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End-of-Life Discussion: An Empathetic Challenge

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My patient is an 82-year-old male with a past medical history of atrial fibrillation, coronary artery disease, heart failure with reduced ejection fraction, dementia, and hypothyroidism who presented to the emergency department for acute shortness of breath. The patient presented with acute respiratory distress and was placed on supplemental oxygen, as his family declined intubation. Imaging revealed a large effusion and occlusion of the right bronchi while cultures revealed infection. A chest tube was placed to drain the effusion. Moreover, a modified barium swallow test showed dysphagia and therefore significant aspiration risk. Given his rapid deterioration, palliative care was consulted and family meetings were conducted throughout his stay. I had the chance to sit in on several family meetings, which included the patient's family and spouse, the hospital palliative team, floor case manager, and geriatric team fellow.

At the very first meeting, I witnessed a mix of emotions from the patient's family, including frustration, anger, doubt, shame, worry, and sadness. I saw how challenging it was for the palliative care team to introduce the topic of end-of-life care to his family and spouse, especially since the patient did not have a living will. Family members disagreed on future treatment and discharge plans, and the room became heated during several occasions. While the family members were arguing amongst themselves, they also exchanged terse words with the palliative physician and geriatric fellow, as they were worried and afraid for their loved one.

End-of-life discussions and decisions are complex and challenging, particularly when a patient is not deemed competent to make their own medical decisions. Our patient was not deemed competent at this time, as he was not at his cognitive baseline and could not make well-informed decisions about his healthcare. . Harrison et al[1] argue that competency fluctuates for patients with dementia, and that competency should be reassessed before making major medical decisions. Furthermore, family members and medical surrogates should always keep the patient's preferences in mind if they are not deemed competent. Some of the most common times when end-of-life discussions are introduced include catastrophic healthcare events, such as discussions about resuscitation, poor response to antibiotic treatment, complex medical symptom management during deterioration and decline, and problems with continued nutrition and hydration, all of which are emotionally difficult issues to navigate. Our patient with dementia was having difficulty with nutrition and hydration in the setting of an infection and effusion; thus, the palliative physician used this clinical dilemma as a segway for introducing a discussion on end-of-life care. Even though our patient was diagnosed with dementia years ago, he never discussed his healthcare values and wishes in a time of medical crisis with his family. In this moment, I realized that, if possible, end-of-life discussions should occur gradually with patients and trusted caregivers. With this approach, all members of the healthcare team can have continued discussions with patients and families, who would also benefit from more time to think about what is truly best for the patient.

During this experience on the geriatric team, I learned the importance of empathy, understanding, and patience when introducing and discussing end-of-life care with patients and their families. I also witnessed the power behind honesty and not instilling false hope. When the palliative care physician answered the family members' emotionally packed questions, he gave realistic and honest responses about the patient's health status and likely disease trajectory. I learned that this approach gave the family members truth without instilling false hope, and it comforted them with such difficult news. He was direct yet sensitive, an emotional combination that I imagine takes years to master, particularly in a palliative care setting.

I also witnessed the importance of cultural sensitivity in respecting the patient/family's needs and desires. During end-of-life discussions, supporting patients and their families on a spiritual level is just as vital as supporting them physically. O'Brien et al[2] argues that providers should respect each family's base of spirituality and recognize spiritual distress. Palliative discussions can often even take precedence over a patient's medical issues towards the end of life when there are little to no medical interventions left. The palliative care physician incorporated spirituality and religion into the family meetings, and his consistent references to their faith provided them with comfort, settled several disagreements, and instilled meaning during times of distress and hopelessness. While this physician shared the same religious beliefs as the patient and his family, I thought about how I would address similar discussions if I did not share a patient's spiritual beliefs. There is something to be said about providers who momentarily prioritize their patient's values and beliefs above their own to comfort them in such fragile situations, and I strive to do the same for my future patients.

I vividly remember one moment when the family members were arguing extensively about discharge plans and responsibilities. The physician encouraged each of them to take a step back and put themselves in the patient's shoes. *"If you were him, what would you want?"* The room suddenly went silent, and they all looked down to think. This question was brief yet immensely powerful, as it forced them to understand not only what their loved one was enduring, but also what he truly wanted. It did not take much time for everyone to join forces with a shared goal: to grant their loved one's wishes. This moment impacted me in so many ways, as I started to think about my previous experiences with patients and families and how the patient's wishes were often not prioritized by family and friends. I realize this theme is common among the geriatric population, particularly for patients who are dependent on others for their activities of daily living. I noticed how patients are put in fragile and powerless positions, and sometimes their caregivers may take advantage of them, consciously or not. While healthcare providers cannot control what happens in a patient's home after discharge, we can be advocates for our patients during their hospitalization and clinic appointments, and we can further respectfully encourage their caregivers to be empathetic and address their loved one's wishes.

As I am interested in caring for the geriatric population in the future, this entire experience has greatly shaped how I view end-of-life care. I was very familiar with hospice care as a prior volunteer during my high school and college years, but I had never witnessed the challenge of introducing the topic of end-of-life care to a patient and their family during an acute clinical event. Before this experience, I understood how to comfort patients and their families during the last hours and days of a patient's life when everyone had already prepared for and anticipated death; however, I learned that a different set of skills is required to comfort patients when introducing the foreign concept of end-of-life care. Exploring the patient's concerns and fears while responding empathetically to their emotions is key. I will always ask myself, *If I were the patient, what would I want?* I would encourage all providers, caregivers, family members, and friends to do the same, as empathy and respect should be at the forefront while imparting medical information to patients and their families, particularly near the end of life.

References

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