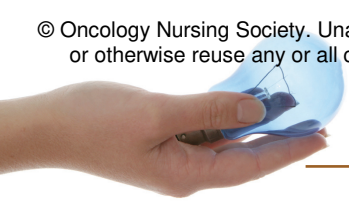

Scar Tissue in the Heart

Way back when I was a much younger nurse, I wanted to work in palliative care. The human resources manager at the hospital where I applied had other ideas for me; it was not until two years later that I began to work in the community in HIV/AIDS care. I learned a lot about palliative care in those years; azidothymidine was not available outside of a clinical trial and everyone who contracted the disease died. I spent many hours at the bedside of young men as they left the world, and I spent many more in tears as I tried to make sense of the losses—so many losses. After five years, I was burned out and left clinical care for a teaching position. Seven years of teaching undergraduate and graduate nursing students made me long for the gratification that only patient care can provide, and I went back to a clinical position in oncology.

I have the great fortune to work mostly in survivorship care; sexuality counseling has become a major part of my work even though I was hired as a CNS with a focus on prostate cancer decision making. When a couple presents with sexual problems, it usually means that they have moved through the trauma of diagnosis and treatment and want life to be the way it was before. While, of course, I empathize with their problems, it still is joyous for me to see them reach this place in their journey. I do not have to deal with the bad times that most of my nursing colleagues do. I don't witness the recurrences, the acute toxicities, the oncologic emergencies. And my patients don't die, at least not on my watch.

But a few weeks ago, I was reading the newspaper at home one sunny morning. I am usually at my desk by 6 am and don't read the paper until much later in the day. But that day I was traveling and didn't have to leave for the airport, so I was paging through leisurely when a familiar name caught my eye in the obituaries. I usually just glance through that section, not expecting to see any names that I know. But this one took my breath away and the tears came to my eyes immediately. My husband glanced up at me with a concerned look. I couldn't find the words to express my sorrow at the brief entry for a 28-year-old, dead within two short years of the diagnosis of colorectal cancer. There was so much more to the story.

DM was one of those patients that entered my office and within minutes had found a place in my heart. He was the same age as my children, 26 at the beginning and now 28 at the end, and he had bright blue eyes and a smile that could charm me like few other patients had. His surgeon had referred him to me, recognizing the sexual side effects of the aggressive surgery she had performed. During the next year, I saw DM often, always without an appointment as he would show up at my clinic when he felt like it, and I would agree to see him, even if it meant that he had to wait while I saw patients who did have appointments. He would sit and talk for a while, describing the problems he was having with a girlfriend or complaining about his landlord. I would listen and allow him to occupy a slightly bigger space in my heart each time. I visited him in the hospital after he had a recurrence and needed surgery. He looked faintly embarrassed when I stood at the end of his bed, and he made excuses for his appearance and the tubes that entered and left his body in full view. He was in pain and frustrated that he had to continue to live with an ostomy and all that entailed. I left feeling inadequate in my ability to help him. And I never saw him again.

That morning when I read that DM had died, I cried for him and the lost potential of his life for the two years he struggled and suffered. I thought about those of you who work with dying and death every day and I cannot figure out how you deal with it. How do you manage to keep going, to keep doing, when the losses pile up one on top of the other? How do you keep your hearts open when they threaten to crack on a regular basis? Where do you put the sadness and the missing and the spaces that these patients and their families leave in your life? The multiple losses that I experienced while caring for those with HIV/AIDS didn't harden my heart those years ago, but they surely influenced the work that I choose to do now that focuses on the future and the new normal of life beyond cancer.

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I would love to hear how you manage the grief and pain of caring for those for whom our treatments fail. I am grateful for the experience of knowing and caring for that young man, no older than my children. He charmed his way into the soft space in my heart and, with his dying, that space contracted and turned to scar tissue, figuratively if not literally. I wonder how much scar tissue can build up before our hearts show the strain . . . or do the scars make our hearts stronger somehow? Tell me about your hearts and how you heal them. I need to learn.

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