The Heritability of Cancer

Leeat Granek

I was 9 years old when my mother was first diagnosed with breast cancer and 25 when she died. The boundary between before and after is so clear that it feels like I have lived two lives. I went from being a carefree, cerebral, quirky child to a rough version of the responsible, reliable, and vigilant adult I would eventually become. With cancer came the fear of losing my mother, and with that fear came an unwelcome but necessary maturity. There were other important life events impacting our family around that time that contributed to this sense of split. We had just moved from Israel to Toronto and knew few people in our new environment. My mother had just given birth to my baby brother, and my parents had bought a new house for our growing family. At the time, I was starting third grade in a new school—the fifth new school since beginning kindergarten. All this in addition to the diagnosis. My mother was only 33 years old—the same age I am now.

While I adapted to everything else—new house, new school, new brother, new country—cancer insisted on sticking around, and it claimed not only my mother’s life but, in many ways, my own. Cancer enters the body of the caregivers in ways that move far beyond the domestic work involved in the running of the house or the management of medications and appointments. It can become part of caregiver DNA through inherited genes, but it often does so in more insidious ways.

My mother lived with the disease for 17 years before she died in 2005. It is fair to say I grew up in the hospital. Over the years, there were multiple surgeries, along with episodes of weekly chemotherapy and daily radiation sessions. She suffered a host of complications that came with metastatic disease and its treatment, including four instances of strep A bacteremia. Many major events happened in the hospital. We ate Chinese food with our matzos on Passover in her room and lit Hanukkah candles in the waiting room where we accidentally set off the fire alarm on the seventh night, to the consternation of the nursing staff. My 11th, 15th, 18th, and 25th birthdays were celebrated in cramped hospital quarters, cutting the birthday cake with a dull plastic knife. Indeed, the last birthday we had together was my 25th, and we marked it in the hospital 2 days before she died. In her last lucid moment, she managed to miraculously lift out of the fog caused by brain metastases to give me a kiss and exclaim “Mazal tov, Leeatie!”

I remember the sounds and the smells. Static codes being called out over the hospital loudspeakers. The haunting “clink, clink, clink” of the staples being removed from my mother’s skin graft and landing with a loud clatter in a silver bowl. The pale green hallways and their antiseptic smell, which I grew to hate. The airless temperature that was neither hot nor cold—hospital weather, I used to call it. The hospital, with its sounds and smells, was my second home.

It sounds awful. And it was a lot of the time, but there were many good moments as well. My mother was smart, intuitive, funny, and astonishingly optimistic. She was always laughing and incredibly giving with her love and affection. We were exceptionally close. Her eyes lit up and her arms stretched out to give me a hug every single time I walked into her room. She would say things like, “Leeatie, I love you so much. I wouldn’t change a single thing about you! How did I get to be so lucky to have a daughter like you?” and “There’s no one in the world I would rather spend time with than you.” I didn’t have to do anything to earn her affection. I felt that I always came first, that I was always wanted and loved, and that my mother was always entirely there for me in every sense of the word.

The hospital days that punctuated much of my childhood, adolescence, and young adulthood were both an annoyance and a blessing. There was nothing else to do but simply be together, which was fun and easy, thankfully. When I was older and no longer living at home, I would sometimes sleep over in her hospital room during her admissions. We would curl up in the twin bed and talk for hours until we both fell asleep, or we would sit together, each absorbed in her own book, comforted by the warmness of being together.

When I think about being a caregiver for my mom, and by extension a caregiver for our family, it was not the hours of care work—the babysitting, driving to appointments, spending time in the hospital—that consumed me. The impact was long-lasting and continues to this day. As a health psychologist and a researcher in the area of
psychooncology, I know the permanent and long-term devastations cancer causes throughout the caregiver’s—in my case, the daughter’s—entire life span. To this day, I have no real sense of what normal physical development for a woman should feel and look like, and in some sense, I never will. I entered puberty around the same time my mother was having her breasts and ovaries removed, which made that phase frightening and emotionally difficult. And now, I have no mother to turn to and ask about my endlessly evolving female form, no mother to guide me through future pregnancies or talk me through gray hair and menopause.

Cancer shaped my young adulthood and my emotional development. At 20 years old, I was dealing with issues facing 60-year-olds who care for ill and aging parents. Because part of me recognized that time was running out—indeed, because I lived almost my entire life with a neon awareness of my mother’s mortality—I was tethered to home and making decisions about school, life, and love that would keep me close to her. I don’t regret these choices or a single moment that I chose to spend with her, and now I have an entire lifetime to come and go as I please. Being challenged with a cancer-driven perspective at 20, however, carries risks of having an entire lifetime being developmentally out of step with one’s peers and unprepared for life events outside a hospital. For example, at 25, I could look death in the face without trembling and without abandoning my mother at her end, but I was unprepared to face the dating world that most young adults would have no trouble navigating. Although I was and remain a loved, nurtured, and supported daughter, cancer diverted the vast majority of the temporal, emotional, financial, and physical resources in our family toward fighting the disease. When she was alive, my mother was fully present in my life. But even her unconditional love could not repair the reality of my out-of-sync development as a child and young adult or today make up for her continued absence in my life.

My absent mother is at the core of a black hole of grief that remains inside of me and that has been painfully pried open with subsequent losses to cancer—my grandmother and my aunt, a professor I admired and family friend that I loved. Each loss re-exposes a subsequent losses to cancer—my grandmother and my aunt, a professional woman I admired and family friend that I loved. Each loss re-exposes a haunting grief I have learned to accept and live with. Grief is a shadow that looms large in my life. It is both the topic I chose to study and the affect I advocate fiercely for,

because as I have learned through my own experiences and research, love and light come from the same place as grief and darkness. The ability to grieve our losses fully also affects I advocate fiercely for,1-4 because as I have learned through my own experiences and research, love and light come from the same place as grief and darkness. The ability to grieve our losses fully also allows us to love and appreciate the people in our lives when they are still with us.

And then, of course, there is the worry: the biannual check-ups, magnetic resonance imaging scans, and mammograms; the surveillance and the false positives and the constant paradoxical tension that comes with the awareness of the nature of these tests provide a false sense of control over a disease that refuses to be harnessed.

The literature about the impact of parental cancer on children at the time of diagnosis, during treatment, after surgery, and even at the time of death is extensive,5-8 but few of these studies acknowledge how much this disease alters the life course of the child well after the parent has recovered or has died. Being a caregiver for a patient with cancer consumed much of my childhood, adolescence, and young adulthood when my mother was alive and charted the course for my future as a health psychologist working in the field of psychooncology. Although many years have passed and although I have a doctorate in hand, several years of postdoctoral training in the field of psychooncology, an academic career studying these issues, and dozens of publications from my research on the psychological and emotional effects of cancer on patients, caregivers, and their families,9-16 from time to time, I still feel like a scared 9-year-old child trying to gain control over this disease and get out of the shadow that cancer has cast on my life.

AUTHOR’S DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

The author(s) indicated no potential conflicts of interest.

REFERENCES