

Not Yet, The Epilogue

By Danielle Snyderman

What book would you choose to read if you knew you were dying?

When I met Charlotte, she was 71 years old, a retired realtor, active gardener, mahjongg enthusiast, avid reader, and widow of her beloved husband with whom she traveled the world. At the time, I was admitting Charlotte for post-acute care at a nursing facility because she had progressive glomerulonephritis and was rapidly losing kidney function. She would soon need dialysis to live.

Charlotte was resolute in her decision not to pursue life-prolonging care. Her choice was grounded in quality of life at all costs, even if it meant she would likely die in the next weeks or months.

While visiting her in her room a few days later, I sat just inches from her bed, her hand lightly resting upon mine, and we spoke of what mattered most to her. She cherished her relationship with family and friends. Books were treasured gifts. When I asked her what she might look forward to, she replied, “I wish I could go to a library one last time.”

Weeks later, Charlotte voiced surprise that death, even when you have fully surrendered to it, is sneaky and inexact in its timing. I introduced the concept of the “in between,” an idea resonating with me after I read about it in a magazine years ago. She had entered an “in between” world that was darker, but there was still sunlight left. We talked about the “right now” and how to embrace it even with the promise the light had already begun to dim.

Fast forward 12 weeks, two months into the COVID-19 pandemic. The threat of COVID had penetrated the world, our nation, our communities, and our patients. Charlotte was mostly bedbound and experiencing symptoms of nausea and shortness of breath. She began to have moments of confusion, but these were generally short lived. Nursing facility patients, many of whom already understood feelings of lack of control over their circumstances, lived the new reality of strict isolation and confinement to a single room. The absence of family members resulted in symptoms and signs akin to suddenly withdrawing life-sustaining medications.

Although health care workers were protected from COVID-19 by masks and face shields, loneliness permeated the air we breathed. The most fundamental connection between physician and patient had changed. As we donned our PPE, we were enveloped in an added layer that would keep us from sitting close to our patients, touching a hand, and leaning in. It was a direct threat to the electricity known as connection.

I hoped to fight against the sterility COVID imposed on the intimacy of patient care by trading in my stethoscope for a book to read to Charlotte. The day after Mother's Day, we piloted our one-on-one book club and selected "I Know Why the Caged Bird Sings" by Maya Angelou. We used the copy I had given my mother when I was a teenager. In recent years, my mom had gifted it back to me with the thought I would read it to my young daughters. With an N95 muffling my voice and a face shield relentlessly trapping the beaded moisture of my sentences, I read the first three chapters to Charlotte from the corner of her room. Though the physical space between us was greater than in previous visits, I started to feel the familiar electricity again. We had created a moment that was uniquely ours. To bear witness to someone who has suffered in the "in between" and to, in turn, create beauty in the "right now" felt sacred.

We would have more chances to read a chapter here and there, but the pace was slow. Early in the book we would complete two chapters a day. On busier clinical days just a chapter, at a slightly faster clip. One morning while the sun's rays snuck between two horizontal slats of blinds, spotlighting her face with laser precision, she offered, "I like the way you read." Then she promptly fell asleep, but I kept reading.

A few weeks later, six chapters in, George Floyd was murdered, and we began to talk about the book in the context of systemic racism and how reading it carried a deeper meaning to us. Charlotte began to rally to the point she was even taking short walks again. She gifted me with a Black Lives Matter T-shirt made by the son of one of the nursing assistants who cares for her. She joined a Zoom book club with friends and started reading Ralph Ellison's "Invisible Man." I shared with her that I was reading Ibram Kendi's "How to be an Antiracist" and described how it reframed my understanding that antiracism is a verb and requires action.

We sat together leaning into our shared whiteness, knowing our reading could not possibly be enough. Still, the words on the page started to land with greater impact and resultant intention for each of us. On her better days, she would read to me while sitting upright in her bed. On days when she was tired, I continued to read to her, sometimes her eyes closed, still listening intently.

I have caught myself looking ahead. The mental math begins. Chapter 11 is a bit longer at 8 pages. My next patient is scheduled in 10 minutes. How long does it take me to read a page? Charlotte has lost 50 pounds and her kidneys are deteriorating as time moves on. I wonder if we will finish the book before she dies. If we do, what other conversations will we never have? Time suddenly feels finite, and yet I cannot seem to complete the equation to determine the opportunity cost of time well spent. I conclude the answer is a paradox; even an anticipated loss feels like an exponential gain. When the patient and doctor both grow from finding the light together, who flourishes more is incalculable. We have not read a chapter in about three weeks. Charlotte's health has plateaued enough that she has accomplished her goal to be able to move into a bigger apartment with the support of hospice. In taking this step, she has begun to narrate a new story, one in which she has voiced she will feel fulfilled even if the story ends a few pages in. For she has fully embraced the "right now".

My copy of the book is set out on the coffee table of Charlotte's new apartment, waiting for us to pick it up when we are next able. The pace is slower as we often share thoughts about many other of life's goings-on. The way this book with its starts and stops has weaved in and out of my life and the many stories it has told represents the preface for volumes yet to come. Charlotte has taught me that even in the most challenging of times, life can be a *Choose Your Own Adventure* story. I look forward to turning the page but will first make sure to savor the words on the page in front of me.

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