A PATIENT STRUGGLES TO BE HEARD

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When I received a call from a nurse notifying me that I had breast cancer, my first sensation was shock. I was at work at the time, and the call came in a day earlier than I had expected. The nurse sounded apologetic, her voice strained yet matter-of-fact. I heard her words—"both biopsies came out positive for invasive lobular carcinoma"—and tried to absorb the reality that I had cancer. But it was as if my being was beginning to float away, almost as though I was having an out of body experience, looking down at myself from above. Floating up and away seemed safest, but I tried to stay seated there on that office chair, to understand what I was being told. My memory is blurry as to what happened next, but I think I called my husband and then I remember driving home within a few minutes of receiving the nurse's call. I texted a dear friend with the news on the way home, and she responded with concern as well as advice to be careful driving.

Part of the shock was due to the fact that I had been told initially that the tiny lump in my underarm was unlikely to be cancer, and this unlikelihood had been reinforced throughout the ensuing series of mammograms, ultrasounds and biopsies. After the shock came a wall of grief. At that point in my life I was going through a period of depression—within the past year and a half or so, I had been laid off from a tenure-track law school teaching job due to plummeting admissions, my mother had become homeless, and I had fallen into a deep attraction, which led me to question my long-term relationship with my spouse. Although I was fortunate to have a new and very rewarding in-house counsel job, I felt lost and had frequent spates of hopelessness. When I wasn't busy, my mind would often start to ponder whether those I was closest to might be better off if I didn't exist. The diagnosis felt like final confirmation that my life would never get back to normal.

In the midst of this grief, and as it gradually abated during the months of treatment, I began to notice how disempowering it felt to be a patient. Cancer patients tend to have a plethora of doctors, and I saw even more doctors than the average patient because I sought second opinions on several issues and also switched oncologists. The feelings of disempowerment

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and even dehumanization were more pronounced with some doctors than others. Indeed, my impression, based on a very small sampling, was that the more elite institutions had less respect for patients. But even in the most patient-friendly doctors' offices, I had the sense that my life had been virtually turned over to the medical profession. What I ultimately found is that, on some level, being a patient is, at least on a de facto basis, synonymous with lacking autonomy.

At the same time, I slowly came to find solace in learning about my condition and taking charge of my treatment options. I learned that cancer is, even for doctors who specialize in it, a terrible void of knowledge. In the midst of my utter terror and my anger about the harsh effects of various treatments, I took comfort in my brain's ability to sort out the complexities of each option, to wrestle with the series of Catch-22's that cancer patients are faced with. I was lucky to have the support of my spouse and many friends, far and near. I leaned on them and cried to them. And yet I often felt isolated in my illness, not because of anything to do with the quality of support I was receiving but because no one in my support network was facing death as immediately as I was at that moment.

At the times when I felt most alone, I took comfort in my brain's workings. I felt that I could, after hours of research and hand-wringing angst, evaluate what the doctors were telling me and choose a course of action. I could talk to the doctors in their own language, and this ability helped me regain some of the power I lost when I walked through the doors of the first doctor's office and became, at least from outward appearances, a person who simply showed up for seemingly endless appointments and obediently followed instructions, a passive recipient of damaging expert treatments that were designed to save my life with little attention to what I might lose in the process.

Sociologist Arthur W. Frank describes how medicine "claim[s] the body of the patient as its territory," quoting a quadriplegic counselor and writer who further notes that, when admitted to a hospital or visiting a doctor, "'[w]e stop being people and start being patients…'"[1] Looking back now, I can see both of these phenomena as aspects of my experience and also can see that it was pushing back against medicine's generalized view of my status as a patient and of my disease that helped me empower myself.[2]

In the course of my breast cancer diagnosis and treatment, there were many times when I felt that my body either had been appropriated by my providers or was in the process of being appropriated—in other words, claimed as medicine's territory. Some were overt and some were subtle. There are several instances that I could not see at all at the time, that are only apparent in retrospect.

First, there was the sheer volume of appointments. In the beginning, the appointments were two or three times a week. The last six weeks of actual treatment (two years out from

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[1] ARTHUR W. FRANK, THE WOUNDED STORYELLER: BODY, ILLNESS, AND ETHICS 10 (2d ed. 2013).

[2] Frank also notes that, in order to conceptualize modernist medicine, "'the diversity of suffering [has to] be reduced by a unifying general view, which is precisely that of clinical medicine.'" FRANK, *supra* note 1, at 11 (quoting CLAUDINE HERZLICH & JANINE PIERET, ILLNESS AND SELF IN SOCIETY 23 (1987)).

completing my treatment, I still go to the oncologist once every three months) required daily appointments for radiation treatment.

Given the driving involved and the time spent sitting in waiting rooms leafing through magazines, worrying about future test results, and anticipating the pain of biopsies and other procedures, these appointments ate up huge chunks of my workdays. Indeed, I still feel a vague sense of nostalgia when I pass the hospital complex where I had surgery and radiation treatment, as one might feel in passing a house she used to live in—a house where difficult things happened, but still a house associated with a formative part of her life. It is not at all an exaggeration to say that that hospital complex where I initially met with my surgeon and had the majority of my tests and treatments became a kind of second home. Part of the claiming of my body was the claiming of my life. Instead of my usual family, social, literary, and law-related activities, my primary focus came to consist of being available to treatment. My customary orbits were disrupted.

Another aspect of medicine's claiming of my body was that the doctors I met with, even those who were the most attentive and compassionate, such as my surgeon, Dr. McDonnell,[3] made assumptions about my willingness to undergo any and all conventional treatments that were recommended. These assumptions may seem completely normal—the vast majority of cancer patients probably attempt to live by these sorts of recommendations, in many cases without a second thought. The drive to stay alive is very strong in most of us, after all. But the perceived normality is tied to the fact that medicine claims the patient's body as its territory. If this were not the case, one can imagine a more equal relationship between the doctor and patient, one in which the doctor routinely solicited information about the patient's wishes and goals for treatment.[4] However, as I discuss in more detail later in this essay, in my experience with cancer specialists of various types, I had to be quite vocal in voicing my questions and desires in order to interrupt the cookie-cutter approach to my treatment. In that sense, I think that medicine's claiming of the patient's body, as described by Frank, is linked (or at least in my case was linked) to another phenomenon described by Frank, namely medicine's reduction of the diversity of suffering (and disease and treatment) to a unifying general view.[5] Both the volume of appointments and the assumptions built into my surgeon's interactions with me were somewhat subtle indicia of appropriation. Nonetheless, from the beginning, I was keenly aware of the disruption caused by the copious appointments. I remember commenting at the time to another writer who had had cancer that I felt like I lived at doctors' offices. My freedom to plan my own activities is something I treasure, and it was startling to see it evaporate in an instant. By contrast, I was too scared during my initial appointments to notice my surgeon's assumptions, and I also think that her assumptions are so normalized in our culture that they were hard to notice.

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[3] Names have been changed to protect privacy.

[4] For a discussion of the need for doctors to learn to listen better, see, e.g., Nirmal Joshi, Opinion, *Doctor, Shut Up and Listen*, N.Y. TIMES (Jan. 4, 2015), https://www.nytimes.com/2015/01/05/opinion/doctor-shut-up-and-listen.html [https://perma.cc/EY2W-DCWE].

[5] FRANK, *supra* note 1, at 11 (quoting CLAUDINE HERZLICH & JANINE PIERET, ILLNESS & SELF IN SOCIETY 23 (1987)).

However, my sense that the medical establishment was attempting to appropriate my body in order to cure it came into full force when I sought a second opinion at a well-known cancer hospital in my area. The appointment had to be scheduled a little more than a month after I was first diagnosed because of the demand for treatment at this clinic. What I walked into—and had, in fact, sought out—was a team approach to medicine in which the newly diagnosed patient meets with a small handful of cancer specialists that will potentially be involved in her treatment. In my case, the team consisted of an oncologist, a surgeon, a physical therapist, a radiation oncologist, a nurse (with the title of nurse navigator), and a medical fellow who was training to specialize in radiation oncology.

So many things went wrong at this appointment that it would be hard to recount them all. For instance, the radiation oncologist never showed up. The doctors who met with me were both late and in a rush. (While I generally think it's understandable when doctors are late, I found the combination of their being late and in a rush upsetting and even infuriating.) The surgeon, Dr. O'Brien, was the one who was most obviously rushing—she was breathing heavily, almost gasping between sentences, and walking and talking fast. I could sense her concern about getting to the next patient and the next.

Another issue was that the fellow on the team seemed very awkward in discussing breasts. He was in charge of having the initial discussion with me, going over a questionnaire I had filled out ahead of time. After he left, while my spouse and I waited anxiously for the surgeon and oncologist to come in, the fellow burst back in and embarrassedly asked me for my bra size, explaining sheepishly that it was part of their analysis. Afterward, I wondered if the fellows—and perhaps all other doctors in the clinic—are hired with no regard for their ability to converse with patients.

However, what stood out most of all to me about that long afternoon at the clinic was the fact that most of the team—particularly the surgeon and the fellow—seemed to have zero understanding that I was a human being who was entitled to make my own medical decisions. Even though the surgeon, who seemed to fancy herself to be the one in charge of the entire team, was a woman, I had the strong sense that sexism was part of the equation in this apparent drive to erase my autonomy.[6] This was, after all, a breast cancer team that met primarily with women.[7] Perhaps the condescending and aggressive attitude of some of the team members was based in part on the sex of the vast majority of their clients. At any rate, I had the distinct sense that I was not playing the role they envisioned for me as an obedient patient who was sufficiently impressed with their expertise to defer to any and all recommendations. The one exception to this point of view seemed to be the oncologist,

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[6] Sexism is longstanding in breast cancer treatment, at least as a historical matter. "[I]n the late nineteenth century…doctors routinely removed patients' breasts without their permission or knowledge." Ann E. Tweedy, *Insuring Breast Reconstruction*, 66 UCLA L. REV. DISCOURSE 2, 29 (2018).

[7] *See Know Your Risks: Breast Cancer Facts for Transgender Women & Men*, FENWAY HEALTH, http://www.thecentersd.org/pdf/health-advocacy/breast-cancer-facts-for.pdf [https://perma.cc/W6FB-AF8R] ("Two percent . . . of all breast cancer occurs in the breast tissue of non-transgender men."); *Male Breast Cancer*, NAT'L BREAST CANCER FOUNDATION, INC., http://www.nationalbreastcancer.org/male-breast-cancer [https://perma.cc/CC7V-XRQ5] (reporting that less than one percent of breast cancers develop in males).

who, when I asked him outright, said that he was comfortable with patients making their own decisions even when they deviated from his recommendations.

The surgeon began with a hurried rundown of all her credentials, highlighting the quality of the schools she had attended and the fact that she taught medical students breast cancer surgery and focused her practice exclusively on breast cancer surgery. During this monologue, it was clear that she was contrasting herself with the other doctors I had been seeing at the smaller hospital, who did not focus exclusively on breast cancer but dealt with other types of cancer as well. Her education and teaching background did not strike awe in me as perhaps they were intended. I had gone to good schools as well and similarly had taught professional students. I have some regard for those types of qualifications but don't see them as the end-all and be-all. Her exclusive focus on breast cancer gave me some pause—I couldn't deny that there could be a benefit to having a surgeon who focused solely on my type of cancer. Perhaps she would know things that those who had to keep up with developments relating to many different types of cancer would not. At the same time, I was dismayed that she was inviting me to look down on the doctors whom I had already been seeing, whom I liked and respected.

After the monologue on her credentials, she told me forcefully that she and the rest of the team had decided that I needed a mastectomy. This was extremely upsetting as I had been planning to have a lumpectomy and had discussed this plan extensively with the first surgeon I had met with, Dr. McDonnell. However, when I told Dr. O'Brien that I planned to have a lumpectomy, she responded, "That will take half your breast," and proceeded to tell me that cosmetically it did not make sense for me to have a lumpectomy. I said I planned to get reconstruction after the lumpectomy, but she shook her head and said, patronizingly, that the team "had decided" that I was a "good candidate for reconstruction" after the mastectomy and that they would refer me to a plastic surgeon and I would be "allowed to get reconstruction." All of these statements were phrased as if I had no agency whatsoever.

I knew that part of her cosmetic argument was based on erroneous information—a radiologist had recently discovered a mistake in one of my MRI reports, which related to the location of one of my tumors, but, when I tried to explain this, she would have none of it. She said she would look at any new test results and reports that came in, but she doubted that they would affect her decision. She also said in a vaguely threatening way, as if talking to a child, that would send a letter to my original surgeon, Dr. McDonnell, and tell her of her (Dr. O'Brien's) recommendation, so that "she will have that." The premise of the threat, as I understood it, was that Dr. McDonnell would be impressed by Dr. O'Brien's credentials and would see the error of her ways. The idea that I should be the one to make my own treatment decisions, whether based on expected cosmetic or medical results, seemed to be, to Dr. O'Brien, preposterous. By simply making an appointment and showing up for it I was perceived to have turned my body over to the team.

The radiation oncology fellow backed Dr. O'Brien up, reinforcing her view that I had no choices to make. He told me that I would not need to see the radiation oncologist because the team was recommending a full mastectomy. The unstated step in his logic was that therefore I *would* get a full mastectomy. The fact that I didn't want one was irrelevant to them. The nurse navigator, a person whose job it was, as her title suggests, to help patients navigate through the maze of providers, also held the same erroneous assumption that I had to follow the doctors' advice. She was sorry, she told me. She was out of the room but had "heard most of it."

Even leaving the issue of possible sexism aside, the entire experience was deeply troubling, and, in that moment, devastating. The clinic was rated highly in a local magazine, and so I had very much hoped to transfer my treatment there and had anticipated receiving very high quality care at that clinic. I had envisioned this clinic as a place where I could be safe in the knowledge that I was receiving the most cutting-edge and highest-quality care that was available, a place where I could go and not wonder later if I had found the right provider or received the right type of treatment. However, the reality I encountered did not make me feel safe at all.

I had known since my first meeting with Dr. McDonnell—which occurred the day after a nurse called me and told me that my biopsy results showed invasive lobular carcinoma—that I wanted a lumpectomy (also called a partial mastectomy) rather than a full mastectomy. A full mastectomy removes all breast tissue, whereas a lumpectomy simply removes the tumor and a small amount of surrounding tissue.[8] Radiation treatment is typically given in conjunction with a lumpectomy.[9] Dr. McDonnell had given me the option of a lumpectomy and saw it as a reasonable treatment approach. A couple more small tumors had been discovered after my initial meeting with Dr. McDonnell, and these were still being tested when I went in for the second opinion. However, I had discussed my preference for a lumpectomy no matter what these biopsy results showed with Dr. McDonnell, and she had agreed that this was a viable option. At the same time, she'd cautioned me that the results of the surgery may not be aesthetically pleasing. She had further warned me that if the margins of the tissue that was removed contained cancer cells, she would have operate again to remove more tissue. This was a significant risk given the type of cancer I had.

Part of the reason I didn't want a full mastectomy was that I wanted to preserve the feeling in my breast, which is not possible with a full mastectomy and reconstruction. But more than that even, I simply wanted to keep my breast for its own sake. I felt—and still feel—attached to it. I began to realize that my breasts were an important part of my image of myself and my sense of myself as a feminine person.

I also planned to have some type of reconstructive surgery after my lumpectomy. I knew from conversations with Dr. McDonnell that, in my case, surgery was likely to have a significant effect on the size and shape of my breast. Furthermore, I had seen my mother's discomfort in wearing bathing suits after she had had a modest lumpectomy and then radiation. (Radiation often shrinks the breast.) Because of my strong feelings about wanting to keep my breast, I was willing to take the risk of having unclean margins and having to

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[8] *See, e.g.*, *Komen Perspectives - Lumpectomy versus Mastectomy for Early Invasive Breast Cancer (February 2011)*, SUSAN G. KOMEN, https://ww5.komen.org/KomenPerspectives/Komen-Perspectives---Lumpectomy-versus-mastectomy-for-early-invasive-breast-cancer-(February-2011).html [https://perma.cc/E5B8-SRLL].

[9] *Id.*

have more surgery. The alternative—a full mastectomy—did not seem attractive even though it would minimize the risk of needing more surgery. Like feminist theorist Dian Price Herndl when she had to make decisions about breast cancer and reconstruction, I found I had to ask myself how much loss I could bear.[10] I did not feel like I could bear much more loss at that point in my life. My mother's homelessness, the loss of my prized teaching job (even though it had been replaced with another very sought-after job), and my relationship struggles already felt like way too much for one person to deal with.

This doctor's visit with Dr. O'Brien and the other members of the team at the well-known cancer hospital terrified me. It was so important to me to preserve as much of my breast as possible and here these experts were telling me that that was not an option. It took me some time to collect my thoughts and remember that, of course, I had a choice. As a lawyer, my mind often frames questions in legal terms, and so it was a comfort to remember the existence of informed consent laws and the due process right to bodily integrity (the hospital was affiliated with a public university). Dr. O'Brien had momentarily frightened me into believing that, in addition to her tacit refusal to perform one herself, she would convince other doctors not to perform a lumpectomy. At that low point—which may well have been the nadir of the entire ordeal of cancer treatment—the most comforting thought I could summon was that I could refuse medical treatment altogether. I could die of those tiny tumors if I wanted. It seems strange now, but at the time, that thought was very reassuring. I was an adult with a legal right to refuse medical treatment. No one could force me to undergo an unwanted surgery. I left that office with my spouse for the long drive home from Seattle through rush-hour traffic clinging to that thought.

It was not that I wanted to die. Although dying had often been on my mind in the months before the diagnosis, ironically, having cancer was teaching me that I wanted to live. But I did want to preserve my autonomy, and my breast to the extent possible. And paradoxically, it began to seem in the upside-down landscape of that clinic that the *only* way to preserve my autonomy would be to refuse medical treatment and actually die. Medicine had claimed my body as its territory. In my brain's distressed logic, the answer was to refuse to engage entirely and thereby thwart medicine's appropriation of my body.

I had not yet read the late writer Kathy Acker's indictment of allopathic breast cancer treatment, but my sentiments in that moment echoed hers: "[C]onventional medicine was reducing me…to a puppet who, separated by fear from her imagination and vision, would do whatever she was told."[11] After rejecting additional treatment beyond surgery, Acker ultimately died of breast cancer. Her refusal was largely rooted in Western medicine's attempt to turn her into passive victim, although her rejection of further treatment was also influenced by her lack of health insurance.[12] As a creative writer and artist who was serving as an adjunct professor at the time of her diagnosis, Acker lacked insurance, and, although

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[10] Diane Price Herndl, *Reconstructing the Posthuman Feminist Body Twenty Years After Audre Lorde's Cancer Journals*, *in* DISABILITY STUDIES: ENABLING THE HUMANITIES 144, 149 (Sharon L. Snyder et al. eds., 2002).

[11] Kathy Acker, *The Gift of Disease*, THE GUARDIAN, Jan. 18, 1997, at T14.

[12] *Id.*; *see also* Jason McBride, *The Last Days of Kathy Acker*, HAZLITT (July 28, 2015), https://hazlitt.net/feature/last-days-kathy-acker [https://perma.cc/G5GC-4CWV].

she had a sizable trust fund, felt that she did not have the resources to pay for additional treatment when it was discovered through surgery that the cancer had spread to her lymph nodes.[13]

Unlike Acker and so many others, I was incredibly lucky to have good insurance at the time of my diagnosis. There is no way to justify the fact that so many people in the United States, when faced with a cancer diagnosis, find that they cannot afford the recommended treatment.[14] Indeed, racial subordination—as well as sexual minority status—contribute to the inability of many people to access medical care.[15] In that sense, my good fortune was at least partly due to white privilege. My fears that Dr. O'Brien would convince Dr. McDonnell not to perform a lumpectomy turned out to be ill-founded. Dr. McDonnell never mentioned the letter from Dr. O'Brien, although I assume she received it (it is contained in my medical records from Dr. O'Brien's clinic). Instead, Dr. McDonnell simply continued to check in with me to ensure that I still wanted a lumpectomy as additional biopsy results came in, and she ultimately performed one. The margins were clean. That part of the journey ended very well. My conviction that I might have to die to preserve my autonomy was not put to the test.

I did return to the clinic where I had had such a difficult experience to see the oncologist I had met with during the team meeting. He had impressed me with his knowledge during my initial visit, and I tried to convince myself that he was better than the rest of the team. However, looking back at my medical records from that first day now, I feel a chill reading the closing lines of his letter to my surgeon: "Thank you for providing me the opportunity to meet with this young lady today. If you have any further questions regarding her management, please feel free to page me directly…." His phrasing in this letter reframes my own unilateral decision to seek out a second opinion at that clinic as a decision of my original surgeon—thereby erasing my agency—and the need to manage my cancer becomes a need to manage *me*. In short, my cancer had replaced my identity and individuality, and, if I ever had any decision-making capacity, becoming a patient had eradicated it.

During the next visit with this oncologist, my first visit post-surgery, I had serious difficulties with both him and his new fellow. The new fellow who was working with him proved the more troubling of the two. I met with the fellow before the oncologist came into the room. Right off the bat, the fellow was disdainful about my having undergone a partial mastectomy, remarking in a snotty tone, "So I see you've had several lumpectomies." I assumed his evident disapproval was due to reading Dr. O'Brien's recommendation for a full mastectomy in the chart notes on the computer screen he faced as he spoke, his back to me and my spouse. In a sense, it seems I was being punished—or at least disrespected—for pushing back against the idea that my body was in the hands of medical experts and was no longer my own.

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[13] Acker, *supra* note 11; McBride, *supra* note 12; Chris Kraus, *"Cancer Became My Whole Brain": Kathy Acker's Final Year*, THE NEW YORKER (Aug. 11, 2017), https://www.newyorker.com/books/page-turner/cancer-became-my-whole-brain-kathy-acker-final-year [https://perma.cc/6CJW-R9WS].

[14] Whites are more likely to have insurance than many other racial groups, and LGBT persons, particularly bisexuals, tend to face additional barriers to accessing medical care compared to heterosexuals. Tweedy, *supra* note 6, at 33.

[15] *Id.*

The fellow also took it for granted that I would be having chemotherapy because the pathology report from my surgery had revealed an infected lymph node. He did not bother to explain why it was recommended or ask me if I wanted to go forward with it in light of the recommendation. Instead, he simply said, “So you’re coming to Dr. Gokhale for your chemo.” To me, this was another indication of the assumption (which seemed to be pervasive in this clinic) that I had yielded control of my own body. What brought me to the outer edge of my ability to maintain composure, however, was the fellow’s response when I asked why I needed chemotherapy.

While I did understand before walking into that room that chemotherapy would likely be recommended in light of the infected lymph node, I still wanted to have the traditional exchange in which the information and recommendation were explained to me. To me, that is part of why one goes to a doctor. Perhaps we could have an alternative system of medicine in which computers make medical recommendations and then treatments are administered by robots, but that is just not my vision of a well-functioning system. I wanted human interaction and at least tacit acknowledgement that I was making the decision about whether to follow the recommendation.

When I asked why I needed chemotherapy, however, the fellow’s ultimate response more resembled a grade school bully’s comment than it did a medical professional’s. He first said, “It’s because you’re high-risk.” When I asked why I was high-risk, he said, referring to the fact that I had had a tumor in the breast tissue in my underarm, “Well, most people don’t have something weird sticking out from their underarm.” I literally gritted my teeth after that, hoping that every subsequent second would be the one in which Dr. Gokhale walked through the door.

It is hard to understand what could have motivated the fellow’s response, but I imagine my questions caught him off guard because it had not occurred to him that I was entitled to any kind of explanation. Instead of being a human being with agency and medical questions about the proposed treatment plan that needed answering, I was supposed to be a passive recipient of treatments. I was expected to be so overcome by the fear of cancer that I would do whatever was demanded of me.

The relief I anticipated with the oncologist’s arrival was very short-lived. When Dr. Gokhale finally arrived, he informed me that he had to give a talk in fifteen minutes. I was devastated. After waiting a full month after surgery to be able to get in to see Dr. Gokhale, the entire appointment seemed to be not only a waste of time but psychologically damaging as well. I resolved to ask all the questions I had planned to as this seemed to be my only chance to do so before undergoing draconian treatments. Worse than his early departure, he could not answer my question about why I was high-risk because he could not remember the contents of my chart. In addition to being upset about his plan to leave the appointment early and his failure to prepare for the appointment, I was also bitterly disappointed that he refused to order a test of my tumors’ genetic make-up that is used to evaluate the likely success of various treatment options such as chemotherapy and radiation.

By this point, I had almost become the powerless puppet Acker described.[16] I literally felt I had no choice but to continue with Dr. Gokhale because of the amount of time that had already passed since surgery. I was desperate to begin either radiation or chemotherapy, worrying more with every day that went by post-surgery. I did contact Dr. Gokhale's office to ask if I could see him without the fellow (the answer, thankfully, was yes), and I also felt modest relief when Dr. Gokhale called to apologize for being in a rush. I would have stayed in that very imperfect situation except that I contacted a medical listserv run by a well-known medical school the weekend after that Wednesday appointment to ask which of the types of chemotherapy that I had been offered would be best based on my pathology. The oncology nurse who responded to my query recommended that I get the test of my tumors' genetic make-up that Dr. Gokhale had refused to order, referring to that test as "the standard of care" for someone with my pathology.

This was the last straw. I could no longer tell myself that the problems with Dr. Gokhale, the fellow, and the rest of the clinic were simply a matter of poor bedside manner, that I was still getting good care. In retrospect, the clinic's apparent inability to treat patients with respect should have been more than enough reason to leave, but at the time I was very scared and not giving sufficient weight to taking care of my emotional well-being. This lack of sufficient attention was partly due to my perception, up until that point, that my emotional needs were in tension with my medical needs. Luckily for me, however, this perfect storm of problems led me to try a different oncologist, one who *was* willing to explain his recommendations and who acknowledged that I had choices. He ordered the test that the listserv nurse had recommended, the results of which allowed me to avoid chemotherapy. In fact, the test results indicated that my chances for long-term survival were slightly better without chemotherapy than with it, so I saved myself a good deal of pointless suffering by changing doctors.

After that extremely negative experience with Dr. Gokhale and the fellow, everything went relatively smoothly. As mentioned above, I changed oncologists and never saw the fellow or Dr. Gokhale again. However, even after changing doctors, there were still instances when I felt that the default was to treat me as a patient rather than a person, where the doctors who were treating me seemed to assume that my body was their territory, that I would accept whatever their recommendation was without much need for explanation.

For instance, the radiation oncologist who was treating me initially had planned to radiate a larger area of my body because I had not had chemotherapy and had had a positive lymph node. But in this and similar instances, I found that by being extremely vocal and seeking additional information by asking questions and researching, I was able to get my needs—for information and to be the ultimate decision-maker—met. In light of the side effects of radiation, I decided against having a larger area (which would have included my collarbone) radiated. This was the right decision for me, though others might weigh the various risks differently. After my two disturbing experiences at the Seattle clinic, I found providers who, instead of treating me "as a diseased object that had to be 'cured' at all costs,"[17] could adjust

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[16] Acker, *supra* note 11.
[17] Tweedy, *supra* note 6, at 29.

to my preference for an active role in my own treatment. Unlike Acker, who ceased conventional treatments partly in response to negative experiences with her doctors and the disempowerment she experienced as a patient, I was able to change doctors when needed for my own well-being. I am now two years out from completing radiation.

I was lucky in countless ways. I had good insurance, an understanding employer, a penchant for research, a detail-oriented mind, supportive friends and family, and a salary high enough to pay co-insurance and deductibles as needed. All of these advantages contributed to my ability to empower myself and disrupt the narrative of a passive patient who is merely acted upon. These advantages, however, did not come about through chance. We live in a country in which such advantages are distributed based on race, income, sex, sexual orientation, non-disabled status, and other factors. My race, income, and non-disabled status all lent me unfair advantages. Moreover, as one radiation oncologist told me when I went to her for a second opinion, I was "lucky to have choices" about how much and what types of treatment to pursue. It so happened that my cancer was not that aggressive or that advanced, and, knock on wood, I lived to tell about it.