Palliative and Supportive Care

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An act of love

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Essay/Personal Reflection

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Abstract

End-of-life conversations are a difficult part of medicine. The COVID-19 pandemic has made them simultaneously more necessary and more difficult. Encouraging patients to have these conversations with their own providers and loved ones can help ensure, when the unfortunate time comes, their end-of-life wishes are carried out. This honors the patient and limits burden on others. Here, I reflect on how my personal experience as both a grieving grandson and as a resident physician has emphasized the importance of end-of-life conversations.

Thanksgiving morning, 10:00 am, a few hours into my exhaustion-induced daytime slumber following a night shift on the general medicine floor as a resident physician. A phone call pulled me out of sleep and into reality. My phone screen displayed "Dad," but this didn't bring feelings of happiness as it usually would. Rather, dread was already palpable in my gut. I knew this call was coming. I answered nervously to hear Dad break the news. My grandmother, his mother, had died.

My grandmother (Ta is our family's affectionate nickname for her) was in the hospital for over a week with heart disease complications. Her last few days were spent in the medical intensive care unit (MICU). After an extensive discussion between Ta, our family, and the medical team, she had been transitioned to comfort care the day prior, with no plan for mechanical ventilation or CPR. Though the news of her death shook me, I took comfort in her *manner* of death — peaceful and without chaos.

In October of 2020, 1 month prior to this unfortunately memorable Thanksgiving, I was working in the MICU of a different hospital. During *normal* times, the MICU is a place of critically sick patients, heavy emotions, and untimely death. However, these were not normal times. The coronavirus disease 2019 (COVID-19) pandemic had taken over so much of our lives. Our news, our thoughts, our anxieties were consumed with by virus. We knew our health system was swamped with the weight of the pandemic. The MICU I worked in was a majority of COVID-19 patients. More than ever before, death and end-of-life conversations dominated our team's collective emotional toll.

The MICU is emotionally taxing for reasons more complex than death. In this setting, physicians often function more as end-of-life counselors rather than healers. We help patients and families understand and come to terms with the gravity of the situation, whatever it may be. Patients are often sedated, unconscious, or unable to communicate their wishes. Unfortunately, even when a patient is quite elderly or chronically ill, it is common for there to have been little discussion regarding end-of-life wishes between the patient and providers or loved ones.

On the flip side, it is evident that the presence of patient advocates at the bedside along with continuing, multidisciplinary conversations between providers, patients, and loved ones leads to better patient-centered care.

Unfortunately, COVID-19 has made this difficult. Providers have found themselves caring for patients without clear end-of-life wishes far more often than pre-pandemic. This brings unwarranted burden on loved ones who worry they are either "giving up" or "prolonging suffering." Families can get into rifts when two parties disagree. Even providers feel torn over our perception of the patient's wishes versus a family's perception. Furthermore, COVID-19 has not only made end-of-life situations more common, but more difficult as well. The pandemic has had the unfortunate effect of isolating us from others, through both physical distancing and increasing rates of anxiety and depression. Hospital visitation restrictions have limited patients' abilities to have these conversations with loved ones. Without ongoing honest and vulnerable discussions, others are too often left hazarding an educated guess as to what a patient would have wanted in an end-of-life situation.

Conversely, when patients have made their wishes clear, loved ones and providers can confidently move forward, jointly advocating a plan of care that honors the patient's wishes.

The lessons provided by the COVID-19 pandemic are plentiful. For me, the most profound lesson burned into my soul is the immense value behind honest, dynamic conversations about end-of-life wishes. COVID-19, in all its evil glory, has emphasized the importance of the subject. Primary care providers play an important role in initiating these discussions as they serve

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as the first line of contact for most patients. We can advocate for both patients and their loved ones by encouraging honest conversations surrounding end-of-life wishes before an illness forces the subject. Bringing up the uncomfortable topic is not callous or rude — it is an act of love.

While the death of my family's beloved Ta was devastating, we were fortunate that she made her wishes clear to us and her medical team. Though we grieved the loss of our matriarch, we did not regret the process. Absent were the specters of chaos, guilt, and uncertainty. She was surrounded by her husband and children at the time of her death. She passed in her sleep, in the peaceful presence of love.

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