

Reflections

It's the Transition that Counts**Dr. Mona Tareen***American Hospital Dubai*

When I reflect back on my fellowship in the States in palliative care after completing successfully my internal medicine residency program at one of the University of Chicago hospitals, I realized that this was my calling. Two stories came to my mind and one in which helped me pursue my masters in a future career as a cannabis clinician and the other reinforcing my passion to manage those who are chronically ill and at end-of-life.

Everyone has a story. By understanding a person's story, we can understand the goals at the end of life. I recall in fellowship having the patient John (not his real name) who had just turned 40 with end-stage metastatic colon cancer. He had progressed rapidly within a year after being diagnosed with FAP. He was an avid athlete working out daily and declined a colostomy bag and therefore refused a colectomy. He said he would rather die than "carry a bag". As his disease progressed, we continue to spend time on the palliative unit to manage his pain and symptoms as we discussed his life in general. I recall the days where his closest relative, an uncle who owned a restaurant in a suburbs in Illinois, would come by and visit him. John would see his uncle from his window on the hospice unit. He would wave to him and show that he had strength. He did this by picking up the chair in the room and lifted above his head to say everything was okay, that in fact, he was okay (when in actuality he was not). It was important for John to show his physical and spiritual strength in managing his terminal disease. He continued to remain appropriate for our hospice unit (based on guidelines). He was initially placed on a PCA pump to manage his pain. He was a Catholic and a strong believer and to a point even tried to convert this Muslim physician, who smiled back at him and stated that was not something that would be possible but that I fully respected his religion and was happy to pray with him. 24 hours before he declined he stated that he knew the following day would be the day where he would approach end of life and stated that he had received this through a dream that he had. The following day as John surprisingly predicted, he developed terminal agitation and as a result had to be placed on palliative sedation. He was briefly woken up 24 to 48 hours after as per protocol ended up having his "last rites"



read to him. He then passed peacefully that following week. End-of-life does not have to be chaotic. It can be a peaceful transition. Things that make it difficult for physicians who are often not ready to discuss goals of care till it are too late, resulting in suffering setting in. This is when their life gets interrupted and thrown into disarray. Palliative care helps to smooth that transition. As one patient once told me when they were ill, hospitalized and found out he had a terminal illness he stated "I felt as if my car was about to crash and there was nothing I could do to stop it". He was elderly, married for 50 plus years and thought of all he was leaving behind.

I often get asked questions on how do we manage to pursue a career in palliative care? Is it not sad? After all, you can't really cure someone. This is the universal questions EVERY palliative physician gets asked. There is no better comfort, then to comfort those who have life limiting illness. To be allowed into their trusted circle as they are emotionally vulnerable. We help patients to "live until they die" as Cicely Sauder's put it. Life begins from alpha to omega, from beginning to the end and its the journey in between that counts the most.

To end this story on a happier note (remember all that is palliative is not Grimm!), I will share a story of another patient with metastatic colon cancer who was in severe pain and had decreased appetite. She had end stage metastatic colon cancer. She was also the first patient I encountered during my Palliative Medicine fellowship in Chicago. Let's call her Sarah. Sarah was on 600 mcg of fentanyl transdermal patch in addition to hydromorphone and methadone. Her overall dose was more than 4000 mg of oral morphine equivalent in a day. You may think that's a whopping dose! You would be right, but Sarah was awake on that dose, interactive and still in pain. I made a home palliative visit given her symptoms. As I walked into her bedroom, where I noticed her mellow German Shepherd lying next to her, a strange odor in the room and a lot of smoke. In looking at her in a very nonjudgmental manner she is exclaimed "I did it!". This took me by surprise as I had not yet asked her any questions. I went on to ask "did what" as I looked at her confusingly not understanding what happened, Sarah went on to explain, that she indeed "did pot", looking ever so guilty. We did share a laugh after the admission as we both knew her comfort was a priority.

This was before it became available in Illinois and legal within the State. How could a medication that helps so many symptoms still be a stigma today and federally illegal within the US? Fast forward to current day we know now that it does help with the slew of symptoms. For someone who is suffering from nausea vomiting to decreased appetite and pain it certainly remains an option in our palliative care tool box. Cannabis is less harsh than the opioids that she was receiving and it does not cause respiratory depression in adults. She ended up dying with her symptoms managed.

Remember, everyone has a story. Remember 100% of us will approach end of life. Having physicians experienced in Palliative Care can help address complex symptoms and goals. It helps patients to celebrate the life they have NOW and helps to smooth the transition.

As Beth O' Leary said in her book *The Flatshare* "people struggle to see it's not about whether she is going to die—palliative care is not just a place to go to slowly slip away. People live and leave then die on our wards. It is about being comfortable for the duration of something necessary and painful. Making bad times easier".