



My Mother Will Dance Again: Through the Lens of a Medical Ethicist

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I heard my footsteps echo as I walked towards the intensive care unit. The somber mood was shattered by the cacophony of shouting. The intensity of the patient's daughter, the surrogate decision maker, had the medical team at a crossroads. Yesterday, she had yelled at the nurses, residents, and the attending physician. My service as the medical ethics consultant had been requested by the health care team to aid in navigating the murky waters between "do no harm" and continuing nonbeneficial treatment. The surrogate had requested aggressive treatment, yet her mother was dying.

Looking through the thick pane of glass into the enhanced isolation room, I saw a person whose face was swollen and pale, her blood pressure supported with medication. She did not respond to verbal stimuli and responded only to a sternal rub—the application of the knuckles of a closed fist in the center of her chest. There was an unending need to suction secretions, so she would not drown in her own fluids. She was enmeshed in a tangle of tubes and lines, penetrating every orifice and multiple vessels. She had not left a hospital bed in over a year.

The patient's daughter looked through the glass gazing lovingly at her mother. I approached the surrogate and we stood, shoulder to shoulder, outside the room. I had been told that she only left the hospital

to work, and returned each night to sleep at bedside. We looked at the same person and saw two different realities. She saw a loving mother and I saw a woman whose frail body would die without the impersonal support of technology and medicines. She turned and said, "This is the worst hospital of all the hospitals my mother has been in. If I don't get her out of here you will kill her." Our conversation began.

The surrogate spoke rapidly, words gushing out, like water from a broken dam. I listened as she shared that her mother was the youngest of eight children from an impoverished family. "Mother had to fight for everything her entire life." Her eyes glistened with pride as she recalled how her mother had worked tirelessly to care for her and buy her own home. She continued, "My mother loved to dance. She was sassy. When she walked into the room, everyone knew she had arrived." It was quiet as we looked through the thick glass. Without my asking, she said she was certain her mother would want "everything done." "Without a doubt, my mother will dance again."

I asked the surrogate to tell me about herself. Like her mother, she worked hard and during her time in the military she had seen her share of tragedies. She shared, "My mother saved my life. I broke her heart. I was into bad things and after I was arrested, my mother insisted that I

join the military to straighten out." She demonstrated her toughness: "I would carry my mother on my back to the next hospital if I could save her," and "I won't ever let her down again." I opened my mouth to speak, but she interrupted. She narrowed her eyes and said, "I know who you are. You are going to tell me my mother is dying. But I have hope."

We move to a nondescript room with posters from faraway places; several physicians join us. I begin by speaking about respectful communication. I clarify that yelling disrupts the care of patients in the ICU and is not appropriate under any circumstances. "If this continues, you will be asked to leave the hospital." At first, she looks angry but then she slumps into her chair. She says softly she will not be disruptive again.

The attending physician explained, again, her mother's medical condition. The surrogate asked well-informed clinical questions and questions regarding ongoing treatment and long-term care. I acknowledged, "She must have been an amazing mother," and "I understand your mother can no longer fight and you are trying to fight for her." She nodded her head in agreement and said,

"My mother never stopped fighting for me and I will never let her

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down again.” I asked if she had other questions. She looked towards her mother’s room and said, “I have hope my mother will dance again.” Then her eyes turned towards me. There was a long pause, as though she was gazing at her own reflection, and she said, “For now.” After the meeting, she marched purposefully to the nurses’ station and apologized for yelling. I was optimistic, thinking her journey of acceptance had begun. That was the last time she looked at me.

The next day, as I arrived, I watched a security guard escort the surrogate out of the building. She had been yelling at a nursing assistant. Over the following days, my calls to the surrogate went unreturned, my texts unanswered. A week later, as I sat writing notes, I heard the call from the overhead speaker for cardiopulmonary resuscitation. Next, I heard commotion, and walked slowly to the room. In the moments before the team arrived at bedside, the surrogate had jumped onto her mother’s bed to begin chest compressions. The team had to physically insert themselves between the surrogate and her mother so they could assist the patient.

After the family meeting, the daughter stopped acknowledging me. Yet, when she was near me in the hallway, she averted her eyes and whispered “I hate you,” so quietly that only I could hear. The first time, I stood in disbelief, unsure I heard her correctly. The second time, I stopped and asked her if there was anything I could do to help. She kept walking, her back to me.

The interaction profoundly challenged me. I understood she was in unfathomable pain and I yearned to help. After reflection, I understood her anger had nothing to do with me. As she rushed past me for the third time, uttering the same words, I envisioned her as a child, her heart full of love, watching her mother dance. I had the awareness that somehow, if she spoke with me, it would shatter her fragile hope. I have learned the value of recognizing when I have done all I that I can. There was nothing more I could do at this time. I started to walk in the other direction to give her the time and space she needed.

The patient remained a full code during the next 4 weeks in the hospital and was later transferred from the ICU to a long-term care facility, with her daughter remaining steadfastly at her side. My calls to the surrogate, after discharge, remained unanswered.

I have worked with people for years and yet I am surprised by the capriciousness of human nature. I have a fantasy that in every case I will be able to break through a surrogate’s denial of their loved one’s illness, and journey with them as they navigate the end-of-life process. However, sometimes a devoted surrogate is unable to peacefully accept the inevitable death of his or her loved one. Often, people only need time to come to acceptance; but not in this case.

I often picture the daughter gazing lovingly at her mother through the thick glass of the ICU isolation room. What was it about their

relationship that prevented her from shattering her own impenetrable glass, and allowing herself to see her mother’s deteriorating condition? Her suffering was a mosaic: denial, anger, grief, powerlessness, guilt, loss, and fear. Was it her military training that hindered her ability to acknowledge defeat? Was it because her mother had saved her life, but she could not help her mother? Did she believe if she willed her mother to recover, she would be free of the guilt and remorse of her past? Could I have done something differently to aid the process, to help free her of her resistance? My compassion could not reach her.

Medical ethics cases are as unique as snowflakes. I am continually learning that even when I do everything by the book and walk away saying to myself “that went well,” it is not always the case. On occasion, after a challenging case, I am bestowed with the gift of humility. I cannot help every person. I can extend my hand to journey with people, but I can only guide them down the path of understanding, grief, and acceptance if they are willing.

Each person must choose to walk the path.

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