

Hope

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“Hello Mrs. K, I’m Dr. Baru, I said.” I squeezed the hand lightly resting on her cover with my own gloved one.

The room was quiet except for the sighing of her ventilator in the background. She had a broad round face with high cheek bones. Her skin was wrinkle-free except around the eyes and the corners of her mouth. She breathed peacefully through her tracheostomy. She slowly nodded her head when I squeezed her hand and her blue eyes shone as she smiled broadly. Her son stood at my side, his mouth set in a straight line his eyes gazing intently at his mom. His handshake was firm and brisk, a single downstroke.

I was called in as the Palliative Care consultant. “She’s in denial,” I was told. “There’s nothing more that we can do for her here.” She had already been in the hospital for 2 months but this was the first time I was meeting her and her son. With the help of the Polish interpreter and her son, who had become adept at reading her lips and translating her breathy rasps, I began to sift through all of the information that they had been told, all of the information they had gathered on their own, and what they understood.

Mrs. K was 59 years old. She’d given up her job as a kindergarten teacher and come from Poland 3 years ago to help care for her first grandchild. Two years later, her daughter-in-law delivered 2 more grandchildren: twins. Just weeks after the delivery, Mrs. K was diagnosed with multiple myeloma. She was told that her prognosis was good and that, with chemotherapy, she had years to live. She thought about returning home but she felt fine. Though she didn’t yet qualify for any kind of insurance, she was getting good care in our County health system. Besides, her grandchildren meant everything to her and her son and daughter-in-law needed her now more than ever.

Five months into her treatment she developed pain in her neck and started noticing numbness in her hands. She immediately went to the hospital where she was found to have a tumor in her cervical spine. Despite early radiation and surgery, she was completely paralyzed and dependent on mechanical ventilation within a week. In a matter of days she had been torn from life as she knew it.

It became clear during our conversation that, though Mrs. K was not physically uncomfortable, being confined to the hospital was difficult for her. Her grandchildren couldn’t visit

because she was on contact precautions. She missed them deeply. She missed sitting on her porch drinking her morning coffee. Unable to move her head, she spent most of her day staring at the ceiling or at the TV watching shows in a language she couldn’t understand. She had met countless doctors, nurses, and medical personnel, endured multiple complications, including a pulseless arrest, and had been placed in 3 different ICUs. Yet she was unwavering in her desire to remain on the ventilator and continue “doing everything.”

Both she and her son expected that the treatments she had been getting would help get her off the ventilator so that she could go home. I struggled to balance their hopes with the information at hand, exploring realistic goals.

“Could she go to a nursing home and wait and see if she will recover? I know they have these for people that are on ventilators,” her son asked.

This was not going to be possible given her disease. Her paralysis was complete and permanent. She would not recover the ability to breathe on her own. Besides, without insurance they would have to pay for these services. It was not realistic to hope for this.

“Could we fly her back to Poland so that she can die and be buried there?”

She was not stable enough to fly without medical assistance. Furthermore, she would need to be in contact isolation given the virulence of her uniquely resistant bacteria. The cost to arrange an air ambulance was exorbitant and unaffordable on her son’s electrician salary. It was not realistic to hope for this.

“Well, if she can’t go back to Poland and can’t get off of the ventilator, could we set up a ventilator at home so that we can care for her there until she dies?”

I explained that this would require help from medical personnel trained in ventilator management. They would also need assistance from individuals trained in palliative care to insure that Mrs. K had adequate nursing and symptom relief, particularly in the event of a medical emergency or a complication with the ventilator. The family would be required to pay for these services out of pocket. After spending hours contacting hospice agencies, medical suppliers, nursing agencies, friends of the family, and community organizations it became clear that even though the family

was willing to bankrupt themselves for their mother's care there was not a safe, affordable solution. It was not realistic to hope for this.

"What can you do for me?" Mrs. K asked.

My tongue sat numbly in my mouth. I felt a tide of shame and sorrow rising. Nothing! I thought, knowing not to say it. At times like this, we often fall back on training; I tried to force her into the round hole.

We can care for you here. We can insure that you are as comfortable as possible for whatever time you have left. We can shift our focus from life-prolonging treatments to those that are purely focused on your comfort. We can stop those treatments that will interrupt the time that you spend with your family, and try to give you and your family as much space as possible to be together here in the ICU. As your death approaches we would work to keep you as comfortable and peaceful as possible and to allow your family to be with you here at your bedside, but we wouldn't try to prolong the dying process.

"I don't WANT to die. I WANT to go home, I WANT to smell fresh air. I'm willing to take risks with my life for that, but not otherwise."

My impotence, my inability to give this woman any of the things that she was hoping for was overwhelming. Her suffering was overwhelming. I was unable to find a thread of hope in her world. I was failing my patient.

Feeling a sense of despair, I told her, I cannot help you breathe on your own or smell the fresh air or be with your grandchildren. None of those goals are realistic. I don't know what I can do for you, but I would like to continue to see you. I want to come back tomorrow.

"I hope you do," she said, her blue eyes shining as she smiled softly.

I was struck by the words. Though my loftier goals had been frustrated, I realized that my efforts and my presence at her bedside alone were easing her suffering—this is something that we all hope for.

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