

Reflections

Do Physicians Have a Twin Obligation of Alleviating Suffering?**Mona Tareen***American Hospital Dubai*

Physicians don't always have the armamentarium to address all the domains of suffering. By definition, based on Cochinov et al 2000, suffering is "an unpleasant sensory and emotional experience" which threatens a person's intactness and sense of self. Diseases which are often incurable need palliation of symptoms including suffering of personhood. As William Osler said "Care more for the individual patient than the special features of the disease".

I most recently encountered a patient CJ with end-stage pulmonary fibrosis. He was 72 years old with pulmonary fibrosis initially diagnosed in 2015. He had evidence of restrictive pattern on the pulmonary function test (PFT), a decrease in his six minute walk test over the course of time and had evidence of pulmonary fibrosis on a CT scan. He was referred to me by his pulmonologist as CJ was now wheelchair-bound on 10 L of nasal cannula oxygen in addition to a face mask which in total was equal to 20 L of oxygen per minute at home. He would desaturate to 70's % when being turned or when he was eating or brushing his teeth. I did not want to burden CJ with a trip to the hospital and initially started with a palliative telemedicine consultation which is a wonderful way to communicate with patients who are unable to ambulate or are restricted to their home. This was soon followed by a home visit. On the first in person visit, CJ was tachypneic, dyspneic, appeared frail and was saturating at 91% with 20 L of oxygen and would desaturate to about 85% when talking. CJ goals were addressed with the presence of his wife. He was quite clear, lucid and had decisional capacity. His fear was to suffer at the end of life. He felt as if he would suffocate as he teared up and said "I just don't want to suffer anymore and what if my breathing worsens? What do I do then?". He looked to me for answers. The back drop to this, I had already touched base with his pulmonologist prior to the visit, he agreed that a DNAR (do not attempt resuscitation) would be best and to help initiate palliative care given these aggressive measures would not change his disease trajectory nor his terminal diagnosis and if anything would be a source of suffering in itself. CJ goals were aligned with his family's and supported by the physicians. He wanted to maintain a DNAR with a



goal to be admitted to the hospital once his symptoms were not well managed at home and thereby addressing his fear of being "unable to breathe". He remained on oxycodone sustained release with morphine sulfate liquid immediate release for breakthrough dyspnea and he was placed on alprazolam for anxiety secondary his dyspnea. CJ breathing became progressively worse at home. As a result, he was admitted to the hospital with hypoxia and distress 2 months later. He was no longer able to swallow and had not eaten for days. I converted his oxycodone to IV morphine and his alprazolam to iv lorazepam. He remained quite comfortable and never required old school "morphine drip". Support was provided to his wife who was overwhelmed questioning if maintaining a DNAR was the right thing to do. It is not uncommon for a patient's family to second guess themselves at end of life. With support and her willingness to share her hesitation, she understood he was terminal and that he was at end of life. She also understood CJ's goals. Psychology was called to provide support to her.

The biggest barrier I had to face were questions from

the house staff and the primary hospitalist caring for the patient. Was morphine hastening death? Would morphine suppress his breathing given he has pulmonary fibrosis? The simple answer, if adjusted to body weight and opioid naive/tolerant status than no in an already dying patient. Education was provided that CJ was on opioids at home and more importantly his respiratory distress and hypoxia was causing him immense discomfort. To let him suffocate at end of life would be a source of suffering in itself and intubation would be a chaotic process in which CJ would never be extubated in addition to failing to alleviate his symptoms unless on midazolam and fentanyl whilst on the ventilator. More importantly, it did not align with CJ's goals. CPR, intubation and resuscitation is never used for management of symptoms, will not reverse the disease trajectory of a terminally ill patient nor will it add to a patient's quality of life. I have heard horror stories of physicians not trained in palliative medicine who withhold opioids for even cancer patients in pain because of fear of hastening death. In this instance, pain stimulates the respiratory centers so opioids will unlikely cause respiratory depression especially when used by a qualified physician. There is a "double effect" in that we, as physicians, have a moral and ethical obligation to control pain and distress at the end of life understanding the intent of the treatment. Similar to Neutropenic fever and sepsis caused by chemotherapy, the intent is to treat the tumor but understanding the risk of neutropenic fever, sepsis and even shock. In my experience, I have yet to see hastening of death with symptom management given the patients majority of times are already dying and I have

already adjusted the opioid based on their opioid naive status, opioid tolerant status, renal or liver failure. This is very different from Palliative sedation which is a topic for another day.

Another aspect of CJ's story, is the realistic approach to goals of care addressed initially by his pulmonologist. No false narrative was given which helped to address CJ's goals with the time he had left. He was able to prepare his family, get his finances in order and let his adult children, who lived in London, know of his limited life expectancy. He loved his family everyday with the time he had left.

As Florence Nightingale once said "I really believe there is scarcely a greater worry which individuals have to endure than the incurable hope of their friends . . . attempting to "cheer" the sick by making light of their danger and by exaggerating their probabilities of recovery. . . the fact is, that the patient is not "cheered" at all by these well meaning, most tiresome friends. On the contrary, he is depressed and wearied".

As physicians, we have twin obligations of addressing goals and to alleviate suffering.

So what happened to CJ? He died peacefully with his symptoms managed on the inpatient palliative care service and with his family around him including his adult children from London. They all received the support they so desperately needed.