A full time job: a year with early-stage breast cancer

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Nobody told me that breast cancer is a full time job. In my case—stage 2 invasive ductal carcinoma, a type responsible for 80% of cases—it turned out to be a job that doesn’t care that you have other responsibilities—two small children, a spouse, a career.

Because I am a social scientist, it was a comfort to document my illness in a format that is familiar. So I set out to make a real time self-study of my breast cancer journey, constructing a spreadsheet to track dates, descriptions, locations, and clinical roles associated with each of my clinical encounters, annotated with summaries and colour coded for purpose: diagnosis, chemotherapy preparation, chemotherapy, hospital admission, surgery, and so on it went.

This is my journey—others may look different, and despite being an active participant in my care, I’ve used the passive voice here, to try to convey a lack of control that I felt, of being taken on a ride that I did not sign up for.

Over a 13-month period, I experienced 16 rounds of chemotherapy, 34 rounds of radiation, and three surgeries, including a mastectomy and a salpingo-oophorectomy. I received care from two medical oncologists, a radiation oncologist, a breast surgeon, a plastic surgeon, a gynaecological oncologist, a radiation oncologist, and numerous nurses and physician’s assistants, not to mention the second and third opinions I sought from all cancer specialties.

I was cared for at four separate locations. There were routine appointments, blood tests, diagnostic scans, a hospital admission for a neutropenic fever and consultations from genetic counselling, ophthalmology, cardiology, dermatology, psychiatry, nutrition, podiatry, and physical therapy.

“Most people work through chemo” was the message. Yes, they do. But as well as the professional kind of work, cancer requires you to take on a second “job.” Between September 2018 and August 2019, 54% of my business days had at least one medical appointment, with only three weeks being appointment-free. For a patient, these multiple direct touchpoints with the healthcare system form a delicate dance of prioritizing topics, symptoms, and concerns over a limited snapshot of a face-to-face encounter with one’s clinician.

On top of these direct touchpoints, there was everything that happened in between—the indirect “care-between-the-care,” as Patricia Flatley Brennan and Gail Casper describe it. Each day (medical appointment or not) had an effort and time cost associated with it—productivity loss due to fatigue, requiring additional sleep and reduced activity levels; management of side effects such as brain fog, gastrointestinal and dermatological issues; emotional distress (both my own and that of loved ones); logistics; countless trips to the pharmacy, purchasing of self-care supplies. I shan’t go on. And now that active treatment is over, I live with an ever-present (and often overwhelming) fear of recurrence.

The perspective of those who straddle both worlds, the bilingual patient-researchers, is of tremendous value. During my journey, I came upon the work of Trish Greenhalgh, whose autoethnography on adjuvant chemotherapy for breast cancer changed the way that I think about wearing multiple hats of a researcher and a patient, and Rosamund Snow—both of whom pioneered efforts to move the needle forward in the need to consider the patient perspective and experience, driven by their own patient journeys.²³

Lived experiences often form evidence that cannot be captured through research which, by definition relies on sampling. Turning the research lens on oneself requires applying something technical to an experience that is emotional and unquestionably biased. The value? A novel unit of analysis—the continuum of care in its entirety—only accessible to the patient, which has the potential to uncover not only the answers that we haven’t yet found, but also the questions we haven’t yet asked. Questions such as: what are the strategies that patients use to navigate aspects of their care continuum, such as managing information? How do patients prioritise which questions and concerns to bring up with their care team (versus what is left unsaid)? How much work is involved in navigating illness, and further, how does “normal” work shift to others—e.g. household and childcare responsibilities?

Representing this work across space and time is necessary to capture care continuity, along with identifying the opportunities for support. Specifically, the challenges and gaps that come to light via such representation (e.g. the fact that my oncologist did not tell me about chemo brain) are opportunities to improve or create education, more effective communication processes, and technological tools and interfaces to help with planning, scheduling, and information management.

And what of the covid-19 pandemic? A positive impact has been the relief of the burden of care through telehealth visits, and information sharing using means other than face-to-face. However, covid’s impact has included care delays, as well as a tremendous increase in “patient work”—for example, through managing logistics in the midst of uncertainty, and covid testing before procedures, just to name a few. It’s also been vital to make sure that, as far as possible, in-person visits continue for certain physical and visual examinations that are essential for safe and effective decision making by clinicians.

² 3
Capturing one’s care continuum in this way is, I believe, an opportunity to shine the light on the remarkable amount of time and effort that is associated with a disease like early-stage breast cancer (where treatment intent is no evidence of disease [NED] status). Even more, identifying gaps and research questions, through this exercise, is a chance to potentially find meaning and purpose in a journey marked with uncertainty and fear. Both are necessary to move the science forward.

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