When Your Genes Betray You

By Nelly Madegwa

My grandmother died of ovarian cancer after a series of misdiagnoses two years before the new millennium. There was hardly any public awareness then and little was known of the disease.

I was named after my grandmother, I barely remember her as she passed on when I was seven. But there was more than just a name that linked us and it was the BRCA 1 mutation we shared. I had known she was sick; in the hazy manner children know things. She was a retired primary school teacher though her true passion was farming. My grandmother had kind hands and a beautiful voice, always humming hymns as she tended to her kitchen garden. But hardly got the time to live out her retirement. From the memories my late mom shared of her through storytelling, cancer first came for my grandmother's ovaries and then for the rest of her, a fate that befell my mother years later, beginning with her breasts.

This bleak history had haunted two successive generations of my family, creeping up and snatching a life as it bloomed, before we realised it was an inside force rooted in our bloodline that passed from generation to generation unseen. My mother was diagnosed at the age of 40, a tragedy as the cancer was already at an advanced stage. The oncologist advised us to look into palliative care as there was little else to be done; at least she would be comfortable for the six months she had left to live. We resisted this truth. How can another human being know with certainty how long someone has to live? Isn't that a truth only known to God? This denial set us on a desperate course and after six months, the heartbreak that befell us left us lost. How can someone deteriorate that fast? Her

hair thinned, she lost weight, her skin burnt.

The night my mother passed away, I woke up in the hush of the night with an ache in my heart. It felt as if something had broken off. I had visited her three days earlier and she had seemed better. We had even had a conversation, unlike the other times when her responses were just fading sounds. The glimmer in her eyes was back. In our culture we believe that you know when death has come for you; it lingers first, leaving clues for those left behind to pick over as they grieve. The glimmer in her eyes was to help us remember her as full of life and hope even to the end. Death sometimes announces itself. For us it was through the oncologist but our refusal to believe in science made death seem like it had arrived in the cold of night cloaked in darkness. My mother passed on in her sleep. In the days that followed we felt like we had been uprooted. Even the sun shone differently; we could see the light yet we didn't feel the heat. The colour had seeped out our canvas, we had been ripped apart, everyone on their own. We didn't know how to be together in sorrow.

After my mother's demise, there were murmurs that the disease was a curse, with some implying that our family needed to do something to expunge it. Could it be true? For there was a clear pattern of ill health. My grandmother had been pious, one of the many characteristics my mother mirrored. After the seven days of mourning that followed my mother's burial, we held a prayer ceremony after which we the bereaved stepped back into society. The fact that my maternal grandmother had also died of cancer was not lost on us and I vividly remember the pastor who was presiding over the ceremony quoting a verse from the bible that spoke of generational curses. It says that God visits the iniquity of the fathers on the children and the children's children, to the third and the fourth generation. I was the third generation. Did God hold me liable for something someone else had done? There was hope, according to the pastor; prayer and fasting would lift dark pall that hung over us.

I was now partly an orphan and that is how, with my good grades, I qualified for a scholarship in the United Kingdom. But I was not sure that the void I would leave behind would be felt, that I would be missed when left for London. Moving away helped though; it made me more detached. I read somewhere that the weight of a death is assessed by its aftershocks, and mine did pile up. I went through my undergraduate studies in a haze, focusing only on what was important — keeping my scholarship. I finished my degree in statistics and operations research and went to graduate school as I worked part-time and this is when I met Anna, a molecular biology graduate student.

I dreaded talking about the thing that had killed my mother, but Anna got me to open up about it, only for me to realise how raw my buried emotions still were 11 years after she had left us. As I explained to Anna my family's history of cancer, she suggested that I get tested for the BRCA mutation, but I was not ill, not yet. If cancer was a curse, there was hope. But a faulty gene? That was beyond my ken. A year later, I was ready for the test that would give me a chance to get ahead of the defective gene if it was in my body.

I had to book an appointment for a risk assessment before I could qualify for the test on the National Health Service. My risk assessment suggested a BRCA mutation; I had a family history of ovarian and breast cancer, and both my mother and grandmother had been diagnosed before the age of 50. I went back for the blood work the following day. You are too young, the genetic counselor said, and she was right. I was 28. The results came back two weeks later and they returned positive. BRCA 1. A gene that produces tumor-suppressing proteins that stop cells in the breasts and ovaries from growing and dividing too rapidly thus preventing the growth of tumors. BRCA 1-positive; a person with a mutation to his or her BRCA 1 gene, meaning either that the gene is altered or broken, impairing its ability to suppress tumors.

I was that person.

Genes work in pairs and we inherit a copy from each of our parents. One copy of my BRCA 1 genes was faulty, most probably the pair I got from my mother. And that was not all; this meant that I was at increased risk of breast and ovarian cancer. This information was paralysing. And even though going into the test I knew I had a 50 per cent chance of being a carrier of the defective gene, I hadn't thought through what I was going to do if the test came back positive. I preferred to take it one step at a time. With a family history that clearly indicated that my mother might have had the mutated gene, I was working with 1:2 risk ratio yet I still felt the universe owed me some good news. It was disheartening. I felt forlorn. The results gave me a glimpse of what awaited me, my possible future as I reflected on my mother's death. For the next few months, as I tried to understand what this meant for me, it felt like I was walking into a void engulfed and knotted by uncertainty. Having the BRCA 1 mutation redefined who I was, my old self peeling away. I didn't just have a mutated gene; I had a 75 per cent risk of developing breast cancer. How do you go through life with this hanging over your head?

The test was a mark of privilege, a possibly altered fate, a choice both my mother and grandmother had not had. I was lucky, yet I still needed to do more.

Having a double mastectomy, the surgical removal of all breast tissue, is draconian to say the least. But cancer is a word too loaded for me to unpack; memories of my mother before the cancer, and what was left of her after, had me on edge. I needed to talk to someone who made me feel at home, my maternal aunt. But whatever had bound us together untill then broke when I mentioned the surgery. For my aunt, to go ahead with the surgery would be to mock God, my faith, her faith and my mother's, and she wanted nothing to do with it. No one in my family wanted anything to do with it. They thought I had been brainwashed.

The most effective precautionary measure is to remove the organs that are at risk at a young age as the risk peaks in your thirties. In my case, it was my breasts. Self-preservation, removing some parts to save others, that is what kept echoing in my mind as I lay on that surgical table before I drifted off. Post-surgery was brutal and my impatience to get quickly back to normal did not help. For ten weeks it felt like time had slowed, the earth had lost its form. I had done the right thing, I knew that. So why did it hurt this much? Anna got me post-surgery bras and lots of teas. I was a foreigner in a foreign country. Having a mastectomy because of a faulty gene made it worse. There was no support group for me; I had to walk this perilous journey alone. I am glad I qualified to have the test and the surgery on the UK's National Health Service — their version of Kenya's National Hospital Insurance Fund; the costs would have floored me.

Do I sleep a little bit more soundly? Yes, although a lot has changed for me. The test and the surgery did not remove the mutated gene; it will always be a part of me and so will the consequences of my proactiveness. I lost my breasts, and my body aches for that loss. Before I could afford reconstructive surgery to regain a semblance of what I had lost, I needed to adjust to not having a part of what so greatly defines being a woman. The first time that I tried to get intimate with someone after surgery and before reconstruction did not go well; the look on his face made me feel like I was an imitation of my old self, that I had duped him. That night I mourned the loss of my breasts, sobs racking my body until I couldn't breathe. I must have passed out; when I woke up it was morning. After that day, things began to change; I had not gone through all that to sulk and take pity on myself. I wanted to live; I was not willing to die for my breasts. I had reconstructive surgery and this time round I had more support — from the man who would later become the father of my child. I had had the surgery for myself; it lowered the risk to 5 per cent. I have made a few lifestyle changes: I am vegan; I don't take alcohol and have a fitness routine. Awareness is power, although that power can be overwhelming.

As for the fourth generation, my daughter, I think of my 5-year-old who may have inherited the gene.

A child of a BRCA 1-positive person has a 50 per cent chance of inheriting the mutated gene. When the time comes, I will definitely talk with her about it and urge her to go for the test even as I remain hopeful that by then non-surgical preventive measures will be available. The test was not just for me. It was for my daughter as well, my way of breaking the curse, freeing the generations to follow. Our first step out of the darkness.

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