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A Team Reacts to a Patient's Death

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Ms A joined our NeighborhoodHELP™ service learning program from its inception in 2010. She continued receiving care from her primary care physician and oncologist and allowed students and faculty to visit her in the NeighborhoodHELP™ service learning program to provide education, attend to her social needs, and support her. Teaching students was important to her; she even chose to continue with the program when her first medical student graduated, though she was losing weight, and her pain was not controlled at that time. An African-American veteran and retired postal carrier delivering mail in Miami's fierce sun, she eventually succumbed to melanoma, which had metastasized to her liver and esophageal nodes despite surgery and multiple courses of chemotherapy. She died within weeks of joining hospice in fall 2014. Through NeighborhoodHELP™, this team grew to know Ms A. Upon her death, each of us reacted uniquely. This narrative strives to describe our reactions and honor this life.

Maite Castillo, Medical Student

I could have never imagined how important Ms A would become to me. She will always be my first patient. I was familiar with her diagnosis and poor prognosis and somewhat naïvely, expected her death as a distant event, without much anxiety or sadness. As anticipated as her death was, it came as a swift, unforgiving, bitter blow. One day, I was supporting her decision to enter hospice and just like that, she was gone, and there was nothing I could do about it. I had not been able to say goodbye or comfort her face to face. My first reaction of shock, a cold unbelieving feeling in the pit of my stomach, was replaced by anger and an ongoing sense of cosmic injustice.

As days went by, I realized I had been avoiding my feelings and faced them. As I processed them, I resolved that I wanted to practice medicine and care for others as I had for her. She inspired me to become more personable, to put that extra time into learning about patients. Even in her last weeks, Ms A was active in her role as a teacher. She was also always ready to learn, asking me about treatment methods. How could I not admire her? I was awed by this woman who had lived colorfully and still fought with tenacity and kindness. Ms A is and will always be an inspiration to me, an example of the kind of relationship I want to achieve with my future patients. She taught me that medicine should encompass the physical, mental, and spiritual well-being of patients.

Sanaz Kashan, MD NeighborhoodHELP™ Palliative Care Physician

It was supposed to be my first visit with Ms A. My colleague and I rang the doorbell and heard Spunky barking. We waited several minutes but no answer. Knowing that a few months ago she had fainted in her house, her lack of response worried us: maybe she had fallen down again? What should we do next? While reviewing our options, Ms A's neighbor approached and told us she was in the hospital again due to intractable vomiting and uncontrolled pain; I started getting worried before I'd even met her.

I finally encountered Ms A the following week at her home, after several hospitalizations due to uncontrolled symptoms and chemotherapy side effects. Ms A protected her abdomen with her hand in painful distress, saying, "The pain is bad, it used to be better controlled with the fentanyl patch, now that they stopped it I can't even sleep at night." I was dismayed when I realized that the hospital had discharged her only on a short-acting narcotic, not the fentanyl patch that she needed to control her pain. After several phone calls and a visit by her

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neighbor to the oncology office that day, Ms A was told by the receptionist that the doctor did not think fentanyl was appropriate for her at this time, and she could continue taking her acetaminophen-hydrocodone as needed. I wrote her a prescription for fentanyl patch. I was angry that the hospitalist and oncologist ignored her words and her pain. Instead they just threw more unnecessary treatments at her. I couldn't help thinking that if I were not visiting her through NeighborhoodHELP™ she would have suffered in pain for days without appropriate medications.

Robert Buckman, British doctor of medicine and author, wrote, "In general, the most common problems are caused by relatively simple errors—faults in common courtesy, failures in listening, or in acknowledging the patient's needs".[1] I was disheartened by my profession; nobody had listened to Ms A.

Ms A, with her advanced melanoma, suffered terribly in the last few months of her life. I deeply regretted that her suffering could have been alleviated by simply listening to her distress and being willing to control her pain in an effective manner. I hope one day soon we stop the overuse of aggressive treatments for patients who are dying and focus on improving the quality rather than quantity of life. Although her stay in hospice was short, I am glad that we were able to address the psychosocial, existential, spiritual, and physical aspects of Ms A's suffering and bring her some measure of comfort in the last few weeks of her life.

Suzanne Minor, MD, Ongoing NeighborhoodHELPTM Faculty

When I think of Ms A, a few memories strike me. She had started reading the obituaries, and I didn't understand why this was important to her, but it was. What would happen to Spunky, her German shepherd mix? She loved telling the story of how he saved her life—after he had knocked her over, he barked until the neighbor came to check on her.

Teaching was also important to Ms A. At the last few student visits, I asked if she wanted to remain in the program, because she seemed fatigued. She was adamant. "God wants me to teach these students!" I was impressed with her dedication and also identified with being committed to something larger than oneself; I had moved to teaching from full-time clinical care to have more service reach. We both needed to pass something on to the next generation.

During our last visit, any movement tired her, and she hoped the new chemotherapy would help her fatigue. She couldn't keep food down. Her oncologist told her the pain couldn't be controlled. We discussed options.

"What is my responsibility?" Ms A wondered. "Am I supposed to keep fighting, though the cancer's growing? Or make my peace?" The oncologist "kept pushing" her about hospice. To her, hospice meant giving up, and she didn't think God wanted her to give up yet. I, too, have asked these questions often when the passing of a close relative caused me to reassess my life. When should I fight, and when should I yield? What does it mean if I let go of my identity as a fighter? Is letting go its own kind of strength? I am slowly learning that yielding may be a more advanced skill than fighting.

I often felt painfully helpless in the face of Ms A's advancing cancer. She rejected hospice for years, unable to accept the idea of giving in. Yet, at the end of each visit, she spoke of how she loved the students coming to see her, and I realized that the visits themselves provided a small diversion and purpose for her.

When I phoned and her relative said Ms A had passed, I was heartbroken even though I knew she was dying. Her death brought up death and losses in my life. Grief demands to be felt; there was nothing for it but to cry and feel the heavy sadness. I was grateful she found hospice and lived with its benefits for the last weeks of her life but lamented that it had taken so long. When I think of Ms A, I bear witness to her feisty, vibrant spirit by teaching well: I hope I role model listening to the patient and supporting and honoring her choices.

Ms A's death affected each of us. In the end, we are just human, with our human emotions and human thoughts. Death affects us all with feelings that must be felt, thoughts that must be worked through. In the busyness of each day, it is restorative to take time to reflect on our feelings and write them down. Through reflection, we have moved forward, each in her own way, whether that has meant honoring Ms A, gaining more peace, moving toward closure, or affirming our passion for family medicine and palliative care.

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Reference

1. Buckman R. How to break bad news. Baltimore: Johns Hopkins University Press, 1992.