2.6%], *P* = .41).

Most of the palliative care consultations obtained during the study period were for management of goals of care (103 [94.5%]). Compared to the patients who tested negative for COVID-19, the patients who tested positive for COVID-19 were more likely to have a palliative care consultation for management of goals of care (70 [100%] vs 33 [84.6%], *P* = .003) and less likely for management of symptoms (2 [2.9%] vs 7 [17.9%], *P* = .02) (Table 2).

The most common reason to obtain neurology consultation was altered mental status in both groups (42 [60%] in the COVID-19 positive group vs 24 [61.5%] in the COVID-19 negative group, *P* = 1.00). The second most common reason was for suspected stroke (15 [23.1%] vs 9 [23.1%], *P* = 1.00). There were no statistically significant differences between the COVID-19 positive and negative groups in reason for obtaining neurology consultation, time from admission to obtaining neurology consultation, or number of notes from neurology.

Hospital admissions were significantly longer for patients with COVID-19 infection compared to those without (32.1 ± 29.1 vs 20.0 ± 17.1 days, *P* = .007), although there was no

Table 1. Demographic data.

Variable	COVID-19 Positive (n=70)	COVID-19 Negative (n=39)	P-value
Female – no. (%)	22 (31.4)	19 (48.7)	.11
Age – years, mean ± SD	69.8 ± 12.6	71.4 ± 16.1	.57
Non-white race – no. (%)	52 (74.3)	26 (66.7)	.50
Pre-existing neurological condition – no. (%)	21 (30.0)	12 (30.8)	1.00
Cerebrovascular disease	11 (15.7)	4 (10.3)	.62
Dementia	6 (8.6)	5 (12.8)	.71
Seizure disorder	6 (8.6)	1 (2.6)	.41
Other	7 (10.0)	5 (12.8)	.92

Abbreviations: COVID-19 = coronavirus disease 2019.

Table 2. Palliative care and neurology consultation data.

Variable	COVID-19 Positive (n = 70)	COVID-19 Negative (n = 39)	P-value
Reason for palliative care consultation – no. (%)			
Goals of care	70 (100.0)	33 (84.6)	.003
Symptom management	2 (2.9)	7 (17.9)	.02
Days to palliative care consultation – mean ± SD	8.2 ± 7.0	5.9 ± 6.3	.09
Number of palliative care notes – mean ± SD	4.7 ± 3.7	6.9 ± 5.4	.03
Reason for neurology consultation – no. (%)			
Altered mental status	42 (60.0)	24 (61.5)	1.00
Stroke	15 (21.4)	9 (23.1)	1.00
Seizure	6 (8.6)	2 (5.1)	.78
Neuro-prognostication following cardiac arrest	2 (2.9)	2 (5.1)	.94
Other	5 (7.1)	2 (5.1)	1.00
Days to neurology consultation – mean ± SD	8.0 ± 9.7	4.8 ± 8.1	.07
Number of neurology notes – mean ± SD	6.8 ± 7.7	6.8 ± 7.0	.10

Abbreviations: COVID-19 = coronavirus disease 2019.

Table 3. Admission and outcome data.

Variable	COVID-19 Positive (n = 70)	COVID-19 Negative (n = 39)	P-value
Duration of hospital admission – days, mean ± SD	32.1 ± 29.1	20.0 ± 17.1	.007
ICU admission	41 (58.6)	20 (51.3)	.59
Duration of ICU admission – days, mean ± SD	18.8 ± 12.7	12.0 ± 17.2	.13
Interventions during admission – no. (%)			
Endotracheal intubation	39 (55.7)	18 (46.2)	.53
Percutaneous tracheostomy	24 (34.3)	4 (10.3)	.02
Percutaneous endoscopic gastrostomy	16 (22.9)	3 (7.7)	.10
Rapid response team activation	35 (50.0)	14 (35.9)	.29
Cardiac arrest team activation	16 (22.9)	5 (12.8)	.45
Palliative extubation	4 (5.7)	7 (17.9)	.10
Code status at time of discharge – no. (%)			
Full code	24 (34.3)	12 (30.8)	.87
Do not resuscitate	14 (20.0)	1 (2.6)	.02
Do not resuscitate and do not intubate	32 (45.7)	26 (66.7)	.06
Time to change in code status – days, mean ± SD	10.2 ± 11.6	10.4 ± 8.9	.95
Death during admission – no. (%)	34 (48.6)	19 (48.7)	1.00

Abbreviations: COVID-19 = coronavirus disease 2019, ICU = intensive care unit.

difference in ICU admission (41 [58.6%] vs 20 [51.3%]) (Table 3). The COVID-19 positive group were more likely to undergo percutaneous tracheostomy (24 [34.3%] vs 4 [10.3%], $P = .02$), although there was no difference in rates of endotracheal intubation (39 [55.7%] vs 18 [46.2%]). Patients with COVID-19 infection were more likely to change code status to “Do Not Resuscitate” (14 [20.0%] vs 1 [2.6%], $P = .02$). A higher proportion of COVID-19 negative patients had a code status of “Do Not Resuscitate and Do Not Intubate” at the end of their admission (32 [66.7%] vs 26 [45.7%]) although this difference was not statistically significant ($P = .06$). Mortality rates were high in both groups (34 [48.6%] in the COVID-19 positive group vs 19 [48.7%] in the COVID-19 negative group, $P = 1.00$).

Discussion

In this cohort of patients who were admitted during the first surge of the COVID-19 pandemic in New York City and were seen by both palliative care and neurology during admission, we found that palliative care was consulted significantly more for goals of care and less for symptom management in the patients with COVID-19 infection. This illustrates the importance of neuropalliative collaboration around prognosis and communication of prognosis to decision makers of those critically ill with COVID-19.

While less common than in the COVID-19 positive group, management of goals of care was also the most frequent reason for palliative care consultation in the COVID-19 negative group. This is consistent with previous studies of inpatients with neurological disorders conducted prior to the pandemic.^{18,19} In sum, our study suggests that even separate from the COVID-19 pandemic, more collaboration may be needed between palliative care and neurology, particularly when it comes to communication and decision-making.

Other noteworthy findings of our study include high rates of ICU admission, intubation, and death in both COVID-19 positive and negative groups, indicating the high severity of disease among patients seen by palliative care and neurology teams. We also found that the most common reason for neurology consultation in both groups was for altered mental status, which may have been particularly challenging for neurologists to prognosticate for, given uncertainties around COVID-19-related encephalopathy. All these factors may contribute to heightened palliative care needs (more urgent evaluation of goals of care, complex medical decision-making) and serve to emphasize our view that more research is needed on communication surrounding goals of care in patients with neurological disease.

There are several limitations of our study. This is a retrospective analysis so causal relationships cannot be inferred from this study. The COVID-19 negative comparison group is not generalizable to patients prior to the study period due to pandemic conditions. The study period represents the first surge in New York City and further work is needed to

understand how the needs and co-management of patients with both palliative care and neurology needs evolved as our understanding of COVID-19 improved. Furthermore, our study did not measure the degree to which neurology and palliative care interacted with each other. There has been increasing focus on palliative care needs of inpatients with neurological disease¹⁸⁻²⁰ and patients in the neuro-intensive care unit,²¹⁻²⁴ but further research is needed into how neurology and palliative care consultants interact. Such interactions include neurology consultants recommending a palliative care consultation based on their assessment of a patient’s prognosis, or palliative care consultants requesting the presence of neurology consultants at family meetings. Future work could be directed to investigate barriers and facilitators to collaboration.

It would also be of value to investigate whether the nature of palliative care needs in COVID-19 differs in patients seen by neurology compared to those not seen by neurology, for example, if neurological involvement is associated with a greater need for goals of care discussions, because these patients may have a poorer prognosis. Patients with underlying cerebrovascular disease or dementia and patients using steroids or other immunosuppressive medications, which are often used for neurological conditions, are at higher risk for severe COVID-19 outcomes.²⁵ Additionally, neurological complications of COVID-19 such as encephalopathy and stroke are associated with poorer outcomes.^{7,26}

Our findings demonstrate that inpatients receiving both palliative care and neurology consultations during the COVID-19 pandemic have a substantial need for clarifying goals of care over other domains of palliative care. The high incidence of encephalopathy adds further complication, as many of these patients lack capacity to engage in decision-making. Yet these palliative care needs may not always be met. Many neurology residency programs offer no palliative care education,²⁷ and up to a quarter of residents do not feel comfortable having end-of-life discussions.²⁸ Similarly, palliative medicine specialists may have limited training surrounding the specific challenges of caring for patients with neurological conditions.²⁹⁻³¹ For example, goals of care discussions represent only 1 facet of palliative care.³² Hospitalized patients with neurological disease may suffer from symptoms that palliative care specialists are familiar with treating, such as pain and delirium, but they may also have symptoms that are specific to their neurological condition, such as spasticity or central post-stroke pain.³³ Further research could focus on optimizing collaborative care delivery and improving reciprocal education within the 2 specialties, particularly given the shortfall in physician workforce.³⁴ It will also be important to identify which patients with neurological disease will benefit the most from palliative care input. Neuropalliative care, an emerging subspecialty of neurology and palliative care, focuses on the specific needs of patients with neurological conditions,³⁵ and may play a key role in shaping future palliative care delivery.

Finally, although this study focuses on COVID-19 as a unique situation where there is heightened need for collaboration between neurology and palliative care, there are gaps in neuropalliative care across the spectrum of serious neurologic illness^{20,30,35} and further research is needed to elucidate these gaps and identify strategies to mitigate them.

Conclusion

The findings of this study emphasize the need for collaboration between palliative care and neurology, which was heightened during the COVID-19 pandemic. There was a particular need for communication surrounding goals of care. These lessons are still relevant with the emergence of new variants of COVID-19 correlating with surges in case volume and may also be extrapolated to future times of increased pressure unrelated to the pandemic. Moving forward, it may be important to understand patients with “long COVID” who will likely continue to have neurological and palliative care needs beyond the acute stage of infection. Additionally, there is a need to improve educational opportunities for neurologists to learn primary palliative care skills, and for palliative care specialists to address the unique needs of patients with neurologic disease. Other directions could look at care delivery models to optimize collaboration between different specialties.

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