

Short Communication

Reflection on Complexity at the End-of-Life—More Nuanced than Simply Treating Patients the Way We Would Want to be Treated

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I relocated to the United Arab Emirates (UAE) just over three years ago, to start a new palliative care service in Abu Dhabi. Palliative care remains a relatively unknown medical specialty here in the UAE both among clinicians and the public. As a new team, we were recently reflecting on some of the more challenging situations that we faced since setting up the service. This case reinforces my belief that palliative care is complex, individualized, holistic care and ‘looks different’ for every patient and their family.

CASE EXPERIENCE

A 16-year-old female patient with a tumor of her spinal cord returned to the UAE having received extensive treatment in the United States. Her tumor unfortunately had not responded to treatment and had spread to the brain and leptomeninges. She was initially under the care of the medical oncology team before her care was transferred to the palliative care team at the request of the patient and her family.

The patient was well-supported by her mother and brothers and there was always a family member in attendance. Although a minor, she had always been actively involved in the decisions about her treatment but on her return to the UAE, she preferred to focus on discussions around symptom control and asked that other discussions be directed to her elder brother, the nominated decision maker.

Symptomatically, she complained of headache and back pain which were well-controlled with standard analgesics. As a result of the tumor location, she started to develop progressive paralysis of all the limbs, lost the ability to vocalize, and developed rapidly progressive cranial nerve palsies. During our many

discussions with her family, we explained the likely trajectory of her condition and explained in detail, the physical changes that were likely to take place because of her condition including cranial nerve paralysis, and how this would affect her ability to breathe. Her family was always very receptive to our discussions and while they were accepting and embraced fully the palliative care approach to caring for their sister—they also felt quite strongly that they were not ready to let the patient go and so wanted life-prolonging treatment (cardiopulmonary resuscitation and ventilatory support), even if this meant that she may suffer for a prolonged period.

They explained that while they understood and respected our explanations, they felt that suffering was an inevitable part of life and in keeping with their beliefs, ‘*it would be good if she suffered more now, as she would reap exponential benefits of this suffering in Heaven at a later stage*’. The family was unanimous in this belief and her brother also relayed that the patient herself insisted on doing everything possible to prolong her life. We broached the option of an elective tracheostomy rather than emergency intubation, but the family insisted on delaying this as long as possible. As expected, she deteriorated further with hypercapnia secondary to phrenic nerve paralysis and required emergency intubation and mechanical ventilation.

She survived for another 48-hours post-intubation and received cardiopulmonary resuscitation (CPR) prior to her death. Her family was very thankful for the care that they received and particularly appreciative that their wishes were respected. They reiterated that while they were sad, they accepted the outcome as part of God’s plan for their loved one.

DISCUSSION AND CONCLUSION

This case prompted much discussion among the team afterwards. Clinically, we knew what to expect and predicted accurately, the natural course of her illness. Many team members felt strongly that the patient herself suffered unnecessarily by being intubated, ventilated, and receiving CPR. From a medico-legal perspective, the patient satisfied the criteria for allow natural death (AND) status which would have enabled the medical team to avoid doing CPR at the time of death. However, in keeping with Article 11 of the UAE Federal Decree-Law No. (4) of 2016 on Medical Liability,¹ even if felt to be clinically futile, if the patient insists on CPR, this request must be honored.

This case will resonate with many clinicians who provide palliative care, and it highlights the complexities and paradoxes that commonly arise at the end-of-life (EoL). There was clear moral distress among the ward staff who felt that she suffered unnecessarily and did not have a good death. In contrast, the family's perspective was that "everything happened as per God's will". The Institute of Medicine's definition of a good death is a death free from avoidable distress and suffering, for patients, family, and caregivers and in general accord with the patients' and families' wishes and reasonably consistent with clinical, cultural, and ethical standards.² Like many things in life, everyone's perception of a good death and suffering is subjective. Although there have been studies conducted within the Middle East region about what constitutes a good death, none of these specifically included a cohort of patients from the UAE.

Although palliative care in the UAE remains one of the lesser-known medical specialties, my experience has been that most patient families respond positively to our input. Published data from our unit³ showed that 76% of patients referred for palliative and end-of-life care (EoLC) accepted a Do Not Attempt Resuscitation (DNAR) status, with 65.6% of UAE families accepting the DNAR status. There are two typical responses following a discussion about a patient's anticipated death and this has already been documented in a previous publication.⁴ The more common response is total acceptance and submission to Allah's will, because of the belief that everything is pre-destined and comes from Allah. The alternative response is a total emphasis on utilizing every medical intervention available to prolong the patient's life. For the latter response, the rationale is that "at least we know that we did our best, we tried everything" and "whatever happens next is as per Allah's will". This case stood out for me because the family's perception

was atypical in my experience. They did not justify wanting life-prolonging treatment for the usual reason—their belief that more intentional suffering for the patient at the end of this life would lead to greater reward in Heaven was completely new to me.

When I started training as a doctor, for patients who were approaching the EoL, the ideal good death was generally felt to be a death in your own home, in familiar surroundings with those you love around you. Over time, it has become obvious that things are much more nuanced – for many patients, they do not want to die at home, they may not have any friends or family able or willing to care for them and hospital is where they feel safe. This idealized version of a "good death" may not be accurate and stems from the so called Golden Rule⁵—*where we treat patients as we would want to be treated in similar circumstances*. As in this case, when a patient and their family's perceptions are so radically different from ours, our perceptions of their suffering may be radically skewed. People are permitted to want things that are different than what we would choose for ourselves. Respecting the Platinum rule⁵; "consider doing unto patients as they would want done unto themselves" may be a more appropriate standard for achieving more personalized, patient-centered care.

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