MEDICAL ETHICS

By Fatima A. Naqvi, MD, CMD

Person-centered Ethics During End-of-Life Pain Management

Mr. Henry was the last patient on our interdisciplinary team rounds. The staff on call told us that he was one of their most difficult patients. His spouse was quite possibly even more difficult; she frequently demanded answers to repetitive questions before she would allow staff members to leave his room. Unfortunately, she had ended up in the hospital with a cardiac event before I was able to meet her.

Our interdisciplinary team included two nurses, a chaplain, a social worker, and myself as the medical director. Each of us was concerned with the four principles of medical ethics — autonomy, beneficence, justice, and non-maleficence — but respect and autonomy would play the most central roles in this particular case.

We stood around Mr. Henry's bed, and he looked at each one of us when we introduced ourselves to him. Mr. Henry, a man in his early seventies (name changed to maintain his privacy), was lying in the hospital bed with the sheet pulled up to his chest. The pallor of his face made it similar in color to the sheet. He appeared extremely irritable and disturbed, and he said angrily, "Another group and bunch of people are here to tell me what to do." He paused and then stated, "I no longer wish to talk to any one of you. Nothing is making sense to me, and I am in a lot of pain."

No one responded to this statement immediately. Instead, the team members found places to settle in the room and gave Mr. Henry their full listening attention, signaling our respect for him. I remained standing by his bed, leaned toward his face attentively, and took his hand to initiate a nonverbal conversation. Mr. Henry grasped my hand in turn, looked at me, then closed his eyes.

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I felt as though he was trying to communicate that no one acknowledged his struggles or pain, or recognized how quickly he was withering away and losing his grasp on his reality. This pause lasted no more than 30 seconds, yet it felt long. None of us were uncomfortable waiting because we all agreed that leaving space to listen to him and his concerns was a sign of respect for him and his autonomy.

Within a minute Mr. Henry opened his eyes again, looked at my face then glanced at my badge. I asked him, "Can you please tell us more about yourself and your pain? This will allow us to support you in the best way we can." He looked at my team members sitting around him, giving him their undivided attention, then he turned back to me and stated, "The pain at my urinary catheter is unbearable. This is the third tube [catheter] that has been changed since it keeps blocking from the blood clots." He sighed. After a pause, he continued to explain that this often happened in the middle of the night, which made it a source of his insomnia.

Mr. Henry did not stop there — he revealed his untold story to all of us. He felt that his life had come to a sudden halt two weeks ago when he fell while going to the bathroom at night. When he couldn't get up from the floor, his wife had called 911 for help. That had been his first — and last — fall. The ambulance took him to the hospital where his test results revealed that he has a disease where he can't make any blood cells or platelets. He told us that many groups of people had come and gone from his room; they'd look at him and tell him things — and he hadn't understood any of it.

He told us that he had been working full time, taking care of his wife (who has many health issues) and their home, paying their bills, and running his life until two weeks ago. After the fall, everything had changed for him, like he was in a fog. He stated that he couldn't fathom how his life could come to a pause like this without any warning. He also was worried about how he would care for his wife. This loss of control had made him very frightened. The team and I acknowledged Mr. Henry's feelings and frustrations with empathy and acceptance.

Based on the histopathology and systemic signs, Mr. Henry's acute myeloid leukemia was a terminal cancer. His hemoglobin was 4 mg/dL and platelets were 5. Once we had started to establish a rapport, Mr. Henry was very clear that he did not want any life-prolonging therapies. He stated that his appetite was very poor, so he wanted chocolate milk and chocolate ice cream. He also wished to be as pain free as possible.

I promised him that each member of my team would make sure he was comfortable and not in pain. We took the time to review his medications with him, and we simplified his regimen to include only those medications that would align with his goal of comfort. Later each member of my team talked to him individually and reassured him that they would support him in every way possible. He apologized and later thanked everyone for their presence in the room.

The chaplain asked him if the team could pray together for him. He stated that he was not religious but didn't mind the prayers. We all collectively prayed for him and left the room, at which time he closed his eyes and appeared more relieved.

I consulted with the urology team to support him by inserting a three-way foley catheter with continuous irrigation to prevent clots. We added routine pain medications based on his age and kidney function. These two simple measures worked: afterward he no longer experienced urinary symptoms of pain.

The next day when I went to see him, Mr. Henry seemed peaceful though still awake. He had no more questions for me. He took a few sips of his chocolate milk and closed his eyes. He passed away the same night, peacefully.

Though Mr. Henry initially had appeared to be a difficult case, simple actions that demonstrated respect for his autonomy resulted in a much smoother transition.

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