

Essay/Personal Reflection

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On a bleak fall afternoon, I walked into an equally bleak room that reeked of chlorine. A bit of daylight shone in through the window, illuminating the silhouette of John, who sat slumped in his wheelchair. As I approached him, I saw that John was well-kempt, his cream-colored sweater spotless. I noticed only one personal item in his barren, cheerless room: a photo of his dog. Everything else was either replaceable or dispensable, standard-issue articles provided by the nursing home.

“Hello,” I started. “I’m the doctor from the nursing home. How you are doing?”

“I’m tired,” John cut to the chase, no energy for pleasantries or friendliness. He knew I was just another doctor in a long line of doctors caring for him as a sick man.

“I see,” I replied and turned to a woman in her late 80s sitting on John’s bed. “You must be Linda.” Linda was John’s wife. She had cared for John at home for years before he came to the nursing home.

“The only thing I want,” John started back, “is pain pills I can ask for, like in the hospital.”

“Sure,” I complied. John needed pain medications. He had been battling HIV for the past 10 years; it gave him dementia and three types of cancer, causing him pain.

“When do you think he can go home?” Linda asked.

“Who said you could ask questions?” John snapped at Linda, his face filled with resentment and hostility. “You’re just asking questions to look smart. We *all* know you’re smart.” He dragged out the word “all” to really enhance the scorn and the sarcasm.

I tried to diffuse the situation. “The hospital told me that Linda is the person to make decisions on your behalf if you were unable to, John.” Psychiatrists visited John in the hospital; he had refused care but was unable to logically explain his requests. The psychiatrists decided that John needed a surrogate decision maker, and that Linda, as his next of kin, should be that person.

“I’m not happy with Linda getting involved,” John spat back. “I don’t want her telling other people about my health. I want to keep it in just the family!” John’s anger filled the room, speaking swelled into yelling.

“All right. Let’s focus on you, John,” I attempted to redirect him. “I’ll make sure you have those pain pills. Deal?” John grumbled but gave a nod in acknowledgment.

I wanted to do more to lift the mood. “Who’s this?” I picked up the photo of the dog.

“Oh, that’s my dog, Daisy,” I handed the photo to John, and he caressed the frame with love. “She died last month,” John’s voice cracked, tears welled up in his eyes.

“Daisy was a part of me, or maybe she *was* me.” When he spoke, you got a sense that a big part of John died with Daisy. “I can’t believe she’s gone.” There was no hatred when John spoke of Daisy, just pure love, the kind a parent has for their child. My heart felt for Linda; she spent most of her days caring for John, only to be reminded that John felt more love for his dog than he did for her.

John got sick again soon after, and Linda decided to send him to the hospital. We complied despite knowing that he would refuse much of the care there. The doctors did what they could and got him back to the nursing home, where I saw John for the second time.

He looked noticeably worse, his cream-colored sweater stained with coffee and bits of food. John was delirious and rambling, flailing, and shouting. Every question was answered with “I just want to die!” repeated over and over. The nurses could not get near him or provide him any care. I called Linda to figure out what she wanted us to do.

“I know he refused care in the hospital.” Linda started, “and they asked me about hospice, which I’m not going to do.”

“Can you tell me why?” I treaded lightly.

“Because I’m afraid that they’re going to take the pills he needs away.” I assumed she meant his HIV pills, “and then he’s going to die.” John was dying anyway, likely from the cancer if something else did not kill him first, but I said nothing.

“My mother-in-law was on hospice,” Linda filled the silence for me, “and they took oxygen away from her. She died after that.” Linda made it clear that hospice was the enemy, a thief under the false pretense of comfort and compassion.

“What about lorazepam,” a common sedative used at the end-of-life to help calm patients down, “to help when John gets agitated?”

“No,” Linda cut me off. “They gave that to my mother-in-law, too. I won’t have that with John.”

“OK, I respect your decision,” I tried to be understanding, “but if John refuses care, what should we do?”

“I don’t know,” Linda uttered after a long pause. There was no simple answer to this question, and I felt for Linda, who bore the burden of providing an answer. “But for now, I want you to do everything possible.”

The image of John shouting that he wanted to die rattled around in my head, along with the guilt of inflicting more suffering on him, but I had no choice. It was not my call to make. I instructed the nurses to give John time and try drawing blood-work a bit later.

With scientific advances, AIDS has morphed from a death sentence to a chronic condition, one you can control with just one pill a day. With this transformation, the scope and content of end-of-life issues in HIV-infected patients also changed. The focus has shifted from planning for imminent death to making multiple decisions related to multiple diseases. However, some end-of-life challenges remained the same. Without advance planning, the next of kin ends up making decisions for HIV-infected patients as indicated by law, but they may not always be the best person to make these choices. Many HIV-infected patients have strained relationships with family members due to sexual orientation or circumstances of how they contracted HIV. Family members may not have a close enough relationship with the patient to know their preferences. Many may not even be aware that the patient has HIV. This perfect storm creates suboptimal end-of-life care for many HIV-infected patients.

John faced these challenges. He did not know how he contracted HIV, but it was not from Linda; she did not have HIV. His inability to explain how he contracted the virus bred doubt and mistrust in his family. John experienced some of his own paranoia about Linda divulging personal health information to other family members he did not trust. But without advance planning, Linda had to make difficult decisions for John as his next of kin, and they disagreed on what was best for him.

What happened with John was not uncommon. Research shows that very few HIV-infected patients have completed advance care planning before getting sick (Sangarlangkarn et al., 2016). Another study found an interesting dynamic: both doctors and patients reported waiting for the other to bring up the topic of advance care planning. HIV-infected patients wanted to protect their doctors from uncomfortable conversations, whereas doctors


felt that planning for the end-of-life takes away hope, especially in patients who have fought to escape HIV-related deaths in the 1980s (Curtis & Patrick, 1997; Mousack & Wandrey, 2015). But death is a part of life, and avoiding the conversation will not ward off death; it will only leave patients vulnerable to uncertainty. Advance care planning is not about giving up; it is about making sure that patients get the kind of care they want. It is something that everyone should complete, especially at-risk patients with HIV.

A month later, John deteriorated to a shadow of his former self. He choked on food and slept most of the day, losing 38 pounds in the process. It was clear that John would never go home again.

The nurse practitioner on our team called to check in on Linda. When she hung up the phone, she told me that Linda had asked if John could have some lorazepam available, her eyes wide with a mix of pleasant surprise and relief.

“Everyone comes around on their own time,” she said with a kind smile, before returning to her work.

I sat still for a while, mentally digesting what just happened and ruminating on whether everyone really does come around on their own time. I’m not sure I’m as optimistic. I know other people who never came around, and while waiting for Linda to come around, John suffered. It was daunting to think that despite everyone doing the best they could, John suffered. My only hope was that, deep down, John knew that Linda did everything out of love, and that at the end, when Linda holds John’s hands as he passes on to the next life, she remembers the love he had for her when they got married 60 years ago.

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