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Letters

# Comments From This Atheist in the Foxhole



Although there is no question that each palliative care team should be fully staffed with social work, chaplains, nurses, and physicians, I have to take issue with a few of the constructs offered in the article *The Urgency of Spiritual Care: COVID19 and the Critical Need for Whole Person Palliation (Journal of Pain and Symptom Management*; volume 60/3, 2020).

Palliative care continues to be committed to wholeperson care. It is our foundation and bedrock. It is why we mandate interprofessional teams; why the 2018 domains laid out specifically the roles and expertise of all these team members. However, the article could have stopped there because that commitment speaks to what every palliative care clinician wants to provide. We also know that each person, family member, and colleague we have contact with is different we are attuned to their specific needs, hopefully hearing their unique perspective to be able to meet those needs. There is no more urgency for spiritual care than there is for psychosocial care. However, both social workers and chaplains have mostly been considered nonessential workers during this pandemic. Perhaps that should have been the focus of this discussion.

This atheist in this pandemic foxhole does not agree that suffering is endemically spiritual or religious. In addition, the war metaphors continue an unproductive binary view of crisis and illness that tend to limit our possible responses. What we absolutely know about this pandemic is the impact on patients, families, and providers is intense and a crisis. We know that the level of compassion fatigue, moral distress is very likely heightened for everyone touched by this pandemic. There are many ways to address these reactions, including offering spiritual support for those who choose it. I would however highlight (mirroring the domains) the expertise of the palliative care social worker as the key person on the interprofessional team with the skill set to assess, intervene, and strategize about these very complex realities. Of course, providing spiritual support is key to these strategies, should this be assessed as a need.

We should be careful what we assume about this crisis and how it is effecting everyone. I suspect there are many atheists in the foxhole. To truly provide whole-person care, we must always ask first, assume nothing, to best meet people's needs.

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## A "Good Death" During Coronavirus Disease 2019: Outdoor Terminal Extubation Facilitates Safe Family Presence for a Dying Patient



#### Introduction

Among the heartbreaking consequences of the coronavirus disease 2019 (COVID-19) pandemic is the large number of patients who have died alone as a result of hospital policies that restrict or prohibit any visitors for admitted patients. These visitor restrictions apply to both patients with COVID-19 and without COVID-19. They are necessary to limit contagion but carry the untoward effect of inflicting additional emotional and psychological duress for patients, families, and clinical staff. These effects are more profound in the case of a dying patient.

For some end-of-life patients, discharge to home hospice may allow them to be with their loved ones during the dying process. However, for the critically ill, ventilator-dependent patients with a plan to transition to comfort-focused care through a terminal extubation, options are limited to honor their preferred place of death. Prior literature describes successful at-home terminal extubation to honor preferred place of death. <sup>1–3</sup> During the COVID-19 pandemic, at-home terminal extubation is a viable option that would allow multiple family members to be present. However, at-home extubations can be prohibitive in patients with hemodynamic instability, an unacceptable distance from hospital to home, or a home unsuitable to accommodate comfort care.

We describe the case of a critically ill patient for whom transition to home was not feasible. We provided an outdoor terminal extubation on a secluded area of the hospital lawn, facilitating family presence while maintaining pandemic safety precautions. To our knowledge, this is the only reported outdoor extubation used for the purpose of facilitating family presence in the setting of pandemic restrictions.

#### Case Description

The patient was a 25-year-old woman with metastatic Ewing's sarcoma. She was being treated with cyclophosphamide and topotecan when she presented with hypoxic respiratory failure secondary to left hydropneumothorax, multifocal pneumonia, and extensive bilateral pulmonary metastases. She tested negative for COVID-19 and was cared for in the medical intensive care unit. Her hospital course was complicated by refractory septic shock and progressive respiratory failure.

An extensive goals of care meeting occurred on hospital day 15 with her father, also her surrogate decision maker. He understood that she was very close to death, did not want her to suffer, and requested transition to comfort. We provided support for his anticipatory grief surrounding his only child's death. We also addressed his hopes and worries surrounding transition to comfort. He expressed devastation that she would be unable to say goodbye to their close-knit family owing to hospital visitor restrictions, which allowed only 1 family member at the bedside of a dying patient. The full, meaningful family included her stepfather, aunts, and uncles.

An at-home terminal extubation was not possible owing to the long distance to her home and the father's fear that he could not live in a home where his child had died. We then offered the option of terminal extubation on the hospital's lawn, to allow her full family to be with her throughout the process.

He expressed excitement and gratitude at this ray of hope in a time of darkness.

The engineering department worked quickly to make the required exterior site alterations to create a feasible space on a secluded area of the lawn. Carpenters built a ramp for stretcher egress, hung a curtain for discretion, and arranged a family sitting area. Hospital security placed personnel in strategic locations to protect the family's privacy.

Our multidisciplinary clinical team, including nurses, a respiratory therapist, pharmacist, and physician, created a medication travel pack, given lack of access to a PYXIS while outside the hospital. Nursing staff hung a new hydromorphone infusion before leaving the intensive care unit. We packed additional comfort supplies including absorbent pads, emesis bags, moistened wash cloths, and nasal cannula.

When all were ready, our team moved her, still ventilated, along with the comfort medications and supplies, to the designated area on the lawn. The palliative social worker met the family at the parking garage and walked them to the outside lawn. The family wore face coverings and upheld social distancing guidelines.

After each family member had spent time at the bedside, the family signaled their readiness for extubation. She was extubated outside and died comfortably within an hour of extubation, surrounded by her father and eight loving family members.

#### Discussion

The COVID-19 pandemic has posed significant challenges to the provision of quality end-of-life care. For hospitalized patients, strict visitor restrictions have further hampered our ability to fulfill end-of-life wishes. This can be devastating for patients and families, inflicting additional distress at an already difficult time.

Palliative literature has shown that the majority of patients prefer to die at home, <sup>4</sup> although only 30% of patients actually do. <sup>5</sup> For bereaved family members, death occurring outside the hospital is associated with better perceptions of end-of-life care. <sup>6</sup> Families of patients who die in the hospital or intensive care unit have been shown to be at increased risk for prolonged grief and post-traumatic stress disorder when compared with home hospice deaths. <sup>7</sup>

Offering death outside the hospital is not always feasible; critical illness, and particularly mechanical ventilation, is often seen as precluding it. The present pandemic has only magnified the obstacles.

Here, we suggest an innovative way to improve endof-life care during a time of strict visitor restrictions owing to a pandemic. Now, when the family cannot come to the patient, we offer a way to bring the patient to the family. Once transferred to a private area on the hospital lawn, she was surrounded by family and allowed a place of death outside the hospital.

The family expressed tremendous gratitude for the chance to be present during their loved one's death. The medical staff was proud to offer the patient a creative "good death"; facilities and security personnel took pride in this very rare chance to tangibly affect patient care. Since this occurred, our institution is moving to creating a permanent outdoor space where terminal extubations can be more often offered.

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