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## Chemo Killed the Small-Talk Gene

URVASHI VAID

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**KEYWORDS** *Urvashi Vaid, lesbian activist, breast cancer activism, breast cancer, lesbian health, lesbian support systems, breast cancer and MRI, organizing around cancer*

1

Cancer surprised me twice: first, thyroid cancer and just last year, breast cancer. My journey through diagnosis, treatment, and recovery struck me at first review to be a depoliticized experience; yet, everything about my cancer journey was profoundly about power—which is what defines the political. I am a feminist activist who came to consciousness in the 1970s, and a lesbian who has worked in the queer movement since 1979. My formative experiences included the women's self-help movement that

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empowered women to know our bodies, to ask questions, and to consider ourselves experts. I also witnessed the urgency and life-saving value of building a lesbian community—I worked on that through the women’s culture movement (musicians, poets, writers were our leaders in the ‘70s and ‘80s, not the politicians). And I spent more than a decade as an AIDS activist, organizing media coverage, protests, legislative campaigns, institutions, and funding to demand a response from cultural, medical, and research establishments to an epidemic, and to people living with HIV/AIDS, that these institutions did not want to address.

These experiences with both lesbian feminist activism and AIDS activism taught me to advocate for myself, to not be intimidated by an expert presence in the room, and to value my lived experience as expertise. Yet, both times, cancer—the ugly specifics of its physical devastation, the mechanics of surviving it, and the structure of the industry that surrounds it—rendered me politically disempowered and personally immobilized. The two cancers left me at the mercy of medical technologies that could not guarantee my health, much less limit their own negative effects. They shrunk my world down to a small sphere of medical appointments, caregivers, and tasks. And they also reminded me of the transformational power of love and community in any struggle to survive.

Despite the fact that I have had close friends with cancer, including various kinds of breast cancer, I knew very little about cancer treatment before my diagnosis. That’s quite amazing given that more than 1.6 million cases of cancer were diagnosed in 2012, and that 226,000 of these were breast cancer.<sup>1</sup> My ignorance left me scrambling—calling friends, reading websites, devouring books, and most importantly talking to women who had gone through the experience I was facing.

## 2

Both cancers were detected only because I had excellent health providers and great health insurance. With the thyroid cancer, I felt a weird swallowing blockage in my throat—and it came and went. I thought it was swollen glands, and my partner Kate Clinton said I should just have our doctor look at it. My brilliant general practitioner examined me and found nodules on the thyroid. He recommended me to an endocrinologist, who ordered sonograms, and then sonogram-guided biopsies, and the confirmation of cancer. My GP referred me to a surgeon and I had the thyroid removed, they found it was in my lymph nodes, so I had radiation. They give you a pill instead of beam radiation; you have to be isolated for a couple of days while you are nuclear. You are actually radioactive for a while afterward and they tell you to stay away from children. I asked about Kate, and the medical technician asked her, “How old are you?” She told her age (in her 50s) and

he said, “Oh it won’t matter.” That callous calculus made me wonder at the ethics of medical treatment and the number of people walking around with nuclear medicine in their bodies, irradiating everyone.

With breast cancer, it was once again my general practitioner/internist, Dr. Michael Liguori, whose insistence on annual mammograms got me detected early. When the mammogram revealed more calcifications than the prior year, we all thought it was nothing, since I have no family history of breast cancer. My doctor referred me to a very skilled breast surgeon at Beth Israel Medical Center. He took a lot of time and care, even reviewed old films for comparison, and concluded there were two spots that looked suspicious, one more so than the other, so he performed a biopsy of that spot.

That first biopsy revealed ductal carcinoma in situ (DCIS). The breast surgeon told me that some people do not even consider this cancer; it’s bad news but not as bad as it could be. The treatment program for this is lumpectomy and possible radiation. But the good news about DCIS is that the cancer cells have not breached the cell wall.

I asked about the other spot. The surgeon replied that he would check it out when he did the lumpectomy. I said, “Don’t you want to do an MRI [magnetic resonance imaging]? Wouldn’t it tell you more about what’s going on this breast?” I was worried also about the other breast although nothing had turned up on it. The surgeon agreed that an MRI is a more precise test, but insurance companies sometimes do not pay for it, so it’s not routinely ordered. Kate, actually said, “I will write you a check.” And we insisted on the test.

The MRI revealed definite activity at the opposite side of the breast, including a node that looked suspicious. I had three biopsies done in one day and that pathology report came back showing invasive breast cancer. I will never forget that when we walked in to see the surgeon we thought I had breast cancer, Stage 0 (DCIS); by the time we walked out of that appointment, I had Stage III—tiny tumors, but designated so because it was invasive and because of the lymph involvement.

A couple of things stood out for me in that whole experience. One, you have to be your own strongest advocate. I was not particularly well informed about any of this before I went into it beyond the fact that I knew that there something called an MRI. It seemed reasonable to insist that before anybody did surgery on my body there should be a more accurate mapping of what was going on. My insistence on an MRI changed the whole treatment recommendation, because when they found multi-focal breast cancer with lymph node involvement, the recommended treatment is mastectomy and chemo.

The second thing that stands out is how valuable it was to talk to people who have gone through this experience to anticipate what to expect. With something as major as this, you need information and practical advice—doctors do not give you that. For me it was reaching out to friends involved in breast cancer work and people referred to me by others who had dealt with cancer. They told me very useful things like to make sure

to gather copies of every test result as you have them done. They told me to take my time and talk to different doctors till I found one I liked. They discussed their experience with different hospitals, and their strengths and weaknesses. They told me to take the time to get a second opinion.

## 3

The second opinion process was nerve wracking—you want to move quickly to get the cancer out, but you also want someone to tell you it's been a terrible mistake. The process involved deciding where to get the opinion, collecting all the test results, biopsy slides and data from various labs, waiting for an appointment, waiting for the re-testing to confirm what you fear. I got the second opinion at Memorial Sloan-Kettering Cancer Center—it was an in-plan hospital on my health plan (which makes coverage cheaper). The breast surgeon I selected was busy, brilliant and efficient. She recommended a mastectomy to remove the tumors, chemotherapy as a systemic treatment, and she told me that radiation might be needed because there could be some errant cancer cell in the skin.

Then the big question arose, whether to have a single or double mastectomy, and whether or not to have breast reconstruction. That was an interesting decision-making process. After asking around, I quickly found women who had breast implants and reconstruction and who were willing to talk. Two good friends who had that procedure said they would never do it again because it was so painful. There was a very funny moment when a social worker connected me to a lesbian I had never met to discuss the reconstruction surgery she had. The very first time I met her, within five minutes, she said, “Do you want to feel my breasts?” And I did! It was quite odd and tender to be feeling up the body of a woman I had just met—cancer creates immediate intimacy. You share at a level that propriety avoids.

It was harder for the hospital to connect me to people who had not done reconstruction. The medical providers make an assumption that women will all want reconstruction to feel “whole.” The breast cancer medical machinery pushes you to consider plastic surgery and reconstruction. It is bundled with the mastectomies because it's easier (and probably less costly) for them and the insurance companies. They push for simultaneous reconstruction even though it is a harder and more complex surgery for the patient, makes the recovery time longer, the mobility more constricted, the risk of complications higher. The resulting implants do not look or feel like a breast. I know many women want that breast reconstruction conversation but I found it all profoundly heteronormative. In fact the whole experience of breast cancer treatment was infused with heterosexual norms that Kate's presence and our overt queerness challenged.

Ultimately, I decided on a double mastectomy—without reconstruction. I did both breasts because I wanted to minimize the chance of recurrence of breast cancer in the right breast. I am very glad I made that decision.

## 4

After surgery, you have to find an oncologist to work with you on drug treatment and follow-up care. Kate and I had also been collecting information on oncologists at Sloan-Kettering and we ended up with an amazing one. It was the old-dyke network, and my surgeon, who came through with the connection. Two activist lesbian friends urged me to see Dr. Larry Norton, who had treated the sister of one my friends. He's a renowned oncologist, head of the breast center at Sloan-Kettering so I thought the chances of getting an appointment with him were low, but my surgeon said it was worth an ask. The friend whose sister had been treated by Larry called him and urged him to see me, and he did.

What I love about my oncologist is that he actually likes his patients and doing clinical practice, and he spends all the time that I need with him. He and his team are amazing. They do a good physical exam, from the start and each time we meet, which I appreciate because it means he is examining my body and not just the paperwork.

During the initial conversation, he recommended 16 weeks of chemotherapy, 8 infusions every two weeks. He was the first doctor to say that it was very curious that I had no family history yet ended up with two bouts of cancer and he theorized it may be exposure related. He was careful to note this was speculation but he was really interested in epidemiology of cancer, not just the treatment. It was quite reassuring to Kate and me that he was engaging in a conversation about my specific history and cancer. Most doctors just look at you clinically and technically, like a specimen, and do not engage with the human story you bring.

Dr. Norton's second recommendation was harder to hear. He found huge uterine fibroids during the physical exam. He wanted me to see a gynecological surgeon, because he was worried about the possibility of excessive bleeding during chemotherapy. So I went to a gynecological surgeon at Sloan-Kettering, and also called my old friend, Dr. Kate O'Hanlan, a dyke doctor, and the most experienced and brilliant gynecological oncological surgeon around for advice. It was clear I had large fibroids—the size of grapefruits and oranges (they always use fruit imagery). So, six weeks after my breast surgery was done, I had to have a laparoscopic hysterectomy. It was truly awful. It felt much harder, and more invasive than the mastectomies. And the recovery was tough. But the body is amazing and resilient and five weeks after that second surgery, I was ready for chemo.

Eventually, they say they will know the genetic make-up of the cancers we get and be able to target drugs to particular forms of cancer (there are something like 12 kinds of breast cancer, for example). But right now, it's all about the odds—like a casino. The goal of chemo treatment currently is nothing more precise than reducing the odds of recurrence. They use a set of drugs that have been clinically shown to destroy cancer cells without destroying you. Chemo is usually a drug combination—mine was ACT: Adriamycin, Cytosin, and Taxol.

Adriamycin was terrifying—I made the mistake of reading about it before the first infusion. Do not read too much on the Internet. It's bright red, like Red Dye #2, and so toxic the nurse has to wear hazard protection to infuse you so she does not get any on her. Yet, it went into my system four times, in combination with the Cytosin. The last four treatments were with Taxol—a monstrous drug that is so bad for your white blood cells that you have to get a shot of another drug called Neulasta each time you get infused, so your white blood cells do not completely disappear! Taxol also has the lovely side effects of neuropathy, horrible aches, and icky-ness.

Chemotherapy was an endurance test. Some of the infusions were four hours long, and sometimes the waiting for a room was hours as well. Kate and I prepared ourselves in different ways. We got a juicer, we bought bland and salty crackers, we got lots of anti-nausea pills, and special home remedies from friends to deal with the binding constipation the drugs produce. We bought lots of greens and coconut water to hydrate and keep flushing the poisons out. My sister sent me a pile of very useful books including one about how to survive and thrive during chemo. I did not have the terrible nausea because I changed the way I ate. Sadly, I could not eat my favorite spicy Indian food, during chemo.

The best thing I did for myself during this whole process was to start seeing a highly skilled medical massage therapist affiliated with Sloan-Kettering's integrative medicine services center. The surgery messes with all your muscles and nerves—especially since they removed lymph nodes. And radiation inflames tissues and makes things tight as well—so massage and physical therapy to maintain mobility and looseness is essential. This amazing woman insured that I could move. Many people also recommended exercise, and so Kate and I walked religiously every morning. At first (after surgeries or after chemo) I could only walk one block with Kate's help. But we persisted. And our morning walks in Riverside Park were deeply healing and important to both of us.

My hair started falling out after the second treatment, so I had it buzzed very close to my head and eventually shaved off. It came back about three months after treatment ended, and it came back curly—totally different from my old hair. I never wore a wig, just hats and scarves. Being bald was

interesting—my 1-year-old neighbor across the hall who was shy with everyone else, suddenly loved seeing me—I think because I reminded her of her bald dad.

## 6

Toward the end of chemotherapy—around the 7th or 8th session—we began preparing for radiation. That involves going to a new set of doctors and labs, getting your breast “mapped” for the radiation field, getting a mold made of your body in the position they want you in for the treatment—so you will be positioned the same each time you go. I waited about a month to recover from the chemo. Then I had radiation for 5 weeks.

For me, beam radiation was the worst of the year-long medical treatments. It does not hurt, and the actual beam is only about 10 or so minutes in duration, but the tension of that experience was daily and exhausting (as was the side effect of the radiation itself). It was just a wretched experience, awful in a whole different way than chemotherapy. Partly this was because radiation was every day—so it’s always present in your life. I felt like a slab of meat on a table, probed and positioned by an ever-changing team of technicians who seemed to have more work than they could handle, like workers on an assembly line. They line you up on the table, in your mold, with a huge machine over you and target the beam radiation onto a field mapped out for your body by a specialist.

It was also hard because Sloan-Kettering’s radiation center is hideous. The radiation facility was under construction at the time I went, impersonal, ugly, institutional, and unpleasant. Everyone had to wait hours for appointments—and when you go five days a week, that is a lot of time in a waiting room. The other cancer patients waiting were fantastic. You get to know everybody, women and men and even some kids, all waiting for their radiation treatments. There is instant camaraderie and story telling.

One of the saddest aspects of the radiation treatments, though, was the unexpected presence of three of my friends from the queer movement who turned out to be in cancer treatment there, at the same time, in the same facility. Two of them had breast cancer and one had an unusual cancer on his arm. It was surreal to be together in that place.

Radiation left me with a large blotchy patch of discolored skin on my chest—like a sideways map of Maine. Fortunately, my skin did not blister too badly, but I was proactive and went to a great cancer-specializing dermatologist who gave me several different kinds of cream and lotions to help. Again, if I had not been proactive, I am not sure I would have gotten the additional salves.

The final step in treatment for me is the daily pill that I take—called an aromatase inhibitor. I think of it as aroma therapy. The drug I am on has



side effects (of course)—it destroys your bones, and leaves you aching and moving stiffly like you are 85 years old and arthritic. I may have to change it if it gets impossible. So far, I am trying to stay active and manage the painful joints and aches.

## 7

When this journal asked me to share my experience of cancer, I found myself sharing a lot of details—a catalog of the medical treatments—and not as much of an evaluation of or reflection on the experience. I am still newly emerging from this experience, so it's hard to be detached. But I chose to tell the story in this way in case it helps someone facing breast cancer to learn a few specifics about what it's like to go through the treatments—there are so many more details that could be shared at each stage.

The story would be incomplete without a discussion of the support I had that got me through. I am profoundly lucky—to have had my partner in life, Kate, go through this with me at every step. I cannot imagine having gone through this without her. We shared the terror, absurdity, sadness, laughs, and pain.

My cancer—from the conversations to doing medical and doctor-related research, to going for tests, doctors' appointments, treatment appointments—became a second part-time job for Kate and me. We kept a daily pill log, along with little notebooks on our dresser, writing down what was happening every day, which was really helpful. Having somebody in the room with me during appointments was extraordinarily important. Sometimes it was even good to have two people in the room, because there were moments when it was hard for Kate to hear some of what was being said.

The intimacy of any ill person with their caregivers is hard to describe. This cancer experience brought intensely personal, quiet moments of connection with Kate. She did it all, from handling my bodily fluids, including changing my drains, and as she says, when you change someone's drains after breast surgery, that's real intimacy. She gave me the shots of Neulasta each week, massaged my aching back, neuropathy-tinged feet and legs, propped me up in pillows at night, dealt with the night sweats, shared the anxiety ridden moments and helped me stay positive throughout. This year marked our 25th anniversary. And we celebrated it by formally getting married on our anniversary date.

Our family of origin and community of close friends were also strongly present throughout. Support also came from my work colleagues, people in my apartment building, business owners in the block I live on who saw me go bald and figured out what was happening, and total strangers who were incredibly kind. One of my sisters lives in New York and she and her

husband were there for every surgery with Kate. My other sister came and cooked for a week! Friends from out of town came and stayed with me during Kate's work trips. Local friends came and cooked dinners, sat with me when I was just stupid from the chemo or tired from radiation.

We watched endless hours of TV shows—Netflix streaming service should be prescribed as an anti-anxiety drug for every person with cancer. Kate and I watched television series and movies during this past year—in waiting rooms on my Ipad, in the hospital rooms after surgeries, and at home, several episodes a day. *The Wire*, *Friday Night Lights*, *Game of Thrones*, *24*, *Damages*, *Mad Men*, *Lip Service*, *MI5*, *Downton Abbey*—the narcotic effect of these television series matched that of the best drugs.

When I first got diagnosed, two friends in DC encouraged us to consider using a website that they had used to manage support during one of their breast cancer treatment years. It is called MyLifeLine.org. The site allows you to create a private, personal Facebook-like website on which you can post information, photos, and receive messages. We used MyLifeLine.org throughout the year to keep in close contact with a large circle of families and friends. It was incredibly helpful. We posted updates sometimes several times a day, described different procedures, results of tests, posted pictures of ourselves in the experience. In turn, our friends posted their encouraging messages—we loved them all, even the repetitive, “go Urvasi,” “go Kate,” or “thinking of you, sending love”—I mean there's only so much people can say after a point. The site cheered us up throughout this ordeal. And it helped our national circle of friends feel like they could provide some support, even long distance.

## 8

A friend gave me a button at the start of my treatments that read—“I may not look like I'm doing much, but at the cellular level I'm very busy.” I worked throughout. Again I was lucky. My work right now involves research, writing, and convening—not a lot of travel, or management, or running an organization, as I have done in the past. Cancer made it hard to concentrate, and it was tough physically at times, but I worked steadily. Throughout the year, I went regularly to my office at Columbia. I took my full vacation and sick days, but I actually wanted to work—because going to work in my office was usefully distracting. I had decided to publish a book of essays before I got diagnosed, and I worked on that book throughout the year. It makes me very happy that the book came out in November of 2012, at the end of my chemo treatments. It's titled *Irresistible Revolution: Confronting Race, Class, and the Assumptions of Lesbian, Gay, Bisexual, and Transgender Politics*.

During chemo I also co-taught a class called “Queer Theory Workshop” with my colleague Katherine Franke at Columbia Law School. We planned

something called “Theory Meets Practice” where she was the queer theory part and I was the queer practice part. Chemo was on the same day as class so every two weeks I would end my chemo, and then Kate and I would take a cab to Columbia. Kate went to every one of those classes with me—so sweet—just to make sure I was okay. They pump you full of steroids during chemo, so I had lots of energy, but on some days in class I looked green, on others I looked yellow, and sometimes I was white. A few days later I would crash after the steroids ran their course. I went to every class except one when chemo took longer than usual.

And on my other volunteer commitments, my colleagues were also incredibly supportive. I continued to participate on the board of the Gill Foundation. They were so good to me, and arranged to have meetings in New York for a whole year because I could not fly. The lesbian SuperPAC board I am on—LPAC—was also incredible. Work was a great distraction.

## 9

This whole experience left me furious at the epidemic incidence of breast cancer and at the current state of breast cancer diagnosis, care, and treatment. The field is ripe for militant action, and yet, for the most part, this kind of activism is NOT taking place.

Breast cancer is a raging and deadly epidemic—yet, it’s treated in the media and by the breast cancer industrial complex as if it’s just a chronic, normal condition that one can “manage” and “survive.” I certainly intend to survive, but breast cancer kills some 40,000 people annually in the United States, and affects over 230,000 new people each year. During my year of cancer treatment, I learned of more than a dozen close friends who had also been diagnosed.

At every stage of cancer—the diagnosis stage, the surgery stage, the chemo and radiation stages—there are differences in how a woman is treated depending on where she happens to go for treatment. The treatment varies not because of the specifics of the cancers, but because of the quirks of the doctors, the knowledge or lack they have, the insurance regimes that they operate under, and the hospital policies and protocols they follow. There’s no national best practice—standard of care that I can discern. If I were to be diagnosed with breast cancer in a small town like Provincetown and seek treatment at Cape Cod Hospital, I would not get the same quality care or even the same protocols of standard treatment, and I think that’s preposterous. Given how much information is available and the ubiquity of this disease, how can there not be a best practice?

Suppose I had not insisted on the MRI and just gone with the advice of my initial capable surgeon. Without the MRI, I would have had a lumpectomy, and then I would have had to go back for another procedure, the

mastectomy, because he hopefully would have found the invasive cancer and lymph involvement during the lumpectomy. Friends I know have had to keep going back after their lumpectomy to have more surgeries to insure that the “margins” between the tumor and the cell wall are wide enough. And they must go for MRI and mammograms every 6 months. Is the extra strain of that continuous monitoring, the multiple trips to the surgeon to whittle away at cancer as it is discovered—is it worth “breast preserving surgery”—which is supposed to be the big innovation in cancer treatment?

One would suppose that after they sandblast you in this primitive way with chemo drugs, they could tell you at the end of it all that the cancer is actually gone. They cannot. What they can tell you are probabilities and these are not yet tailored to one’s particular chemistry or cancer. Similarly, with radiation—the experience varies drastically depending on which hospital you go to. And again, when it is over, they cannot tell you much about a prognosis.

How much money is being thrown at breast cancer research? Billions upon billions. And yet, there is not a great deal of coordination of that research—no overall strategic game plans to pursue cures or even causes. Research institutions compete and do not share information. Trials are taking place and I do not know if there is a central repository for patients to access. Scientists make fortunes selling their marginally effective treatments to drug companies. And drug companies in turn make fortunes marketing toxic and relatively useless drugs. They have no incentive to stop cancer—just to maintain us on their drips.

The drug development process seems actually counter to the best interests of the patient. If researchers can clinically prove that a drug is going to kill cancer cells for 12 weeks versus 6 weeks, that’s considered a success. What happens after the 16th week to the body of the patient? We do not know. The pharmaceutical company is delighted because they have a new drug in the pipeline and the researchers are delighted because they get kudos for extending something by 6 weeks. The academic researcher gets tenure but the patient does not have an improved quality of life or get an improved prognosis.

There’s a clear need for an ACT UP type direct action movement organized around diagnosis, treatment, and care for breast cancer. Wonderful groups exist for advocacy, education, and support—Breast Cancer Fund, Breast Cancer Action, for example. But they are not organized to mobilize the anger and energy of breast cancer survivors and our families to pressure and demand an improvement in diagnosis technologies, in drug development, in standards of care and treatment, in health insurance coverage, for example.

Power yields to demands and demanding requires us to take it to the corporate suites, the staid university research centers, the oncology conferences, and the governmental bodies that are not exercising their clout enough. I see

so many sites of potential engagement to challenge the hideous machinery of drug development, the lack of coordination among researchers, and the lack of patient-centered care and treatment—like we did during the AIDS epidemic.

## 10

One of the strangest side effects of this whole experience has been its impact on my ability to make chit chat. A lot of time in nonprofit-based political activism is spent in small talk—the fundraiser is ubiquitous because it is essential. Yet, chemo seems to have killed my small-talk gene. I find myself standing awkward and mute in situations in which I normally thrived. My tolerance for small talk and my filter are off. Some unsuspecting person comes up to me and asks the common question, how are you doing? And instead of the expected answer (just great, how are you?), I find myself launching into a detailed explanation of how I am really feeling. Even the mortified look on their faces does not stop me. The best resolution has been to not go to places where small talk is required.

I finally have the time to feel and to mourn now that treatments are done. I also am quite exhausted. Certainly I am relieved it is over, but that feeling is laced with uncertainty about the future. I guess I will feel more confident after the five-year marker or whatever marker that puts you in another category statistically. I wish they could tell me more precisely. Two things I feel very clear about, though: both material and immaterial things matter in dealing with cancer. Health insurance must be universal and we cannot let it be deprived to anyone. And creating loving communities around people dealing with illness is essential for anyone dealing with cancer.

## NOTE

1. American Cancer Society, *Cancer Facts and Figures, 2012*, accessed August 12, 2013 at <http://www.cancer.org/acs/groups/content/@epidemiologysurveillance/documents/document/acspc-031941.pdf>