

Palliative medicine in intensive care unit during a pandemic

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ABSTRACT

The coronavirus disease-2019 (COVID-19) or severe acute respiratory distress syndrome coronavirus 2 (SARS-CoV-2) pandemic has changed the landscape of medical care. Efforts made to limit the spread of the deadly disease have impacted the specialty of palliative medicine in ways that could not have been completely predicted or appreciated. The consequences of these changes have been most evident in the care of COVID-19 patients and families within the intensive care unit. The policies meant to keep staff, patients, and families safe, greatly changed the way that palliative medicine could be provided. This article provides a more in-depth look at how the practice of palliative medicine adapted to such difficult and constantly changing times, particularly in aspects of family meetings, communication, paternalism, managing emotions, death, and grief. Despite the ongoing challenges presented by this virus, the specialty of palliative medicine may be well suited to adapt and flourish.

KEY WORDS: Critical care, intensive care unit, medical intensive care unit, palliative care, palliative medicine, pandemic

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INTRODUCTION

Palliative medicine can be defined as a specialty service that provides comfort to those suffering and struggling with life-changing conditions. The Center for the Advancement of Palliative Care (CAPC) defines palliative care as, “Specialty medical care for people living with a serious illness.”^[1] Palliative medicine is known for its flexibility, adaptability, and the emphasis that is placed upon “meeting the patient and family where they are.” The service provides immeasurable value to patients and families and is widely considered to be an integral part of the standard of care in many areas of the hospital.

The intensive care unit (ICU) can be a challenging place to integrate palliative medicine. While the multidisciplinary approach is a core tenet in the ICU, the complexity and

acuity of each case, coupled with highly knowledgeable and intensely focused colleagues, can make it a logistical battle. Arranging a family meeting or holding a bedside discussion can be fraught with barriers rarely appreciated on a regular medical–surgical unit. This same environment that presents these obstacles, however also, benefits immensely from the involvement of palliative medicine. The specialty provides an opportunity to streamline goals, avoid unnecessary treatment and spending, provide staff support, and lessen the incidence of posttraumatic stress disorder (PTSD) for patients and families, while also addressing moral and ethical dilemmas.

The coronavirus disease-2019 (COVID-19) virus has presented the world with crises and catastrophes that no one was fully prepared to handle. It has had an incalculable

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toll on frontline workers, patients, families, hospital budgets, personal protective equipment (PPE) obtainment and storage, etc. It is fair to say that COVID-19 has forever changed the landscape of our lives, both in and outside of the hospital. Therefore, it is of no surprise that palliative medicine, within the ICU setting, has been vastly impacted as well. Interestingly, though, it could be argued that in many ways, palliative medicine providers are uniquely suited to face this trial as they have a role in supporting and guiding other providers and staff, managing symptoms, and working with frail individuals with multiple comorbidities; while also providing care and support for families and friends.^[2]

Riverside Regional Medical Center, a not-for-profit, level II trauma center, is an urban hospital in Southeastern Virginia. The hospital, of approximately 450 beds, 18 of which are in the medical ICU, prepared for the logistical aspects of treating large numbers of COVID-19 patients, as did many other hospitals across the country. What could not be fully prepared for, or even anticipated at the time, was the implications that these changes would have on the practice of palliative medicine.

FAMILY MEETINGS

Family meetings have long been considered to be the “procedure” within the specialty of palliative medicine. While each practitioner’s style may vary, the principles of this communication tool are sound and its importance cannot be overstated. Under traditional circumstances, family meetings serve to meet the needs of rapport and trust building, communication, education, boundary setting, self-care, dignity, honoring wishes, supporting autonomy, and self-determination. Typically, these meetings are highly structured. They offer an opportunity for the patients and families to express their understanding of medical concerns, ask questions, and begin to learn more about the medical obstacles they are facing. Family meetings also offer a venue for tackling highly emotionally and culturally sensitive questions about code status and limitations of medical care. Even under the best circumstances, with highly trained palliative medicine providers, these meetings can be arduous and quite emotional.

In its response to COVID-19, we made major changes to the visitation policy, for the safety of patients, staff, and also the community. The unintended impact of these stricter visitation policies within palliative medicine was the severely limited ability to have these goals of care defining “procedures.” Literally, overnight, family presence vanished from the bedside and these meetings were taking place over the phone, via Zoom or FaceTime conferences. It seemed disorienting and sudden to go from navigating a family conference with both verbal and nonverbal indicators of understanding to nothing. Where once an appropriate touch to the shoulder could be offered to convey warmth, support, and sympathy, the

team was forced to rely simply on words which can be coldly inadequate.

While certainly not impossible, the opportunity to gain trust and rapport is limited when social distancing requires 6 feet or more. The palliative medicine team quickly began to see these conferences become much longer than a typical 60 min meeting. The ability to communicate the intricacies of very complex medical situations was tougher and now seemed to carry much more dire consequences. Nonverbal expressions of understanding and reassurance were far less visible than ever. Often, there was an absolute loss of words to adequately describe the emotional and physical suffering being witnessed.

Taking video conferencing to the bedside was an attempt at problem solving. Allowing family members to “see” the seriousness of their loved ones condition often held more weight than the information they frequently received from staff at the bedside.^[3] Unfortunately, this practice felt constraining and cumbersome. Staff, like at many other facilities, faced limitations in PPE. It could be questioned whether using PPE to have a video conference at the bedside to “show” family their loved ones was an ethical or even practical use of PPE. In doing this, was PPE being taken away from other more critical staff members?

The sounds of ventilators, dialysis machines, intravenous pump beeping, from almost every room in the 18-bed unit, limited the opportunity for meaningful conversation. Medical providers, respiratory therapists, nurses, and care partners understandably interrupted to provide necessary care, while the palliative medicine team gingerly worked toward addressing some of the most difficult of medical questions. The majority of our COVID-19 patients were sedated, ventilated, and at times prone, leaving them unable to know they were even being filmed, much less be able to participate.

Even with the additional steps of video conferencing, and supporting families who simply wanted their patients to “hear my voice”, these efforts were not enough to fully help these families understand the true devastation of this disease. Daily, families seemed to be bombarded with new hopes of treatments from the media and it remained challenging to help families be cautiously hopeful and yet realistic.^[3] Family conferences were happening more frequently and taking longer, but seemed to be less productive. It could be said that investment into this area of palliative medicine’s toolkit is easily doubled.

COMMUNICATION

In the absence of what we know, it is common and normal to create our own version of the truth. More and more during the COVID-19 pandemic, it became evident that the palliative medicine team was not only working to improve medical literacy for family members who could

not be present, but was also working to “undo” the version of the truth that families had created by not being present at the bedside.

The typical tools palliative medicine practitioners rely upon to be efficient and effective; were woefully inadequate. Active listening and compassion is much harder to convey when not sitting in the same room with a family. Displaying open body language and nonverbal indicators of understanding to build trust and express empathy, lose much of their importance through a screen.^[3]

It became harder for families to understand and appreciate the circumstances of their loved ones, which understandably provoked emotions of fear, anger, desperation, and utter helplessness. It was equally challenging for practitioners to interpret the feelings and needs of families. Daily, it became more evident how clearly, we relied upon the nonverbals and body language to help guide these challenging conversations.^[3] More time was spent restating and rephrasing information that perhaps would have had more weight and meaning when it could be underscored by the sounds of struggled breathing from a loved one or the offer of physical touch to convey support.

Moral distress, changes in self-confidence, and increased emotional strain seemed to impact practitioners who normally navigated ICU cases with relative ease. The COVID-19 pandemic demanded adaptation not just within the hospital but also within personal practice and team members consistently adjusted to accommodate to the often-rapid decline of patients and to “meet the patient and family where they are”. Things that ordinarily would be considered impractical or unreasonable became viable options. The palliative medicine team tried new techniques, video conferencing of a variety of platforms, recording images, taking pictures, writing wishes, etc., all in the hopes of bridging the physical and emotional gap that had formed between patient, family, and medical team members.

PATERNALISM

As more and more families struggled to fully understand their loved ones medical situation, many providers were faced with the prospect of needing to become more paternalistic. Typically, within palliative medicine, the utmost care and attention is given to self-determination and preserving a patient’s right to choose their care and treatment, regardless of a team member’s personal views or even the desires of other medical providers. It could be said that palliative medicine teams are the “tour guides” that allow patients and families to view and understand their options for care.

However, in a time when there were rising concerns for appropriate use of resources, paternalism became more

evident and arguably more necessary. While there was never a lack of effort in trying to identify the patient’s wishes and wants, more and more recommendations were being offered, or given unsolicited, to help in decision making. Interestingly, these recommendations seemed to be needed and even wanted from families who were still struggling with indecision, likely secondary to their absence at the bedside.

Perhaps these exercises in paternalism were introduction to the decision-making that could follow, should we face the onslaught of COVID-19 patients that were initially forecasted. While triaging medical resources was not exercised in the initial wave of patients, it was on the minds of all those providing care. There was an understanding that at some point, a triage system, that could impact the life expectancy of our patients, may have to be implemented.

EMOTIONS

COVID-19 did not change the emotions that already flooded our ICU. However, it did add new feelings and it heightened the ones that were already familiar. This had vast implications that changed the overall dynamic.^[3] Our ICU staff rose to the occasion to care for their patients, but the uncertainty and anxiety was palpable throughout the unit. Intense attention had to be paid to donning and doffing PPE just perfectly. There was increased strain attempting to keep families updated via telephone calls that seemed to pour in. Uncertainty about how to proceed, when current efforts did not seem to be working for their patient, was palpable. This heightened emotion is not atypical, but was more and more evident as the number of COVID-19 patients increased.

As stressors climbed, the dynamics within the multidisciplinary team also changed. At times, there were heated exchanges, tears that dampened masks, and fears that made walking into a room more challenging than it ever had before. These same feelings also impacted the palliative medicine team’s ability to care for patients and families. Dynamics within the unit and team have the potential to impact the care provided in innumerable ways.

More than ever before, efforts of the palliative medicine team were directed as much to staff, as to patients and families. Uncertainty, fear, moral distress, anxiety, anger, grief, loss of control; these are only some of the many emotions being pushed to the side when caring for a critically ill patient; whose illness risks your own safety. Emotions such as these put staff members and critical care providers at higher risk for burnout and compassion fatigue, which requires attention, support, and validation.^[4] The palliative medicine team was spending increased time visiting with staff, questioning how they were handling things, asking about families, finding reasons to be grateful, and opportunities to laugh.

The palliative medicine team also found itself impacted by the heaviness of these emotions. While these emotions were not unfamiliar, the weight of them was amplified by the extended and numerous family meetings, increased emotional investment, and care for staff at the bedside. Team members described feeling “exhausted” by the intensity of the emotion expressed by family members who cannot be at the bedside.^[3]

DEATH AND GRIEF

It is not altogether uncommon for someone to die in a hospital alone. However, even when no one is there in that last moment, the presence of friends and family has been felt and appreciated throughout the prior journey. Death within an ICU can be complicated by decisions to de-escalate care or palliatively liberate someone from the ventilator. These decisions and the events that follow, in the era of visitation restrictions, greatly increased the likelihood that a patient would die alone with little or no contact with their families. This idea of a loved one dying alone engenders fears of the patient not being cared for, suffering due to physical or existential pains, and concern that they will be treated as a number and not the valued member of society that they are.^[5] Palliative medicine helps minimize or in the best situations even alleviate these fears. It is the ongoing goal of palliative medicine teams, and now an expected standard, to help patients have “a good death” where at all possible.^[6]

Efforts were made to accommodate families and patients when able, with the use of technology. Exceptions were made for terminally ill patients if able. While these allowances carried therapeutic benefits for many more individuals than just the patient, there was significant risk involved. Time, attention, and emotional energy were invested daily into weighing the risks of introducing potentially sickened visitors into the ICU or having a visitor become exposed to COVID-19 during their visit. It felt as though allowing or denying a visit had life-altering and perhaps life-threatening consequences.

Never before has the palliative medicine team played the role of “gate keeper.” In constant interaction with nurse managers and administration, concessions were made and visits did occur. Palliative medicine team members escorted families to and from ICU beds or in some cases death beds. Never before was the burden of telling a family member of a dying patient, “You only have 30 min” laid at the feet of the team. It was often the palliative medicine team that heard the understandable, but fiery anger, of those who could not be present or loved ones who felt they were being “cheated” of their opportunity to say goodbye.

All types of staff members took on new roles as surrogate family. Many sat at the bedside, offered to assist in face time calls, or held the phone so that family could hear their patient’s voice one last time. While their presence

was selfless and offered some comfort for family member’s not present, it may have left behind scars and unresolved grief. Being present with those who die often elicited more emotional investment from staff than ever before. Some of those staff members may continue to experience vicarious trauma for the patients and their families; both of whom were alone. To compound this new role, many staff members experienced multiple losses within a shift, not even having the time to emotionally process their first death before facing another.^[4]

While grief support and counseling remains available outside the hospital, in pre-COVID times, the palliative medicine team strived to do it in person when possible. Typically, the palliative medicine team can help begin this process, even before death, by introducing the “what ifs” of a loved one’s medical journey and perhaps initiating feelings of anticipatory grief. However, this experience became much less possible in a time of restricted visitation and social distancing. Allowing family members to have a role in their loved one’s care helped with a sense of closure. The limited visits and restrictions impacted the opportunity to “say goodbye” in person. The long-term implications of this separation and lack of closure cannot be fully known now, but should be anticipated to have long-lasting implications that will require support for families and caregivers in to the future.^[4] Even before this outbreak, there was the understanding that patients and families within ICU tended to have higher rates of PTSD and prolonged grief; hence, providers of bereavement services are anticipating increased rates of complicated grief and depressive symptoms.^[4]

To not be present for the death of a loved one can bring with it feelings of guilt. To not be able to appropriately mourn for a loss may prompt feelings of anger, injustice, and lack of closure. Family members and medical staff alike may experience a lonely kind of loss, a sense of disenfranchised grief, as their mourning and pain cannot be appropriately seen and validated by those around them.^[4] Some specific cultural or religious rites and rituals could not occur as dictated, potentially leaving family with uncertainty about their loved one’s spiritual journey.

CONCLUSION

Palliative medicine is an adaptable, flexible, source of comfort, and support for patients, families, and staff facing a life-changing disease. The palliative medicine team’s abilities have been stretched and tested by the trials of COVID-19, especially within the ICU. Processes have been adjusted to meet the needs of this new time with COVID-19 and the patients and families who are suffering through it. As the past is looked to for lessons, it seems clear that palliative medicine teams will be asked to do more with less. As the future is looked to with hope, it is more evident that more needs to be done to not only prepare our medical community for future pandemics, but to ensure quality

palliative medicine can be provided to those who live and die through it.

Arguably, palliative medicine may not be as effective at lowering length of stay or time on the ventilator, as it was in the pre-COVID era. It has however proven itself to be an integral part of multidisciplinary care within the ICU that can help patients, families, and colleagues alike navigate these changing and challenging times.

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Conflicts of interest

There are no conflicts of interest.

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