

WOMEN'S HEALTH STUDY

SUBMISSION TO THE HOUSE OF COMMONS

STANDING COMMITTEE ON HEALTH

JANUARY 11, 2024

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Diagnosed and living with de novo stage 4 breast cancer since March 2019

THE QUESTION

How have the current breast cancer screening guidelines impacted me?

BACKGROUND

NATALIE KWADRANS

I always had a healthy lifestyle and ate well. I was a university-level volleyball player. I competed for Team Canada as a snowboard racer from 1995-1998. I lived in British Columbia when I found a lump in my breast. My GP sent me for imaging. Upon getting the results, I was told I had “lumpy” (doctor’s word) breasts and should get screened every 2 years, which I did until I moved to Alberta in 2007.

In 2008, I found a GP near my home in Calgary’s suburbs. I asked my GP for a mammogram but was told screening started at 50. I explained I was “lumpy” and should be followed but I never got a referral.

Life went on and several years later, I got married and had two children. I had a great career. Professionally, I held multiple designations: MBA, CPA-CMA, and a now-lapsed PMP. In December 2018, I left a Director of Strategy position at an international bank to become the Vice-President of a small company. I developed and taught university courses at three different Canadian universities on the side. I was also undertaking a MSc at HEC Paris. My life was perfect until, five days after my 46th birthday, I found a tiny split pea sized lump in my right breast. My GP sent me for screening, though told me it was only precautionary since I was too young for breast cancer. I felt reassured.

Immediately after getting my mammogram and ultrasound, the Radiologist came in the room and told me he didn’t like what he saw. He insisted I book a biopsy for the following week. He sent my imaging results to my GP and referred me to the Calgary Breast Health Clinic. On March 18, 2019, I was diagnosed with aggressive, triple-positive breast cancer. How could that be if I was too young for a mammogram?

LIVING WITH TERMINAL CANCER

THE INITIAL DISRUPTION

My life was turned upside down. In three weeks, I saw four different doctors, had six different types of imaging done, had bloodwork drawn twice and started chemotherapy. I went on medical leave. My kids were scared, and we all cried. Often.

CHEMOTHERAPY – APRIL TO SEPTEMBER 2019

On April 9, I had my first chemotherapy. During treatment, we discovered my cancer was in my breast, lymph nodes, sternum, right 5th rib and my T11 vertebra. My official diagnosis was stage 4, de novo breast cancer. I was told I had ~22% chance of living the next 5 years.

Physical effects: I received three types of chemotherapies over six months. I was getting bloodwork done before each infusion. I had my regular quarterly scans in addition to cardiac imaging due to the toxicity of the chemotherapies. The physical effects were horrible: painful mouth sores, exhaustion, large plantar blisters from acute neuropathy, nausea, severe bone pain, fevers, shortness of breath, hot flashes, vision changes, etc. Because I had to suck on ice cubes during infusions, wear ice packs on my hands feet to minimize the side effects, I developed PTSD. To this day, I feel nauseated at the sight of iced water.

Psychological impacts: The chemotherapies caused severe brain fog. Sometimes I couldn't string two sentences together. I had memory loss, mood swings, sobbing fits, fear, concern, self-pity, helplessness, emptiness, loneliness, etc. Many of these feelings extended were also felt by my children, parents, and husband. Over time, my husband and primary caretaker became distant, increasingly irritable, and angry. The kids were the victims of the changes in our family dynamic, and it even impacted them at school. My daughter was bullied after I had dropped her off one day and the kids saw my bald head. She cried for weeks. We got extensive therapy.

Financial impacts: With no short-term disability plan, I went on EI and my self-employed husband worked more to cover the bills. New expenses arose. Our transportation costs more than doubled with my weekly hospital visits and parking fees required at almost every single medical facility I went to.

SURGERIES – OCTOBER 2019

In early October, I had a mastectomy and lymph node dissection on my right side.

Physical effects: Post-surgery was filled with pain, drains with bags hanging out of my chest which I needed to empty daily and grogginess from pain killers. I needed help getting dressed, doing my hair, etc. I developed lymphedema and needed lymphatic drainage treatments. I also required physiotherapy and massage to regain my range of motion.

Psychological impacts I felt isolated and depressed. My young children were fearful of me: bald, lopsided, emotional and in pain. They learned that I would die earlier than most of their friends' parents would. They grieved as I went through my various treatments. Therapy continued.

Financial impacts: I moved onto my long-term disability plan (LTD). It pays slightly more than EI, but my CPP-Disability and any other income, such as investments, got clawed back from the LTD amount. Our transportation costs were through the roof. New expenses appeared for post-mastectomy tops to hold the drain bags, mastectomy bras, and a prosthetic breast. Only a fraction of this is covered by insurance. It was a \$1,000 blow on our reduced income.

CONVENTIONAL CHEST RADIATION – NOVEMBER/ DECEMBER 2019

Four weeks post-chemo, I met with a Radiation Oncologist. He scheduled more scans, chest mapping and "tattoos" to set me up for radiation.

Physical effects: Everyone told me radiation was so much easier than chemo. That wasn't my experience. I had skin burns that bled, oozing wounds that needed regular bandage changes, etc. It hurt to shower. I wasn't allowed to take a bath. The fatigue was beyond anything I have ever experienced. By mid-November, I rarely left my bedroom. I needed food brought to me.

Psychological impacts: I felt like a burden. I was unable to go downstairs to celebrate my daughter's birthday or spend Christmas with my in-laws who had flown in. I was alone in my room listening to the whole of the family have fun. It was heartbreaking, isolating and depressing.

Financial impacts: Transportation costs increased again as hospital visits were daily 3.5 weeks. My insurance limits for professional services were maxed out, meaning we were incurring sometimes up to \$3,000 in incremental expenses between my lymphatic drainage, massages and physical therapy for myself, in addition to therapy fees for my family.

SPINAL SBRT RADIATION – JANUARY 2019

I received SBRT radiation, which is short in duration but more localized and intense.

Physical effects: Fatigue worsened, and I was sleeping ~16-18 hours/ day. I was virtually bedridden. It wasn't until early February that I was able to make my way downstairs alone, but I'd require a long nap from that exertion. I fractured my T11 after a fall in May.

Psychological impacts: The exhaustion was unbearable. One day, I told my husband that I didn't think I would wake up after my nap. I told him I loved him and to tell the kids the same. I believed I was going to die that day.

ONGOING TREATMENTS

I started daily oral hormone blockers in November 2019 as well as two different immunotherapy infusions. I continue to receive these two infusions every 3 weeks. Every quarter, I also receive a zoledronic acid infusion to slow the cancer in my bones.

Physical effects: I had severe vision issues, from dry eyes, retinopathy and cataracts. I had two cataract surgeries in June 2022. My neuropathy continues to get worse. I lose balance and fall regularly, I drop items, my limbs are numb. My back pain never ends. I've managed pain with opioids, nerve blockers, and most recently, nerve ablation. I also experience explosive bowel movements post-treatment. Managing my household chores is increasingly difficult.

Psychological impacts: The side effects of treatment can be debilitating and embarrassing, especially if I can't find a washroom in time. Having to continually rely on others to help chips away at my self-esteem. I live on an emotional roller-coaster. Caretaking eventually took a toll on my husband. He left me in 2020. We share custody of our two children.

Financial impacts: My lack of energy means I have to pay for areas my friends don't help with, such as housekeeping, laundry and occasionally doing groceries. I've explored all community resources with my social worker and have exhausted all of them or I don't qualify as I am not a senior. I often rely on the Food Bank for food and grants/ subsidies so I can register my kids in sports.

PROGRESSIONS

PROGRESSION TO MY RIGHT HIP – JANUARY 2021

I continue to get scans every quarter to monitor the cancer progression. In January 2021, the cancer metastasized in my femoral head. I needed SBRT radiation therapy once again. The impacts described earlier with my spinal radiation were the same with this one.

PROGRESSION TO MY RIGHT HIP – JANUARY 2022

Almost exactly a year later, multiple new lesions appeared on my femoral neck and into the femur itself. SBRT wasn't an option with so many lesions. Conventional palliative radiation was offered, though not recommended as my oncology team didn't feel it would kill all the cancer. My other options were to try different chemotherapy or receive a full hip replacement. My oncologists felt the hip replacement would give me the best outcome.

Physical effects: These were much worse than I anticipated. The pain was unbearable, causing me to shake and sob. I needed a walker for weeks before trading it in for crutches. I needed someone to sleep in bed with me in case I had to go to the bathroom or needed something. I dreaded having to go to the bathroom, and most times, I didn't make it. My 80+ year-old dad was cleaning pee or diarrhea off the floor. It was awful. I eventually wore adult diapers until I could manage on my own.

Psychological impacts: I remember thinking that I should be the one helping my dad, and not the other way around. I was embarrassed. My children were terrified I was not going to live through this progression. My daughter, who was 8 years old, asked my dad if they could euthanize me the way my boyfriend had done with his dog a few months prior. My dad was in shock and couldn't believe his granddaughter asked him that. No 8-year-old child should ever have to think about euthanizing their parent.

THE QUESTION ANSWERED

The current breast screening guidelines failed me. Two out of three GPs look to the guidelines, which are not only outdated, but based on a fundamentally flawed trial¹. Modern research shows that screening women in their 40s can save lives. However, because of these guidelines, two GPs dismissed my requests for screening. As a result, I was diagnosed with stage 4 de novo breast cancer when my life could have been saved.

There is debate as to whether the risk of a false positive outweighs the benefits of screening. I would say it does not. I went from being a productive member of society to a burden to taxpayers. The psychological scars that my preventable cancer diagnosis have left on my children and family cannot be erased.

RECOMMENDATIONS

1. Ensure patients point of view, and those of their immediate families and caretakers, are heard and included in the guideline development.
2. Use modern research to create guidelines that will save women's lives and reduce suffering.

¹ Yaffe, M. J., Seely, J. M., Gordon, P. B., Appavoo, S., & Kopans, D. B. (2021). The randomized trial of mammography screening that was not—a cautionary tale. *Journal of Medical Screening*, 29(1), 7–11. <https://doi.org/10.1177/09691413211059461>