

Before I Let Go: An End-of-Life Narrative

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Abstract: This writing was inspired by the loss of a long-term family friend. In the research on hospice and end-of-life care, there is little focus on the lived perspectives of Black individuals who are involved with hospice services, and even less work that focuses on this experience for Black women and families. I wrote this from the perspective of an academic who works primarily with health inequities and a social worker who spent much of my direct practice experience working with individuals who were critically ill and often making decisions near the end of life. Through this piece, I implore us as a profession not to lose sight of who we are and why we do this work.

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Walking into an inpatient hospice unit to see a loved one is never easy. Having a practice background in medical social work and previous experience with hospice in both my personal and professional life can make walking into these spaces fraught with anxiety and fear. For me, this fear does not stem from confronting death and dying, but from the knowledge that I will likely witness disparities in care and pushback against patient and family wishes at the end of life. This fear is compounded by the fact that I am a PhD-level Black academic who is a health equity scholar with an abundance of experience in direct practice social work in healthcare settings. Sometimes I want to scream with frustration and other times I resolve to use enough jargon so that medical professionals see that I have some understanding of the medical system and that my humanity will then be recognized in these spaces. Even this takes a toll over time, but I have seen the results of hurried care and rushed decision-making—and have felt invisible when seeking medical care for myself and others. I often feel hyper-aware of my identity when I am in healthcare spaces. I have the education and the ability to advocate for myself and others, but I also understand that my being Black, large, and vocal may cause me to be treated and regarded in a specific way that diminishes my voice and agency in these spaces. Previous research has posited that Black individuals struggle to access care at the end of life due to factors such as cultural mistrust, having values in conflict with hospice philosophy, and a lack of awareness of hospice services (Cort, 2004; Washington et al., 2008), but that is not the only reason I want to tell this story. This story centers around the importance of cultural humility in hospice care, pain assessment, pain management, and communication at the end of life. I want to talk about one experience—why it matters to me, and why it should matter to you.

Again, to start from the beginning, walking into an inpatient hospice to see a loved one is never easy. The unit I am speaking of was located within a nursing facility in which an entire floor was contracted out to be used by this hospice. I was visiting home to see my mother who wanted to see a close family friend (we will call her Janice) who was now residing in this hospice unit. “Janice” was a 58-year-old Black woman with a terminal illness at the end of her life. I have known Janice and her family my entire life. I had seen Janice a year ago at her home and at that time it was clear that she was very ill. Even back then, she had been gaunt, and when I had hugged her, I had felt all the bones in her body as I embraced her. It was good to see her then,

but it also made me feel sad to see a once loud, sassy, unapologetically free Black woman whose personality was so big now seem so small.

My mother informed me that Janice was now in the inpatient hospice unit and that she wanted to visit her. I did not hesitate to say yes. I wanted to see her again, but I knew that she would not look like the person I had known for most of my life and that this would be a tough experience. My mother and I walked side by side on a Sunday into the main entrance of the building and were greeted by an empty front desk with a sign affixed to it that said, “Please use the phone to call the floor to speak to staff.” This building seemed empty, and I could hear the echo of our footsteps bounce against the walls as we walked through the hallway. In addition to the hospice inpatient unit floor, the building housed a skilled nursing floor and a rehabilitation floor. As my mother picked up the phone to find out which room Janice was in, a man in a hospital gown wheeled himself outside of the main entrance alone. I scanned the area behind the front desk and saw a set of buttons underneath a small glass pane that said, “Only security personnel may touch.” It almost felt as if the building had been abandoned. My mother hung up the phone and told me to which floor and room number we were headed. We stepped off the elevator onto the inpatient hospice floor. I noticed the inconsistent overhead lighting as we stepped through the first set of doors that led to the hospice floor. Once we arrived on the hospice floor, the lighting was much dimmer in these hallways. I thought to myself, “Maybe this is to project some type of calmness here—it ain’t working.” The next immediate thing that I noticed was that in every room and sitting area all the patients were Black, while most of the staff were White. This alone, is not surprising, but it took me off guard and I wondered to myself, “Why?” I thought to myself that this is exactly what I study, and I began to wonder if this was just a coincidence—and if not, why are Black people being disproportionately referred to this hospice company and ending up in the inpatient unit instead of engaging with hospice services at home? Racial concordance in care is a topic that I have thought about often but seems particularly salient in advanced care planning and end-of-life care (Ejem et al., 2019). I have found that wondering if any of your medical team will look like you—and knowing that it is unlikely—is a normal part of navigating healthcare while Black.

We walked up to Janice’s closed door and knocked. We entered just as a nurse was exiting the room. Janice’s room was large and vacuous; her sister sat on a couch covered in a white hospital-issued blanket, and her daughter sat in a chair directly next to her, one hand on her mother’s side with her body almost leaning into her. Music played in the background softly, but insistently. Janice lay under a mass of blankets. Her body was not visible, only her head and neck. She did not look like herself. Even across the room, I could hear her faint breathing as her mouth was flung open. She was skeletal, and what little weight I had seen on her a year ago was gone. My mother had seen her less than a month ago. She was still walking and talking then. I had seen this before; I knew that she did not have much time left. There was nothing else that needed to be said about Janice and her condition. Just as my mother and I sat down, Janice’s daughter stood up to follow the nurse to continue a discussion. We sat in Janice’s presence and chatted with Janice’s sister. Although she could no longer respond to us, I hoped that she knew that we were there and that we cared for her. Our families have known each other for many years—we had experienced several difficult losses together, and without saying it aloud we knew that were on the brink of losing another person. Although we were in the Midwest, Janice

and her family had strong ties to the South and even spoke with colorful, lively Southern accents. These accents always made me feel comfortable, but I recognized that many people assumed that Janice and her family were poorly educated because of the way they spoke or presented themselves. This made me angry. I wondered if they were being treated well in the hospice unit.

My mother and I sat and chatted with Janice's sister. Her daughter came back into the room, and you could understandably feel a certain heaviness that accompanied her presence as she reentered the room. She said, "Well, the nurse wants me to agree to up my Mom's meds because she is in pain and that likely Janice will let go [die] if her pain is under control," and she continued to say, "The social worker came in earlier to say that the medical team believes that Janice is uncomfortable and that she should consider upping the medication so that she won't be in pain anymore." I felt for Janice's daughter, who was not yet thirty and had to make complicated decisions about the end of her mom's life with the support of her family. I thought about the confluence of factors that made this situation difficult. First, it was a Sunday, so the regular physicians and nurses were unavailable, and Janice's care was managed by a physician who was not as familiar with her. Janice's daughter felt the decision to increase Janice's medications was akin to giving up on her mom, and she just was not ready to let her go even though she acknowledged that her mother was actively dying. In addition to the unfamiliar staff on duty, there were no Black staff to communicate with Janice and her family. You may read that statement and wonder, "Why is that important?" I will tell you why it is: Janice's family, like many other Black families in the United States, have a unique lived experience. Racism and discrimination are factors that influence how Black people navigate medical systems. The ability to communicate with your care providers and for those providers to value your lived experiences is critically important, especially at the end of life. Black people's lived experiences are not only centered around oppression and racism. Our narratives include resilience, perseverance, and living our truths with courage and dignity. To truly know us is to appreciate the complexity of our culture and the nuances within it that make us who we are today.

Janice's daughter shared her concerns with Janice's sister, my mother, and me, and she said, "I know what my mom would want, but I don't know if I can do what she would want me to do." I wondered to myself if she had been this open with the unfamiliar staff who had known Janice for only three days. Just as that thought ran across my mind, someone knocked on the door. It was the physician rounding that weekend. He was a tall White man with a bright countenance who said, "How's Janice doing today? I'm doctor so-and-so, and I'll be working with you since your regular doctor is on vacation this weekend" as he walked through the door. My mother tapped my knee, and I knew that it was time for us to go. I knew that I would never see Janice again. I wondered how she would have felt about all of this—I knew that she would have wanted to be at home and not die in a hospital or hospice facility. I later found out that Janice's own mother was conflicted about her dying in their family home because she believed in the spiritual world and that her daughter's spirit may be trapped in their home. For many of us scholars and scientists, this would be regarded as a magical belief at worst and a check in a checkbox next to spiritual beliefs at best. For Black Americans, spirituality is particularly important at the end of life and should be at least considered in how hospice services partner with Black families (Dillon et al., 2012). I wondered to myself, "How did Janice get here and

why did the medical system direct her and her family to this place? If she was a 58-year-old White woman, would the same thing have happened?” As my mother and I walked back to the car, I felt no relief. I knew that this was not what Janice would have wanted. I also knew that it was her time and I wondered if she could hear us talking while we were in the room visiting her. I hoped Janice would find the strength to let go.

For me, the personal and professional are inextricably connected. These health inequities are not just theoretical or examples that exist out in the world that are separate from my life. This is a reminder that many social work scholars live and directly experience these inequities in their homes and amongst their families and friends. As my career progresses, I strive to bring the wisdom, hope, and knowledge instilled in me through my ancestors and lived experiences—both in practice and in my own life.

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