


Understanding the Intensive Care Unit Experience of Patients and Relatives at the End-of-Life During the Coronavirus Disease 2019 Pandemic

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Abstract

The coronavirus disease 2019 (COVID-19) pandemic has had a significant impact on patients and relatives' experiences of end-of-life care, as well as changing the provision of these services in intensive care units (ICUs) across the world. Established methods for assisting relatives through the grieving process have required modification due to the unique features and circumstances surrounding deaths from this disease. This mixed-methods study from the United Kingdom (UK) aims to review data from patients who died in a large ICU (the unit had a capacity for more than 100 ventilated patients), over the course of approximately 1 year. The inpatient noting of these patients was reviewed specifically for details of visiting practices, chaplaincy support, and patient positioning (prone vs supine) prior to death. Using this data, recommendations are made to improve end-of-life care services. To allow relatives the opportunity to attend the ICU, there is a need for early recognition of patients approaching the end of life. Clear explanations of the need for prone positioning and increased access to chaplaincy services were also identified.

Keywords

coronavirus disease 2019, pandemic, end-of-life care, bereavement, prone position, chaplaincy

Introduction

End-of-life care can be defined as “care given in the period leading up to death when it is acknowledged by all involved that death is inevitable” (1). The high mortality rates from coronavirus disease 2019 (COVID-19), coupled with the ease of transmission of the virus, have significantly impacted end-of-life care and bereavement processes.

Visiting restrictions were implemented in majority of the United Kingdom (UK) hospitals to help reduce the spread of the virus and to protect visitors. At our institution, visiting was completely suspended, for the duration of the study period with exceptions being made only in certain circumstances (2). The impact of these restricted visiting policies on the emotional well-being of relatives is well documented within the existing literature (3). While restricted visiting policies were in place, staff mainly communicated with relatives over the telephone. The need for clear, accurate, empathetic, and consistent communication with relatives during end-of-life care is well recognized, but this has been more challenging during the COVID-19 pandemic (4).

Isolation of the terminally ill, depersonalization of individuals through the use of masks or visors while wearing gowns, distanced observation, isolated removal of a corpse, and remote identification of the body are defining features of patient deaths from COVID-19 (5). Furthermore, bereaved family members may often have to grieve alone without practical and emotional support (6,7). Families have also been restricted in their abilities to hold funerals and other memorial services (5,6). The opportunity for individuals to embrace each other on such occasions and to assist friends and family going through similar grieving processes has

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also been restricted (8). These factors have led to a complete change in grieving practices.

A cornerstone of providing emotional support for relatives and patients at the end of life is through the use of chaplaincy services. Support can be provided to patients and relatives by chaplaincy representatives from the patient's faith background. Furthermore, those who do not follow any particular faith have found immense comfort in accessing these services. In our intensive care unit (ICU), chaplaincy services were provided face to face, however, during retrospective data collection, situations where there was a need or preference to provide remote chaplaincy support were identified.

COVID-19 ventilation practices in themselves have created additional challenges for staff in the ICU. Prone positioning (a technique where patients are rotated to be laid on their abdomens to improve gas exchange and oxygenation in acute respiratory distress syndrome) has been widely used during the COVID-19 pandemic (9,10). In this position, patients can appear depersonalized and faceless. Patients with COVID-19 often require multiple forms of invasive organ support within the ICU, with previous studies showing that relatives may view these interventions as dehumanizing intrusions (11). Prone positioning might further compound these feelings.

This study aims to review and evaluate visiting policies, chaplaincy support and the effect of depersonalization of patients in the prone position on end-of-life care in the ICU, with a view to improving our practices. Case note review of all patients who died in the COVID-19 ICU at our institution between March 1, 2020 and March 20, 2021 was undertaken, with a focus on analyzing documented discussions with the next of kin.

Material and Methods

This study was designed and conducted as descriptive mixed-methods research. All patients who died while hospitalized in the COVID-19 ICU at the Queen Elizabeth Hospital Birmingham (QEHB) between March 1, 2020 and March 20, 2021 were included in the study. The departmental registry was used to identify a total of 173 patients who fulfilled this criterion. Routinely collected data were obtained from the electronic hospital system (PICS System, Birmingham, West Midlands, England) for all 173 patients. Information included patient characteristics and demographic data (age, sex, and ethnicity).

COVID-19 status was confirmed by the results of a polymerase chain reaction (PCR) test, with only one exception. For patients transferred to the QEHB ICU from another hospital, the inpatient noting was also reviewed for information of positive swabs performed at the referring institution.

Patient notes were reviewed for documentation of religious faith. The date of hospital admission and transfer to ICU was taken from the departmental registry. Data on prone positioning, chaplaincy support, and visiting were obtained through a review of the inpatient noting with use

of the search function in free text to obtain key pieces of information. As well as reviewing the noting, the "inpatient service requests" tab was checked to see if chaplaincy support had been requested.

The date and time of death were taken from the verification of death documentation in the inpatient noting. If a time of death was not specifically stated in the patient noting, then the time of the noting being logged on the system was used.

The patients were divided into 2 groups, depending on when the death occurred. The first group covers deaths occurring between the period of March 1, 2020 to July 31, 2020 inclusive, and the second group covers deaths occurring between August 1, 2020 and March 20, 2021 inclusive. This division is in keeping with the national pattern of admissions to intensive care during the first and second waves of the pandemic in the UK. Although medical care evolved over the course of the study period as understanding about COVID-19 increased, there were no changes in the provision of end-of-life care in our ICU between the 2 waves. This included our visitation policy and the provision of chaplaincy support.

Statistical analysis was completed using the statistical package of Microsoft Excel (Microsoft Corporation). Continuous data are presented as means (standard deviation, \pm SD) or medians (Interquartile Range, IQR: Q1-Q3). Categorical data are presented as numbers (N or %). Percentages were recorded to the first decimal place.

Differences in mean length of hospital and ICU stays were calculated assuming unequal variances with a one-tailed Welch *t*-test. Comparison of mean lengths of time prior to death for which chaplaincy support was sought, were calculated assuming unequal variances using a Welch's two-tailed *t*-test. Statistical significance was predetermined as $P < .05$.

Results

The case notes of all 173 patients who died between March 1, 2020 and March 20, 2021 in the QEHB COVID-19 ICU were reviewed. One hundred seventy-two patients had COVID-19 confirmed on a viral PCR swab and 1 patient had a negative swab but was treated for COVID-19 based on clinical suspicion. Out of the total No. of 173 patients who died, 47 patients were admitted to the QEHB ICU following transfer from another unit in the West Midlands.

Fifty-nine deaths occurred in the first wave compared to 114 in the second wave. One hundred eleven patients (64.2%) were male and 62 patients (35.8%) were female. The mean age of the patients was 62 years (\pm 12). In terms of ethnicity, 77 patients from Black and ethnic minority groups died (44.5%) with only 60 patients (34.7%) identifying as "White British." Thirty-six patients (20.8%) had their ethnicity recorded in their case notes as "not known" or "not stated".

Religion was not routinely recorded as part of the demographic data and could therefore only be identified through

review of the inpatient noting. In total, 53 patients (30.6%) had a religion identified from their inpatient noting. The most common religion was that of the Islamic faith, with 37 (21.4%) of the total 173 patients included in the study identifying as Muslim. Of the remaining 16 patients with an identified religion, 7 (4.0%) were Catholic, 3 (1.7%) were Christian (non-specified), and 2 (1.2%) were of the Sikh faith. One patient of each of the Adventist, Anglican, Hindu, and Buddhist faiths made up the remaining 2.3%.

For the 173 patients, mean length of hospital stay at the QEHB was 16.4 (± 11.1) days with a mean ICU stay of 13.6 (± 9.8) days. Comparing mean length of stays across the 2 waves, patients in the second wave had a significantly longer mean length of stay in the hospital of 17.6 (± 11.6) days compared to 14.1 (± 9.6) days in the first wave ($P < .05$). Similarly, a statistically significant longer mean length of ICU stay of 14.5 (± 10.2) days versus 12.0 (± 8.8) days was noted across the second wave.

One hundred nineteen (68.8%) patients had visitors attend them in the 48 h immediately prior to their passing. Of the remainder, 45 patients (26.0%) had no visitors and 9 (5.2%) had visitors attending their bodies after their death. Of those who visited within 48 h of death, 84 (70.6%) were present at the time of death.

Of the 173 patients included in this study, 135 (78.0%) were placed in the prone position during their ICU stay according to clinical need. Review of case notes identified that prone positioning was mentioned in communications with relatives of 119 patients. 16 of these 119 patients were in the prone position when visited.

Chaplaincy support was sought for 55 patients (31.8%) during their ICU stay. This was initiated by the family members of 29 of the patients (52.7%). This was more than double the No. of requests initiated by ICU staff (11 (20.0%)). It could not be determined from the inpatient noting who initiated chaplaincy support in 14 (25.5%) of cases. There was 1 case, where chaplaincy support was initiated by the pandemic family liaison service. The median number of days prior to death that chaplaincy support was initiated was 0 (IQR 0-4). There was no difference in the mean number of days prior to death in which families initiated chaplaincy support (7.3 days) compared with when this was done by ICU staff (6.9 days) ($P = .95$).

Discussion

Visiting

During the data collection period, the visitor policy at our hospital allowed for up to 2 visitors during end-of-life care. In line with national guidance, visitors had to self-isolate after attending the hospital. The majority of patients 119 (68.8%) had visitors attend them in the 48 h immediately prior to their death, however, a notable number did not (54 [31.2%]). Although specific, granular data for pre-pandemic visitation were not routinely recorded, there were no restrictions on visiting prior to the pandemic. Reasons for relatives

not attending included the following: pre-existing self-isolation requirements, fear of risk to themselves from entering the ICU, not wanting to have to undertake self-isolation precautions after visiting due to personal commitments, and living too far away from the unit to realistically make it prior to their relative dying. Although not all of these reasons can be addressed through adjustments to end-of-life care provided by healthcare professionals in the ICU, it does allow staff to develop an understanding of the issues and concerns faced by relatives.

Early discussion about visiting practicalities to enable relatives to plan potential visits during end-of-life care is of key importance. There is evidence that not being able to say goodbye to a family member can act as a risk factor for chronic grief (1). However, as is the case generally in critically ill patients, death can occur suddenly in patients with COVID-19 and its prediction is therefore not always possible.

Our results show that the majority of relatives wanted to visit loved ones at the end of life. However, some may not want or may not be able to stay until the point of their loved one's death. Furthermore, witnessing death is recognized as increasing the risk of relatives developing chronic grief (1). The authors recommend that prior to entering the unit, relatives should be made aware that there is no necessity to stay until the point of their loved one's actual death. This allows relatives to come to terms with the finality of death in an individualized manner rather than creating a COVID-19 end-of-life pathway that all relatives must follow.

While restricted visiting is known to impact all ethnic groups, there is evidence that the impact is greater among minority ethnic groups. The inability to fulfill religious and cultural responsibilities is cited as the main reason for this. Furthermore, communication over the telephone with relatives, for whom English is not their first language, could further isolate them (12).

Prone Positioning

Multiple studies have attempted to generate models in assisting grieving relatives with the unique features and circumstances surrounding deaths from COVID-19 (13,14). However, none of these consider the patient's position when relatives see them in the final stages of their life.

Prone positioning is a well-recognized intervention in the treatment of invasively ventilated patients with COVID-19 in ICUs (7,10,15). As such, many staff are likely accustomed and desensitized to seeing patients in the prone position and therefore, when communicating with relatives, they may forget to mention this as a treatment prior to relatives attending. This could increase the distress of seeing their loved ones at the end of life. When considering the distressing features of a "bad death," seeing loved ones suffer can trigger pain for relatives (14). The unnatural and medicalized appearance of an ICU will no doubt trigger such emotions for many relatives as they gaze upon their loved ones. This could

also be further worsened when their loved ones are in the seemingly unnatural prone position, depersonalized and faceless. Of the 119 patients who were visited by next of kin in the ICU, 16 (13.4%) were in the prone position.

The clinical necessity for patients to be in this position should be explained to next of kin in advance. Prone positioning can be a life-sustaining intervention and if a patient were changed to a supine position they could die before their relatives were able to attend. The authors, therefore, advocate that when caring for a critically ill patient with COVID-19, if a patient is being placed in the prone position this should be communicated to relatives at the earliest possible opportunity.

A family liaison service was set up expediently during the pandemic to assist in communication with relatives. This service, which was run by medical students supervised by senior physicians, aimed to update relatives on a daily basis over the telephone. The service was fundamental in allowing ICU clinical staff to have more time to focus on their clinical duties (16). Where possible, the same member of the team would call the same family at the same time of day to reduce anxiety for the families in terms of delays in communication or unexpected calls. These conversations provided the opportunity to explain the need for prone positioning to relatives. This may have assisted in alleviating the distress of seeing their loved one in this position, even if this discussion was not immediately prior to the visit.

While hypothesizing that seeing a critically ill patient in the prone position is likely to have a significant negative emotional impact for relatives, the authors recognize that the relationship may be complex and that there is a need for further, detailed qualitative data to determine what feelings this has and its impact on grieving processes. Although there is evidence that similar critical care-based interventions, such as mechanical ventilation, can provoke negative emotions in relatives, there is also a recognition that positive emotions can be invoked when they are seen as a sign of care or as a lifeline (17).

Chaplaincy

The hospital chaplaincy service is a resource that can be utilized to support patients and family members. In our center, religious and humanist representatives offer spiritual support and can provide the appropriate last rites.

In our study, 44.5% of patients who died were from a Black or minority ethnic background with 34.7% identifying as "White British." This is in keeping with national statistics indicating higher risks of death among patients from these ethnic groups when compared to "White British" individuals (18). Compared to the 2011 census, (the last year for which data are available) an overrepresentation of Black and Asian ethnic groups was seen among our COVID-19 deaths. These ethnic groups account for 44.5% of COVID-19 patient deaths represented in this study but make up just 14.1% of the West Midlands population (19).

It is of note that changes in palliative care practices in response to COVID-19, despite being consistent across different ethnicities and religions are thought to have potentially had a greater impact on some minority groups based on different values and needs (12).

Chaplaincy support was sought for 55 patients, with this most commonly being requested on the day of death (median 0 days, IQR: 0-4). The majority of patients who died in the ICU received no chaplaincy support and this may reflect a potential failure of the discussion of availability of this resource. Additionally, literature on the perceptions and experiences of ICU nurses identifies that there is a belief that the role of chaplains overlaps with that of what ICU nurses can offer in the way of listening, praying, and counseling (3). We suggest that the role of chaplains and that of nursing staff are both vitally important and that together they could work synergistically for the benefit of the patient and their relatives.

It is thought that a No. of families may not have received chaplaincy support due to a lack of awareness of this service. The authors, therefore, recommend making patients and relatives aware of this support at the earliest opportunity. The family liaison service could act as a means of spreading awareness of chaplaincy support in the future. While chaplaincy is not limited to those of a religious faith, the authors note that "religion" was not recorded in the demographic data of the digital noting system used in the ICU. Routine inclusion of this data in the future would prompt staff to consider such services when a patient is initially admitted to the ICU. Furthermore, we note that the support of the Humanist chaplain was not requested for any of the patients in our study. We recommend increased staff education on the availability of this service for those patients who are of no defined religious faith.

From the feedback received via the family liaison service, many Muslim families requested passages of the Qur'an to be played for their loved ones. This was achieved by a "Qur'an cube" being placed near the patient which played the designated passages requested. When families were informed that this was an option, they often expressed sentiments of thanks and relief that their relative would receive spiritual support that they were unable to offer them at this time.

During data collection, a case was noted of a chaplain who was unable to attend in person due to being in a high-risk category for COVID-19. In this scenario, there is evidence from the literature regarding the effective use of "virtual" pastors who can provide support remotely via teleconferencing. The authors advocate that hospitals and ICUs preempt such scenarios by having the facilities for virtual chaplaincy in these cases (20).

Other End-of-Life-Care Considerations

The high mortality rate of COVID-19 makes deterioration and the need for end-of-life services a real possibility for all patients admitted with COVID-19. Thus, the authors

recommend that a patient's wishes are ascertained upon admission to the hospital to ensure that this opportunity is not lost should a patient lose capacity later on.

It has been recognized that among relatives of patients who die in the ICU, there is a prevalence of Prolonged Grief Disorder of approximately 9.8% (21). End-of-life care in a COVID ICU environment has likely caused an even greater psychological and emotional impact on relatives and on health care teams due to the high mortality rates. The 90-day ICU survival rate of patients with COVID-19 is approximately 60% compared with an 80% to 85% survival rate of non-COVID 19 patients (22,23). In order to compare rates of prolonged grief in relatives following death during the pandemic compared to other times, the authors recommend that further research be undertaken in this area. The authors also recognize that bereavement support is often needed for longer than just the immediate period surrounding death. The hospital held memorial services to honor those patients and staff members who had died from COVID-19. These aimed to provide ongoing support to those affected by loss during the pandemic.

The COVID-19 pandemic has placed an unprecedented strain on the ability of critical care workers across the UK to provide the high levels of care for their patients they strive for. Staff has commented on both physical and emotional intensity of caring for patients with COVID-19 as well as the difficulties of working with personal protective equipment (24). This study recognizes the need for further high-quality data focusing on the impact of bereavement on relatives, and on the challenges that critical care workers face when providing high-quality end-of-life care.

Communication through video conferencing software was utilized on the unit during the pandemic if a patient could give consent for this. Given the severity of their disease process, only a minority of patients were able to do this once they were admitted to the ICU.

Limitations

There are a No. of limitations within the design of this study. First, a No. of patients were transferred in from another ICU leading to incomplete data as certain details from the transferring unit were not available to the researchers.

For a No. of variables, data could not be determined due to a lack of documentation (eg, in 14 out of the 55 patients for whom chaplaincy support was provided, it could not be determined who requested this support). Considering this, it is apparent that the quality of our data is fundamentally dependent upon the quality of data inputted contemporaneously by clinical staff during a patient's admission.

The authors recognize that pre-pandemic data was not readily available to specifically compare end-of-life care practices prior to the pandemic to those observed in the study. Having this data would allow more meaningful comparisons to be drawn between the 2 time periods. The authors suggest that this data be routinely recorded in a standardized format for all future admissions.

Data on religious faith was not always noted for patients in the ICU and the authors recognize this as a limitation to the study. In the future, routine documentation of this data should form part of the minimum demographic dataset to be recorded for each patient.

Conclusion

This study provides an insight into the end-of-life care practices in a COVID-19 ICU during the first and second waves of the pandemic in the UK. It reviews and subsequently identifies key areas in which end-of-life care practices can be improved. Early recognition of the patient who is approaching the end of their life so that relatives can attend, explaining the need for prone positioning, and improving access to chaplaincy services are areas that need to be focussed on to improve end-of-life experience in the ICU. It is essential to continue to develop an understanding of how best to support patients and their relatives during end-of-life care in this ongoing pandemic.

Declaration of Conflicting Interests

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Note of Reference


Throughout this article, we have used the term "relative" to indicate the patient's next of kin. In the majority of cases, this was a family member, however, on occasion this was a friend or other individual of significance to the patient who was advocating on their behalf.

Institutional Approval

At the request of the administrative team, we have added the institutional approval statement to the title page as below for anonymization purposes prior to it being added to the manuscript at production stage: Institutional approval for this study was granted via the Clinical Audits and Registries Management Service (University Hospitals Birmingham NHS FT, Birmingham, England) under registration number CARMS-17006 on March 31, 2021.

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