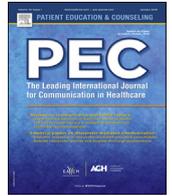




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Discussion

An N of one

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Unless you are a visiting nurse or oncologist you might not have seen a breast that has been decimated by a cancer that ulcerates with relentless aggression through the skin. I am neither of those things, and I hadn't. I have worked in health care all of my life, as a physical therapist, then a developmental specialist, and now as a mental health professional. It was in none of those roles that I encountered this image, an image so graphic that it was too disturbing to include in this article. In June 2016, I received a call from my brother in London telling me that his wife's triple negative breast cancer had returned and she had been given three months to live. I arrived on their doorstep days later and, as I live in Cleveland, Ohio this will give you some idea of how much she is loved. Too many things happened for me to provide a blow by blow of each momentary triumph, desperate loss, and gloriously nothing-filled days. Cancer has its own variable arc that marches with hubris over the plans we have for life.

I have not lived in England since I was eighteen. Although I still describe myself as English, the 'proper' Brits don't see me as such. My linguistic cracks and slurs peg me as a Yank and indigenous to that is the expectation that I will be demanding, presumptuous, entitled, and puffed-up. I am definitely demanding but the other three are artifacts left over from the days of the Great Migration and the clash of the Puritans. Anyway, we as a family had questions. My sister-in-law (G) had questions that she had no real belief she had a right to ask. She played around on the edge of them as if pondering whether she should have porridge for breakfast or bacon and eggs; as if she had all the time in the world and that either choice would make little difference. We all sat in her living room with the letter in her hands dated April 23, 2016: "... she is aware that without treatment, or if she does not respond to chemotherapy then her prognosis is likely to be very limited indeed – just two to three months." Today is June 27th and by this determination she has about four weeks left, and no, she was not aware.

She looked at me and, in the kind of apologetic tone that someone uses when they believe their existence is too much trouble, told me that she wasn't ready to die. She was fifty seven years old, she had a four year old grandson, the garden was only just starting to reflect her hard work, there were still fights to be had and shoes to buy. She couldn't believe that the paper in her hands was to be the full-stop at the end of her life and she didn't

believe that there was anything she could do to challenge that. There were no appointments scheduled, no consults with a care team, no one sitting down with her to reflect upon the meaning of it all. So demanding old me sprang into action: "let's look at some clinical trials" I said, my voice loaded with American resolve, "there must be something we can do." There was and we did it, eventually finding an oncologist who was willing to consider her for his Keytruda trial.

Of course consideration and inclusion are the not the same thing and, although she never made it onto the trial protocol, she wasn't languishing, receiving no treatment at all. Hope resurrected. No longer were the daily changes to her body to go unassailed, she was back under somebody's watch. Even when there is nothing you can pump into a body that is going to make a difference, being in the hands of a thoughtful caregiver makes every difference. G.'s decline was slower than predicted and as ugly as she feared. There are a lot of lonely hours to be spent trolling the internet for images of fungating tumours and the limited ways in which they can be managed. I came back to London three more times and, as the clock ran down on her resistance to hospital, she finally agreed to call in Macmillan hospice care. Within days we were delivered of the accoutrements of death: a commode, mattress, insufficient oxygen (why the hell only two litres), and a comfort package that my brother thought was to be used to put his wife down. He wasn't completely wrong. G. died on January 22nd 2017. She wasn't brave - she was plagued by a pestilence whose hallmark is its total lack of prejudice. She was terrified that her death - like her life - might not ever count. She needed a voice and someone to acknowledge her pain. We each need that and I write this for you, at her request, so that she might be counted.

G. grew up much like I did, in a family that was as disparate as it was chaotic and as predictable as it was random. We weren't expected to rise to much and flat lines have a way of keeping the trajectory of life a little too close to death. G. was funny, self-deprecating, scared, oh so very scared at times, often choosing the familiarity of her sitting room over even a solo meander down the local high street. When she found out that her life was winding down she, perhaps like so many others, began to take stock of what she would miss, what it would be like. "I'm not ready to go," she said to me, "I want to see my grandson grow up, the sun on my flowers, and to feel something other than afraid." Yes, she actually said that and I too felt the rumble of a solar plexus coming to grips with what the world might be like without me in it. We often use

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words like proud, dignified, courageous and warrior when describing someone's journey with cancer. G. hated to hear anyone describe her with those adjectives. They weren't words she would use. She was angry, confused, ashamed and sometimes repentant for all of the real and imagined ways in which she might have contributed to feeding the ugly beast that ate at her breast. "I had a beautiful body once," she said to me. "I never thought so at the time of course - who does - but when I look at myself back in the day I am sad for everything I missed about myself." It was hard to hear her describe the loss of herself expressed with such tenderness. This was one of many moments that I had to step out of the fear of my own death and listen to what she had to say about hers, she was after all the one dying here.

There were some things that went well in her final months; her last birthday, a trip to the spa for her first ever facial, a ride on an open top double decker bus, day trips with her sister and a totally unplanned meander around the Westfield Mall in Shepherds Bush. We never did find that belt. Not so good was her final acute hospital stay (before the truly last one) when she was admitted for sepsis, rallied despite looking as though she had already crossed the Hanging Bridge of Ghasa, suspended between life and death, and the day she discharged against medical advice because no one had

come to assess her for home oxygen and a commode chair. I say it again, two litres is not enough. There is not much trouble you can get into with more when you are gasping for breath and hoping to at least call time on some of the suffering.

G. didn't die at home. She had mixed feeling about her bedroom being the walls of her entombment but she loved the broad window and how possible it was to keep the curtains back at night and still have privacy. Death of course is private and I share hers with you because she wanted her story told and she asked that I find some way to do that. To show you what some cancers look like and to tell you that her life had nooks and crannies that the letter sent April 23rd 2016 didn't reflect. She was not aware until then that she was in the terminal prodrome and, even with that awareness, the fog of disbelief sometimes had to descend so that she wasn't always forced to see so clearly the true end. She wanted someone in the outside world, beyond the nurses, doctors, social workers and technicians, some of whom were absolutely magnificent, to know that her life, although hard, was hers and one she still wanted. She asks that you don't wait until your own final hours to cherish being cherished and to hold the small part of her that I have shared with you as evidence that not only do we all count but that we all want to be counted.