The need for early referral to palliative care especially for Black, Asian and minority ethnic groups in a COVID-19 pandemic: Findings from a service evaluation

Abstract

Background: Palliative care services face challenges in adapting and responding to the COVID-19 pandemic. Understanding how palliative care needs and outcomes have changed during the pandemic compared to before the pandemic is crucial to inform service planning and research initiatives.

Aim: to evaluate the impact of COVID-19 on symptoms, clinical characteristics, and outcomes for patients referred to a hospital-based palliative care service in a district general hospital in London, UK.

Design: A retrospective service evaluation. Data were extracted from the Electronic Patient Records.

Setting/participants: The first 60 inpatients with confirmed COVID-19 infection, referred to the hospital palliative care service between March 1, 2020 and April 23, 2020, and another 60 inpatients referred to the hospital palliative care service between March 11, 2019 and April 23, 2019 were included from a general hospital in East London, UK.

Results: Patients with COVID-19 have lower comorbidity scores, poorer performance status, and a shorter time from referral to death compared to patients without COVID-19. Breathlessness, drowsiness, agitation and fever are the most prevalent symptoms during COVID-19 compared to pain, and drowsiness pre-COVID-19. Time from admission to referral to palliative care is longer for Black, Asian and minority ethnic patients, especially during COVID-19.

Conclusion: Early referral to palliative care is essential in COVID-19, especially for Black, Asian and minority ethnic groups. There is urgent need to research why Black, Asian, and minority ethnic patients are referred later, how palliative care services have changed, and possible solutions to setting up responsive, flexible, and integrated services.

Key statements

What is already known about the topic?

- Patients with COVID-19 are at increased risk of severe illness and death
- Palliative care services are facing challenges in adapting and responding to the COVID-19 pandemic
- Black, Asian, and minority ethnic populations receive suboptimal palliative and end of life care due to lower access to services, lack of cultural sensitivity among healthcare providers, language barriers, previous negative experiences, and conflicting values between family/religion and the notion of palliative care

What this paper adds?

- Patients with COVID-19 have lower comorbidity scores, yet they have poorer performance status and their time from referral to death is significantly shorter compared to non-COVID-19 patients
- The prevalence of breathlessness, drowsiness, agitation and fever and the use of subcutaneous infusions to manage symptoms are higher during COVID-19 compared to pre-COVID-19
- Black, Asian, and minority ethnic patients are referred later to palliative care compared to White ethnic patients, especially during COVID-19

Implication for practice, theory or policy

- Early referral to palliative care for patients with COVID-19 is essential, especially for Black, Asian, and minority ethnic groups
- There is urgent need to research why Black, Asian, and minority ethnic patients are referred late during COVID-19, how palliative care services have changed, challenges in providing care and effective solutions to setting up responsive, flexible, and integrated services.

Introduction

It is estimated that the mortality rate from COVID-19 varies from 1% to more than 20%[1–4]. Emerging data suggest that older people and those living with comorbidities are at risk of severe disease, and death[3,5]. Although certain clinical characteristics and outcomes of COVID-19 have been described, the focus has been mainly on mechanical ventilation, and the use of extracorporeal membrane oxygenation[6,7].The limited available data relevant to palliative care described clinical characteristic and outcomes during COVID-19[8]; however, there is lack of data demonstrating how outcomes have changed during COVID-19 compared to pre-COVID-19. Currently, many palliative care services are facing challenges in adapting and responding to this pandemic[9,10]. In order to effectively adapt and inform a responsive palliative care service planning and future research initiatives, it is important to understand how palliative care needs and outcomes have changed during the pandemic compared to before the pandemic.

Aim

This paper evaluates the impact of COVID-19 on symptoms, clinical characteristics, and outcomes for patients referred to palliative care in one NHS district general hospital in London, UK.

Method

Design and Setting

A retrospective service evaluation using data from the Electronic Patient Records held by a district general hospital in London, UK, by comparing patients with confirmed COVID-19 infection in March and April 2020 with those who did not have COVID-19 in March and April 2019. The hospital provides general health services at the hospital and community across East London, and beyond. The hospital serves one of the most ethnically diverse, economically deprived, and affected areas by COVID-19 in the UK in March and April 2020[11]. The palliative care service is an advisory service where patients are referred by their primary medical team. During COVID-19, the service adopted a proactive approach for identifying patients with palliative care needs through frequent ward rounds, attending multidisciplinary team meetings of acute medical units, and by providing short and focused teaching to healthcare professionals at the bedside while providing palliative care consultation[10].

Sampling

Data were extracted on the fir*st* 60 inpatients with confirmed COVID-19 infection, referred to the hospital palliative care service between March 1, 2020 and April 23, 2020, and the 60 inpatients, referred to the hospital palliative care service between March 11, 2019 and April 23, 2019. Throughout this paper ‘during COVID-19’ refers to patients with confirmed COVID-19 infection from year 2020 and pre-COVID-19 refers to patients who did not have COVID-19 from year 2019.

Data Collection and Analysis

The total number of referrals between March 1 and April 23 was collected for years 2019 and 2020. Data were extracted from the Electronic Patient Records by clinicians (C.C., M.F., and A.R.). Variables included: demographics; time from admission to referral, and to death or discharge; Charlson Comorbidity Index[12]; Elixhauser Comorbidity Index[13]; clinician-assessed phase of illness (stable, unstable, deteriorating, and dying) characterized by care needs and appropriateness of care plan[14]; Australian-modified Karnofsky Performance Status[15]; symptoms at time of referral; use of subcutaneous infusions and their clinical effectiveness to manage symptoms based on documentation at follow-up assessment. Data were analysed using IBM SPSS for Windows v.25. The statistical tests used were appropriate to the data type and distribution, and included descriptive statistics, independent samples t-test, Mann-Whitney U test, Chi-square, univariate analysis of covariance (ANCOVA).

Results

The total number of referrals between March 1 and April 23 was higher in year 2020 (n=105) compared to year 2019 (n=70). Table 1 summarizes patient demographics, reason for referral, phase of illness, use of subcutaneous infusion, and discharge destination between pre-COVID-19 and during COVID-19 groups. The cohort consisted of 120 patients (60 pre-Covid-19 and 60 during Covid-19). Thirty-one patients were men pre-COVID-19 vs 34 during COVID-19. The mean age was 79.9 (39-98) pre-COVID-19, and 77.8 (59-98) during COVID-19. There was no significant difference in age or sex between the two groups.

The majority of patients were Black, Asian and minority ethnic in both groups. There was no significant difference in Black, Asian, and minority ethnic patients between the two groups.

Phase of illness was found to be significantly different between the two groups with the majority of the referred patients being in the dying phase during COVID-19. The use of subcutaneous infusion was significantly higher during COVID-19,

Table 2 shows the distributions of age, Charlson Comorbidity Index, Elixhauser Comorbidity Index, time from admission to referral, time of referral to death, and time of referral to discharge between both groups. The Charlson Comorbidity Index scores were significantly lower during COVID-19 compared to pre-COVID-19, with mean scores of 8.65 and 5.77. The Elixhauser Comorbidity Index scores were also significantly lower during COVID-19 compared to pre-COVID-19, with mean scores of 14.98 and 6.57 Time from referral to death was significantly shorter during COVID-19 compared to pre-COVID-19, with means of 5.29 days to 1.96 days. Time from admission to referral and time of admission to discharge were non-significant between both groups.

The Australian-modified Karnofsky Performance Status scores were significantly different between the two groups with none of the during-COVID-19 group scoring higher than 40 (table 3).

Differences in the distribution of comorbidities were found (table 5). Hypertension and diabetes were most prevalent during COVID-19, especially among Black, Asian, and minority ethnic patients compared to metastatic cancer and hypertension pre-COVID-19. Differences in the prevalence of symptoms were found (table 4). Drowsiness, breathlessness, fever, and agitation were higher during COVID-19 compared to pain and drowsiness pre-COVID-19.

There were no significant changes or interactions to any of the above analyses when age, ethnicity or sex were included or used as a covariate. It must be noted that the small sample size of the various sub-groups became an issue for some of these tests. Table 6 shows the pattern of some responses for Black, Asian, and minority ethnic and White ethnic patients before and during COVID-19. Time of referral from admission was longer for Black, Asian, and minority ethnic patients especially during COVID-19, with a mean difference of 3.94 days between Black, Asian, and minority ethnic and White patients during COVID-19. Pre-COVID this mean difference was only 0.27 days. There is some evidence that female Black, Asian, and minority ethnic patients tended to have the longest time from admission to referral. However, this is non-significant.

Discussion

This is the first report to compare clinical characteristics, palliative care outcomes and symptom burden of patients referred to a hospital palliative care service before and during the COVID-19 pandemic. The main symptoms experienced by patients with COVID-19 are breathlessness, fever, drowsiness, and agitation. This is similar to the findings of a study describing symptom profile of COVID-19 cases referred to hospital palliative care services[8]. Pain and drowsiness were most prevalent pre-COVID-19. The majority of patients (56.7%) were referred for terminal care followed by symptom control (40%) during COVID-19. This is consistent with earlier reports which demonstrate that clinical deterioration in COVID-19 can occur rapidly[2,7,16]. Time from referral to death was significantly shorter during COVID-19 compared to pre-COVID-19. However, many of these patients were referred for symptom control instead of terminal care. This highlights the need for more focused education on recognising dying among healthcare professionals. It also highlights the importance of early referral to palliative care in COVID-19 and setting up a responsive, flexible, and integrated hospital-based palliative care service[10]. Given the symptom burden, psychological distress, and the potential for rapid deterioration and death[16–18], it is crucial for healthcare organisations to integrate palliative care into COVID-19 pandemic planning. The number of subcutaneous infusions required was higher in patients with COVID-19, and the majority were effective in managing symptoms. This is similar to the findings of a case series describing the use of subcutaneous infusions and their effectiveness in controlling symptoms in COVID-19[8]. Therefore, it is vital that services stock sufficient quantities of subcutaneous infusion pumps to ensure adequate control of symptoms.

The Elixhauser Comorbidity Index and Charlson Comorbidity Index scores were significantly lower during COVID-19 compared to pre-COVID-19, yet the death rate was significantly higher, and time from referral to death was significantly shorter for patients with COVID-19. Our data suggest that the Australian-modified Karnofsky Performance Status might be a more useful predictor of mortality than the Elixhauser Comorbidity Index or Charlson Comorbidity Index in COVID-19; however, further research is needed in this area.

Black, Asian, and minority ethnic patients, especially women, tended to be referred later to palliative care compared to White ethnic patients, before and during COVID-19. This reflects inequity in palliative care provision for Black, Asian, and minority ethnic groups[19], and the non-uniformed impact of COVID-19 across ethnic groups[20]. Evidence suggests that women are less likely to receive pain medications[21] and are more likely to present with advanced illness[22], assume a caregiver role[23,24], and experience a palliative care referral[25] compared to men. Our data suggest that women from ethnic minority groups are referred later than men. Further research on gender bias and

palliative care from an intersectional lens is needed. This will help understand how multiple social categories such as gender and ethnicity intersect at the individual experience level to reveal interconnecting systems of privilege and oppression at the macro socio-structural level. Routine data collection and research are needed to account for the key characteristics of each group within Black, Asian, and minority ethnic which could lead to different outcomes.

This service evaluation did not include data on patients with COVID-19 who were not referred to palliative care. Also, no referrals were received from the intensive care unit where the mortality rate for patients with COVID-19 is around 50%[26]. Severity of symptoms was not measured as time from referral to death was very short. The effectiveness of subcutaneous infusion in managing symptoms was based on follow-up subjective assessment as per the clinician notes in the Electronic Patient Records. We were not able to compare incidence with referral rates locally as community testing was limited and only patients requiring hospitalisation were tested for COVID-19 at the time. The small sample size did not allow for robust testing, and therefore, we could not draw firm conclusions about differences between the varied ethnic groups.

Conclusion

Patients with COVID-19 have lower comorbidity scores, yet they have higher prevalence of symptoms, lower performance status, and deteriorate and die quicker. Therefore, early referral to palliative care in COVID-19 is essential. Black, Asian, and minority ethnic patients tend to be referred later to palliative care compared to White ethnic patients, especially during COVID-19. There is urgent need to research why Black, Asian, and minority ethnic patients are referred later during COVID-19, how palliative care services have changed, challenges in providing care and effective solutions to setting up responsive, flexible, and integrated services.

Ethics approval: The project was registered with the Department of Quality Improvement (registration number: 2021206).

Declaration of conflicting interests

Author K.G. was hired and paid as a statistician to run statistical analyses

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