

## Three Art Educators in Cancerworld

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### ABSTRACT

*This article contains essays about our experiences in the culture of cancer. In our own stylized voices, we three art educators use autoethnographic narratives and personal images to enhance understanding of our experiences with this illness. Because of our cancers, we created a new form of community by expanding our relationships with each other and sharing our experiences with and in the place we call cancerworld. In our stories, we each use our voices and images differently—some illustrate and some express emotions through anecdotes or artwork. All of them are honest and forthright.*

*Cancer leaves physical and emotional marks—scars that are created with scalpels, radiation, chemotherapy, and mental distress. Cancer's treatments leave visible signs and invisible traces on the individuals who have cancer and their families, friends, and colleagues. But we also find that experiences with cancer can bring clarity to personal values and purposes in life and renewed academic vigor and creativity.*

*Living in cancerworld is not easy, and reading about it may be distressing and disturbing. But being exposed to the culture of cancer, much like exposure to other cultures, can be useful for interrogating our personal art as well as our research and teaching practices.*

### INTRODUCTION

A holiday card sent out by the OSU James Cancer Center states that "Everyone knows someone who had or has cancer." The card is based in fact—Chustecka (2007) confirms that cancer will affect one in two men and one in three women in the United States, and the number of new cases of cancer is predicted to nearly double by the year 2050. Both of these

predictions are based on statistics collected by the Surveillance Epidemiology and End Results program at the National Cancer Institute. The three of us are those unnamed "someones" on the card.

In this article, the three of us who have been treated for cancer share the personal tales of our cancer realities in order to break the cultural conspiracy of silence that surrounds cancer and other bodily reminders of fragility and death. We openly iterate traumas and the importance of community for individuals dealing with cancer and, by inference, other chronic diseases. As art educators, we include in our narratives aspects of our workplaces and how they affect our experiences of having cancer and enduring its treatments.

We use autoethnography as our methodology. As are all stories, ours are partial, as Stuhr, Krug, and Scott (1995) wrote—all stories, including research, become partial tales of our experiences. Our stories are embedded in contexts, told from particular points of view, and dependent on our own reasons for telling them. But cancer requires stories, and oncologists, radiologists, chemotherapists, nurses, patients, patients' friends, and others are the storytellers. We tell our stories introspectively as three individuals living in the culture of cancer, as patients, and as art educators in higher education. Two of us, Pat and Terry, work in the same department, and we are joined by Debbie, who had been a visiting professor at our university. We first agreed among ourselves to become public about our cancer experiences and to seek publication in this journal. So we wrote our stories independently, shared them amongst each other and with others, individually made revisions, and then constructed an introduction and conclusion.

Our approach is guided by research that has established autoethnography as a legitimate way to investigate and deliver meaningful knowledge about culture, identity, and communication. For example, Tedlock (2005) explains "authors working in the genre attempt to heal the split between public and private realms by connecting the autobiographical impulse (the gaze inward) with the ethnographic impulse (the gaze outward). . . . The issue becomes not so much distance, objectivity, and neutrality as closeness, subjectivity, and engagement" (p. 467). Feminist, sociologist, and educator Laurel Richardson (1997) used autoethnography to interrogate her experiences with the academy. Richardson (2007) and feminist curriculum theorist Patti Lather (1997), using fractured and disjunctive narratives, incorporated their autobiographical experiences along with their ethnographic research and writing about women with chronic illnesses and death. Stacy Holman Jones (2005) focuses her work on socially resistant efforts, and advocates autoethnography as "critical intervention in social, political, and cultural life" (p. 723) because "looking at the world from a specific, perspectival, and limited vantage point can tell, teach, and put people in motion" (p. 763); "Autoethnography writes a world in a state of flux and movement," and it can create "charged moments of clarity, connection, and change" (p. 764).

In our stories we relate imagery that is important to us as markers of our journeys. Each of us is also marked with the scars of cancer and of the medical interventions used on our bodies. Although our scars were not inflicted as design, like the plastic surgery (dis)figurements of contemporary performance artist Orlan (Hirschorn, 1996), our bodies and minds are changed from surgeries, radiations, chemotherapies, stresses, and recoveries. The use of imagery helps us to confront and communicate the impact of cancer on our lives and on the lives of others.

Our experiences within the culture of trauma and cancer changed each of us in significant ways, some subtly, and some dramatically. In this collaborative and active text, we closely interrogate our experiences, values, hopes, and angers, finding meaning in various spiritualities, work, and living situations, families, colleagues, and students.

Many patients who experience a severely traumatic event describe a process of personal transformation and growth (Folkman, 1997; Jaffe, 1985; Tedeschi, Park & Calhoun, 1998), in which an earlier feeling of meaninglessness became transformed into a feeling of living a more meaningful life than before (Schaefer & Moose, 1998). In other words, during and after their initial upheavals these people searched to make *appraisals* of their lives, of themselves, and of their personal and interpersonal values. They tried to make transitions on an existential level, to escape from the absurdity and senselessness that seemed to be the only things they were offered (Wong, 1998; Yallong, 1980b), and tried to give a new and positive meaning to what had happened to them (Dunn, 1994; Ebersloe & Flores, 1989; Tedeschi et al, 1998; Thompson et al, 1988; Weenolsen, 1991).

Additionally, in *The Wounded Storyteller*, Arthur Frank (1995) observes that the ill "learn by hearing themselves tell their stories, absorbing others' reactions, and experiencing their stories being shared . . . the body, whether still diseased or recovered, is simultaneously cause, topic, and instrument of whatever new stories are told. These embodied stories have two sides, one personal and the other social" (pp. 1-2). He goes on to state that the personal purpose of the ill telling stories is to "give voice to the body, so that the changed body can become once again familiar in these stories" (p. 2), and "Stories have to repair the damage that illness has done to the ill person's sense of where she is in life, and where she may be going. Stories are a way of redrawing maps and finding new destinations" (p. 53). And further, he describes that the social purpose of the ill telling stories is to become witnesses rather than merely survivors when he states, "Becoming a witness assumes a responsibility for telling what happened. The witness offers testimony to a truth that is generally unrecognized or suppressed. People who tell stories of illness are witnesses, turning illness into moral responsibility" (p. 137).

## TERRY: CANCER I

In May of 2002 I was on the examining table for my annual physical. When the doctor thumped the right side of my abdomen I said, "Ouch!" He ordered a sonogram to check my liver because I had a recent liver infection that we thought was healed. Days later while the technician rolled a sonar device over my abdomen, she paused, asked me what I was there for, and I said, "a possible liver problem." She left the room and returned with a man in a lab coat and asked him, "Is that something there?" He said, "Yes," and walked out of the room.

I drove from the clinic that Friday morning thinking I had liver cancer. I remembered Jim Hutchens, a Department of Education colleague, chairperson, associate dean, and dear friend whom I greatly miss, had recently died of stomach cancer that had spread to his liver. The time between his diagnosis and death was about five months.

While driving away, I was surprised to realize that I was not afraid to die. I have had a rich life. I was surprised to realize how important my work was to me. I was grateful that *Interpreting Art* (2003) was in press, and I thought I might be able to complete a new manuscript that was already under contract, but I doubted that I would have time to complete scheduled revisions of two of my criticism books. I also wanted to make more paintings, ones that would be joyful to look at. If I was going to die, I wanted my work to live.

I was sad to think that I would not see my granddaughters grow up. Emma, age three, would remember knowing me, but Vivian and Tess were toddlers. I consoled myself knowing that Jesse and Amy, my son and daughter-in-law, took good care of the girls and each other, and he and his family would be fine without me.

I simply and involuntarily blocked thoughts about my wife, Susan. I went to school. Susan would have been working with her Montessori children, and I did not want to be home alone. I cannot recall how and when and what I told her or what she said.

On Monday, the doctor called with results: a small growth in the kidney. He was concerned, but he said that my weekend of imagined death by liver cancer was unfounded. Tests followed. On June 18th, Susan's birthday, we were in a surgeon's office. The kidney "had to come out." He couldn't "just pop the kidney out" through a small incision in my side; he'd have to go into the abdomen and explore. The scans also showed irregular lymph nodes.

"Where?" I said.

"Around your kidney, near your lungs, on your ankle and vertebrae," he replied.

Susan was ashen. I could not believe him. I was working, playing tennis, going to yoga classes, and felt perfectly well. I asked him to repeat the word *vertebrae*. He did. I wanted to see a picture or model. He didn't have any in the room, so I asked him to spell it.

"V-E-R-T-E- . . ."

I said, "Oh, vertebrae!" I left believing that the lab had mixed-up my scans with someone else's.

I went into surgery on September 10, 2003, scared but confident. I awoke from surgery euphoric: I was alive, and Susan was smiling. I examined tubes coming from my mouth, my nose, my penis. I was fascinated by a very long cut stapled together from below my sternum to below my navel. The surgeon came in brightly, telling us that he had opened me up, taken everything out of my abdomen, put it on the operating table, examined it, and found no cancer; the growth in the kidney was "renal cell carcinoma," and the suspicious lymph nodes were "granular" but not cancerous. I was cured.

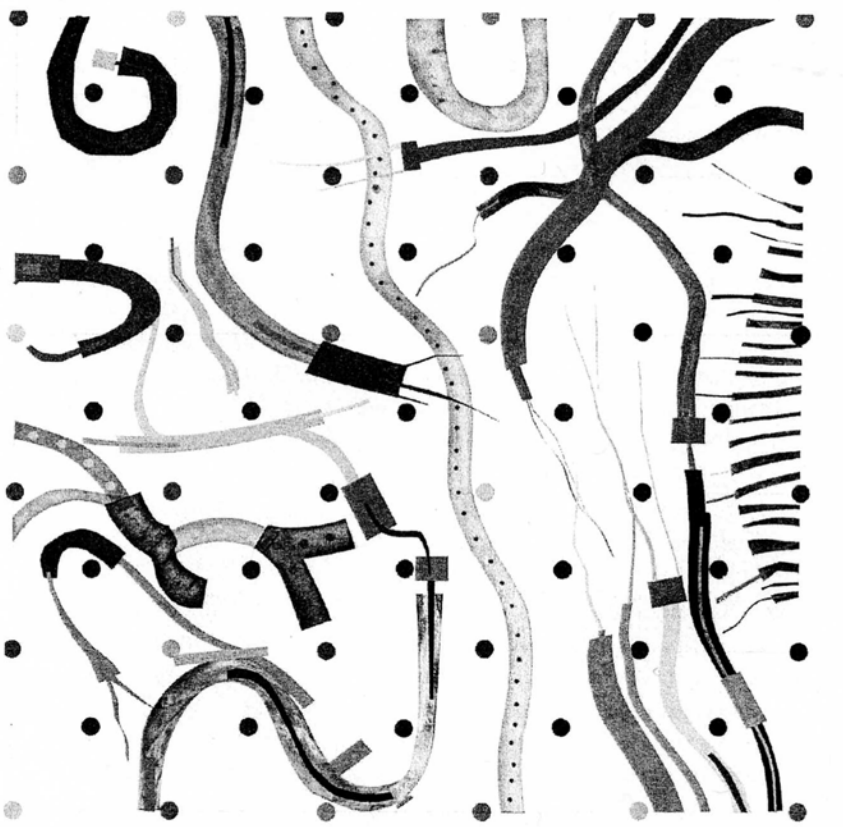
## TERRY: CANCER II

Regularly scheduled scans continued to show problematic lymph nodes. The radiologists' reports consistently indicated cancer; my doctor and the surgeon did not think I had cancer but sent me to an oncologist anyway. After three years of work with an oncologist, I was diagnosed with Hodgkin's lymphoma. It is a "good cancer" to have—it has a high cure rate, but mine is stage 4B (5 = death), and I am not young. If chemotherapy doesn't work, I will have a bone marrow transplant. If I die from lymphoma, I will, in the words of my doctor, gradually lose strength, eventually be unable to get out of bed, and fade away.

And just two months before my diagnosis with Hodgkin's, Susan's son, Michael, age 28, a Navy rescue swimmer, died unexpectedly while on leave at his aunt's home in Florida. The afternoon that Susan got the phone call I was at RISD working with Paul Sproll, who is the head of art and design education at the Rhode Island School of Design in Providence. Susan reached me in my hotel room that night from a phone booth in the Memphis airport on her way to Tampa, flying alone. She was coherent but sobbing. I have never been so close to such sorrow as a mother losing her child. While enduring the loss of Michael we also faced losing each other.

I made this painting (See Figure 1) after kidney surgery and before diagnosis of lymphoma and the prescription of chemotherapy. The painting is a positive and colorful wondering with paint about what was going on in me at the cellular level. The painting also functions for me at the macro level as a wondering about my place in existence.

FIGURE 1



Terry Barrett, "Visualizing My Innards", (color) acrylic on paper, 15 by 15 inches, 2005.

So after Thanksgiving of 2006, I began chemotherapy—ABVD (Adriamycin, Bleomycin, Vinblastine, Dacarbazine) once every two weeks for eight months, finishing in July of 2007. As I write this in November 2007, I have "post-chemo stress disorder," which goes something like, "Now that I'm probably going to live, what am I going to do, can I do it, is it worth doing, and when will cancer return?"

## TERRY: SNAPSHOTS

### PRAYER

After surgery, when Jesse told Emma that Grandpa was okay, she said, "Well I was praying for him!" I am happy to credit Emma for my kidney cure.

When a former mentor heard of my lymphoma, he sent me a caring e-mail that he closed with, "I'd even pray for you if I thought it would do any good."



During kidney cancer, many people told me they were praying for me. I wondered but did not ask: Whom are you praying to? What are you praying for?

During Hodgkin's many people tell me that they are praying for me. I am grateful, and welcome their prayers as love, which is enough, and healing love, which is more.

I do not pray but am sometimes "prayerful." Most mornings I read spiritual material such as Deepak Chopra (2004), Jean Shinoda Bolen (2007), Gordon Livingston (2004), Margaret Wheatley (2002), and Kurt Vonnegut (1997). During the months of chemotherapy, in our living room in an overstuffed leather chair, I meditated with mindfulness (Coleman & Gurin, 1997) for hours at a time on anything that came to mind. Three times I read the same book by Rachel Naomi Remen (2006), a Jewish medical reformer. Currently, Pema Chödrön (2004), an American Buddhist nun, inspires me.

## BLESSINGS

Illness in America bankrupts people. I am afraid to see Michael Moore's movie critique of our health industry, *Sicko*. And it was just by luck that three years before the diagnosis of my kidney cancer, Susan's daughter was selling AFLAC supplementary health insurance. We enrolled for cancer coverage, but later dropped it as an unneeded expense. Unbeknown to us, Erin kept paying our premiums. To date, her kindness and wisdom has saved us more than \$20,000 in out-of-pocket expenses.

I think it is mysterious that I said "Ouch" when my doctor thumped my abdomen. The cancerous growth within my kidney was less than two centimeters in size. It was undetectable by touch. Had I not said something, the doctor would not have sent me for sonar, and the cancer would have likely gone undetected because renal cell carcinoma is asymptomatic and lethal.

Through a friend in the San Francisco area with prostate cancer, I learned of the Wellness Community, a national organization with regional locations offering free help for people with cancer and their families. It's a safe place to cry. I tried group therapy there but I was overwhelmed with the severity of people's conditions. I tried classes in Qigong, a traditional Chinese medicine, non-martial art that uses physical postures, movement, and breathing patterns to maintain health or serve as therapeutic intervention, but the leader and the group were too evangelistic for me and I abandoned it. I joined the yoga group and continue to attend. I have sessions of Reiki there, which can be thought of as a passive form of Qigong that is used for channeling healing energy. On one occasion, I alerted the Reiki healer to my lungs, which were seriously toxic from Bleomycin. During the session I felt movement in a spiral direction outward from my chest. On my next visit to the pulmonologist, after examining my new scans, she said, "What did you do? Your lungs are clear!" I am happy to credit Reiki for that cure.

Chemotherapy nurses are the most skilled, kind, understanding, and empathic of all the nurses who have worked with me. I experienced some mean or incompetent nurses in surgery recovery, but not in chemotherapy. Chemotherapy nurses also have crucial knowledge about the side effects of chemotherapy that the oncologists seem unaware of.

I am very fortunate to have Pat as my chairperson: She *knows* cancer. I am able to openly share experiences with her and to hear hers. As a result of exploratory surgery during the removal of my kidney, on two occasions I was hospitalized for adhesions and upper intestinal blockages, and experienced some of the pain that Pat has frequently endured for great lengths of time. Such compassionate sharing reduces isolation.

Debbie is visiting the department when I am in the muddle of stress disorder as a result of enduring chemotherapy. I feel crazed to be depressed now that I am finished with chemotherapy and seem to be cancer-free. I did not know of Debbie's cancer. When she told me, I asked her if she had a hard time after she had finished chemotherapy. She told me she was suicidal. I feel less odd because of her generous admission.

### **MORNINGS**

In the hospital after kidney surgery, from about 4:00 a.m. on, I longed for the sun to come up and for Susan to arrive. During chemotherapy and now, Susan "visits" me every morning. First we hug in my chair, then she sits on the ottoman, and we share our thoughts and feelings, and smile, frown, grimace, laugh, and cry. We alternately process losses concerning Michael, losses due to cancer, and gains from both. We have new openings of hearts and minds with those with whom we interact as a result of these exchanges.

### **WORK**

Throughout treatments I came into school daily, and I taught, advised graduate students, and wrote. With Pat's support, I taught online so that I could work when I was able and rest when I wasn't.

Chemotherapy compromises the immune system. So does stress. Meetings cause me stress. Pat generously allows me to temporarily absent myself from faculty and committee meetings, but during times when I look better than I feel, I think colleagues resent my absences.

Many days during chemotherapy, getting from my living room chair to my desk at school was an accomplishment. I don't come to work to prove anything, but to stay stable and to think and act like a healthy person.

During chemotherapy I did not have the energy or spirit to make paintings. I've recently begun one as an expression of desire to live and to contribute.

### **WELL-MEANING INSENSITIVITIES**

After I told the members of my department that I had cancer, a graduate student stopped me in the hall, and with concern and what sounded to me like a finger-wagging tone said, "You work too hard," implying that I had caused my cancers. I smiled and thanked her, knowing that she meant well, but felt monitored and admonished.

A staff person said, "You know, you don't *have* to come in!" I nodded and realized that although I like my work, she may not like hers.

A former doctoral student tried to cheer me up with an e-mail about chemotherapy, and wrote, "It'll be over before you know it!" What I knew every waking moment was exactly how many doses of chemotherapy remained.

On campus we have a psychologist whose specialty is helping faculty and staff who are well to deal with colleagues who are ill. Both the ill and the healthy need education about illness in the workplace.

### **SURPRISES OF KINDNESS**

While in the hospital, Susan and I made a list of all the people who sent cards, flowers, gifts, or made phone calls and visits to wish me well. I have the list pasted in one of my scrapbook journals, and I continue to paste in meaningful e-mails. I do not want to forget.

Gordon (who at the time was chancellor and at Vanderbilt and who is now president where I work) and Constance Gee, my longtime colleague, showed up in our bedroom on a Sunday afternoon during my home-recovery from kidney surgery, with a huge pot of

mums. They were in town from Vanderbilt, heard of my condition, and spontaneously negotiated their way to a nursery and our house. I did not feel important enough to be acknowledged with their time and presence, but it strengthened me.

After I began chemotherapy, Karen Hutzal, our newest and youngest university colleague, offered to advise my online MA students. I accepted, with a sense of humility that I could use help, and with gratitude for her generosity at a time when she was likely challenged with the pressures of a new position and her own heavy work load.

I mentioned to a friend that people were nicer to me after they learned that I had cancer. She told her daughter who wondered aloud, "Why do you have to have cancer for people to be nice to you?" Since having cancer, I am trying to be nicer to people.

## HAIR

At first being baldish was liberating: I didn't need hair. I learned, however, that my ever-changing scalp signifies to others a variety of things from fashion statement to butch or macho or urban chic or pro-military . . . but I am not those things—I want my hair to signify chemotherapy. But I do feel infantile without pubic hair.

## NAILS

Chemotherapy attacks fast-growing cells, thus loss of hair and weakening nails. I watched my fingernails crack and the tips pull away from my fingers. I have a large toenail that is black and falling off. I was recently heartened by meeting a long-lost friend who is five years out from treatments, who confided, "They almost did me in." Karen lost all twenty nails, has damaged vision, and endured tear-duct implants. She said she'd do it all again. Her zest for life inspired me.

## DROPPINGS

One morning I told Susan that her cat had pooped on our bedroom floor. She said, "That's odd." When I cleaned it up, it didn't look like cat poop. I realized it was *mine*. It must have fallen out of me the night before when I got up to urinate. Two days later I found another dropping on the bathroom rug. I learned that Velban causes peripheral neuropathy, a deadening of nerve endings in the extremities of the body—the fingertips, hands, toes, feet, nose, lips, *and* anus. I've written and taught about 'the abject' (Kristeva, 1982) in art. I've used Cindy Sherman's "ugly" bodies series, Kiki Smith's sculpture of a woman urinating pearls, and Paul McCarthy's scatological performances (Barrett, 2008). I've assigned art critic John Berger's (1991) essay, "A Pile of Shit." I quote Milan Kundera's (1984) definition of 'kitsch' as "a denial of shit." Nothing, however, has been as abject to me as seeing my own excrement on the floor and my being unaware of how it got there.

## COGNITION

I had finished conducting an oral MA exam, and when I signed the form, I did not know the year. I was too embarrassed to ask. I went to my office, looked at my calendar, and then returned to the exam to sign the form. I learned that chemotherapy alters the mind. They call it 'chemo brain,' a trivializing term that used to be linked to women on chemotherapy for breast cancer and was patronizingly dismissed. Oncologists are finally taking it seriously (Gross, 2007) and it now has a name: Treatment-induced Cognitive Dysfunction. It's supposed to be temporary. Currently I am intelligent in the morning but by evening I struggle to follow the novels I read.



## SPRING

When it turned warm during chemotherapy I felt the need to grow something in the ground. One day I used my energy to get to the nursery and buy some flowers. The next day I bought two small dogwood trees. I was able to plant six impatiens each day until the flat was in. I planted one tree a day. After each planting I sat exhausted, panting, and sweating but renewed. I placed the trees where I could see them from my home studio. I water the trees by bucket. I worry about them when their leaves wilt.

In our flower garden I broke a personal norm and planted what I saw as unattractive flowers because they were gifts given to us. I let my strong sense of aesthetic sensibility be overcome by wanting to honor people's care.

## STEROIDS

When Bleomycin inflamed my lungs, I was put on steroids. They didn't improve my lungs, but boosted my emotions, and gave me a false sense of strength. I would stay at school too long, and would discover too late that I was physically and emotionally exhausted. Many times I struggled to get back to the chair in our living room.

The steroids altered my schedule such that I was awake and up and reading by three in the morning and asleep by six-thirty or seven in the evening. I enjoyed my new strange schedule. I looked forward to ending days early with the escape of sleep and awakening to new mornings stimulated to live.

## FEARS

Although I am not afraid of dying, I am afraid of being infirm. I am also afraid of being perceived in the field as ill and professionally finished in my career as an art educator. I am still here! I tell myself I am in mid-career.

I fear that my cancer has not gone and that I will have to endure a bone marrow transplant. My fear was lessened when I heard that a transplant is not an option for a colleague in art history who has non-Hodgkin's lymphoma. He developed the disease decades ago while a young man on digs in Afghanistan. He refers to his disease as a sleeping tiger. When his current regimen of treatments fails, he will die.

## DEBBIE: REVISITING THE DARKSIDE

Cancer. Seeing or hearing the word still gives me chills, my stomach quivers, and my mouth tightens as if to forcefully restrain any overt response. Then I take a deep breath and slam the word into a tiny dark pocket deep in my psyche and I quickly lock it, hoping that it will not slip out again. But of course it does and the process starts all over again.

This is the first time I have willingly opened the metaphorical lock, unleashed the word and its signifiers, and attempted to spend time with memories that hurt a lot and push outward the tears that usually don't quite escape my eyes.

I learned early to take care of my own cuts and bruises and never to complain because no matter how bad it felt, complaining always made everything worse. Stoic is a good word. Pretend is another. Pretend I do not hurt. Pretend life is ordinary. Pollyanna is a good metaphor, but not necessarily the child Pollyanna of the book and the movie—a more mature Pollyanna.

I've known cancer intimately and like any new and dangerous lover, it took over my conscious and unconscious thoughts while family, work, everyday objects, and mundane ordinary details of living competed for my attention. Even Mick Jagger often visited me in

my morphine-induced dreams, and quite frankly, I miss him! Unlike Hollis Sigler (1999) who confronted her cancer with artwork and activism, I pretended life was normal when I could, and I slept stoned with Mick when I couldn't.

There was no history of cancer in my family. I freaked out when the nasty hemorrhoids turned out to be cancer of the anus. What I thought was really bad was really worse. I didn't want to tell anyone because, damn, it was not only scary, it was embarrassing. Anus, Uranus, junior high jokes. Butt jokes, the butt of jokes. The joke was on me but it wasn't funny.

I tried to figure out a way to fix it without telling anyone. I couldn't. I couldn't figure out any way to go to the hospital without a ride so I told my best friend. We'd just attended the funeral of a good friend who died from breast cancer, so I knew that sharing my news would freak her out. It did. After multiple tears and deep breaths, she convinced me to tell my daughters, and they freaked out too. I told my boss, but he coolly replied that if I was absent from the building, even on days I wasn't teaching, I would have to take sick days. I couldn't do that because I figured I'd need them at "the end" so I went to school most days, even if it was to walk slowly past the mailboxes in the main office and then go back home. I told my colleagues when they noticed the port-a-cath, and they covered for me on the days when I couldn't make it up the steps of the School of Art. But I stopped answering the telephone.

My cancer (note how I take ownership) had one pretty certain cure—a permanent colostomy. Shit, no! I thought. I will not go on with a bag of shit permanently attached to my belly. No. No. No. This solution signified to me, no more sex, never. No more sexy. never. I was NOT ready to become the asexual being I envisioned. For the year before *THE NEWS*, I'd been working on a series of *Post-menopausal Sexy Goddess* drawings and I was just at the point of reconciling my own pan-sexy aging healthy body, so this was absolutely the wrong time to even consider a life of never sexy, never sex. Against the wishes of my daughters Bridget and Morgan, and my best friend, and my doctors, I said no. Absolutely no. They could "fix" me without the colostomy or I would go gently into that good night, which I was positive would be better than no sex ever again. And they did fix me, but not easily.

My team of nurses, technicians, and doctors were wonderful. I presented them with a challenge and while they may not have understood or agreed with my reasoning, they worked very hard to kill the cancer without killing me. This wasn't as easy as novices to cancerworld might think. There were the gymnastics we designed to present my bare ass to the radiation-zapping machine (which had no girly stirrups), the daily blood tests, and nearly weekly fresh plasma transfusions. I fought traditional practice to wear a newly designed (yet relatively ugly) chemo bag (like a big fanny pack) that facilitated frequent small doses of chemo rather than having to sit for hours and hours at the cancer center—I just couldn't do that. And I fired the home nurse because I did not want her tone of voice in my life.

My daughters processed my cancer differently. Bridget called, but rarely visited and when she did it was with nearly constant tears. Morgan moved out of the dorms and back home for the duration and stoically schlepped me here and there, listened to my ranting and occasional raving, and oftentimes told me in her lovely Libra tone of voice, "Ma, please just take a pill."

The poisons of chemo and radiation and the indignities of the treatments did a job on my body and on my notions of self-worth, self-respect, personal identity, modesty, and interpersonal relationships. I retreated into a self-imposed hermitage with my cats, novels,

dreams, art, and writing. I taught my classes on automatic pilot and even published one chapter in a book because I'd promised, and I didn't know how to get out of it without telling. I frankly don't remember very much of those months.

I knew I was going to die so I bought a silver Mitsubishi Eclipse (because every one needs a sports car before they die), and I co-signed for a red Eclipse for Morgan, and then Bridget showed up at the dealership and bought a black one in solidarity. I wrote a script for the funeral I fantasized (with *Michael Row the Boat Ashore*, *Alleluia* sung in a round by the mourners). I signed a "do not resuscitate" form and made out a will leaving half of everything to each daughter.

I made two death masks and embellished and entombed them with signifiers of my family and friends who had already died; holy cards from funerals, objects that reminded me of them, and of course pictures of them with smiling faces, blissfully unaware of the bleakness their premature deaths would cause. I pounded beautiful copper nails into their wooden coffins and tied equally beautiful thin but very strong copper wire around my heads as life and death lines. I added jewelry, just because I could. I made them beautiful as I struggled with ugliness and darkness, thinking that my daughters would love these representations of me when I was gone. They hated them then, and continue to dislike these reminders of our conjoined but individual fears.

FIGURE 2



Figure 2: Deborah L. Smith-Shank, "reflections on my own mor(t)ality," ceramic death/life masks and wooden boxes with wire and mixed media, 2002.

Cancer smacks with physical and psychological trauma. Like other trauma, it transcends words, images, and explanations. Such events are unspeakable, unrepresentable, and their traumatic character is defined precisely as the inadequacy of expression to apprehend, represent, or recollect them. McHugh (2002) agrees that "language, narrative, history, and self-representation must grapple with material stimuli that exceed the capacity of their symbolic systems. . . . A traumatic event outdistances a subject's ability to experience, possess, and represent it" (p. 242). My cancer exceeded comfort-

able identity signifiers. I had always taken my body for granted. It had always fit within social and physical norms and it very nicely served my desires. Suddenly everything ordinary was out of control.

One result of poisonous treatments was that my nether regions swelled and stopped ordinary functioning without pain. With swollen labia and a raw anus from the radiation, going to the bathroom became a dreaded performance. Pain became ordinary and screaming my inconceivable discomfort during previously ordinary bathroom activities scared my cats and Morgan. It scared me. It scarred me. It changed me in ways that I am only now realizing.

Eventually the treatments were complete, the pain receded, and my body started behaving in nearly normal fashions. Recovery though, that's a slippery notion. After the entire business of chemo and radiation, and after I returned from taking Bridget and Morgan to Jamaica to celebrate my tentative cure, it still wasn't over. It wasn't until after the hubbub of cancerworld that the blues, suicidal thoughts, and bleak dreams led me to seek help from a gentle therapist and mood altering legal pharmaceuticals. I hated the drugs so I stopped taking them. I figured the nice therapist wasn't really helping, so I left her kindness to fall again into the deepest and darkest psychological abyss I'd ever known, eased only once in a while by those dreamy sessions with Mick Jagger.

Apparently my feelings were pretty normal reactions to post-traumatic stress but I didn't know it at the time. Like other PTS sufferers, for a while I self-medicated with alcohol and played with other metaphorical matches. But that period of my life didn't last very long. I don't know why it ended or why I was so fortunate, but one day I woke up with good energy and I started making plans to travel to exotic places. I began an intimate relationship with a good and caring man. I got immersed in university committee work and I started writing and making art while playing very loud rock-n-roll.

The most significant event that blasted my lingering depression into insignificance was the birth of Morgan's baby, Trent Lei Jansen, who fills my world with light, song, play, and delight. Though the dark side does still lurk in the shadows, it is pretty much contained inside that locked pocket of my psyche. These days, at least most of the time, even the ordinary is a serious cause for celebration.

Now, I've learned how to say ANUS, but still it's after a pause and a breath. I've made metaphorical artwork acknowledging my body's visceral and conceptual betrayals. And right here and now, writing this essay is like primal therapy. I scream my affair with cancer and broadcast it like a scary freaky person on the Jerry Springer show.

I am delighted to write with Pat and Terry, yet at the same time I am reluctant to examine cancerworld too deeply and intimately. Since my cancer adventures, I have written about Hollis Sigler's cancer (2003) but not my own. Keeping my memories, pains and complaints locked up is far easier for me than letting them loose. I don't want people to know I was/am vulnerable. I don't want to revisit the dark side. I don't want to say "cancer of the anus" out loud, or even think about it. I don't want people to feel sorry for me. I don't want to be classified as a survivor—whatever the hell *that* means).

I want to put this whole cancer episode behind me and never ever think about it again. But it doesn't work that way. It's not really about what I want and don't want. Not if I believe (and I do) the lyrics of the song Mick and the boys repeatedly sang in my dreams and repeat when I turn on a golden oldies radio station:

*Ah, you can't always get a-what you want  
No, no baby  
You can't always get a-what you want  
Tellin' you right now  
You can't always get what you want, mmm!  
But if you try sometimes you just might find*

*You just might find, that ya  
Get what you need  
Oooh, yeah!  
I'm tellin' the truth, babe  
Ooow-ooh!  
Ooow-ooh!  
Ooow-ooh!...*

Jagger & Richards (1969)

Thank you Mick, Trent, Morgan, Bridget, Marybeth, Buck, Kerry, Doug, Suesi, Beau, Jim, Susanne, Pat, and Terry for giving me what I need and helping me find the courage to acknowledge and forgive my body's transgressions and continue the journey.

## **PAT: CANCER**

Oh my God!!! How did Terry and Debbie write their sections of this article so quickly? I can't even stop my fingers from shaking as I try to type mine. This auto-ethnographic narrative method is tough stuff!

### **ACKNOWLEDGING CANCER**

My cancer was slow growing—a gradual, sneaky illness that crept up on me and made me sicker by the years. I didn't know that colon cancer is usually slow growing. I was told that my cancer could have been active for up to fifteen years. I remember vividly when I finally acknowledged that there was something seriously wrong with me. I was jolted out of a deep sleep and found myself sitting bolt upright with my arms out in front of me as if an invisible marionette handler had pulled me into this astonishing position. I was covered in a cold sweat and thought, something is seriously wrong with me and it is possibly, probably, *cancer*! I felt panicked and wondered why I was thinking this. Was it because the pain had incrementally grown so bad that I finally had to admit it? Was it that I subconsciously now acknowledged that the severe gas pains, vomiting, and diarrhea could not possibly be just another stomach flu or intestinal virus? Was it that I decidedly admitted that being tired from the moment I awoke and having to struggle to put in a full day at the university was not normal? And the blood, all that blood, could it really come from internal hemorrhoids like I'd been telling myself? Or was it the conversation that I had with Debbie the week before at a visual culture meeting at Kerry Freedman's and Doug Boughton's home? Perhaps all of this evidence just became too overwhelming and my unconscious mind just finally kicked me in my conscious brain-butt and said wake up and do something about this! I put my slippery, cold arms down and felt exhausted. I'd call my doctor tomorrow. But I didn't. I didn't until a week later when Debbie phoned to ask if I had. Then I did.

I made an appointment with my regular physician. By now I felt he had me pegged as a hypochondriac. It seemed I had been visiting his office for one or another of my symptoms for years. There was the acid reflux, numerous stomach ailments, low grade fevers, tiredness, and nausea. Prescription pills took care of the reflux and the other ailments were diagnosed as viruses or stress. Nothing could be done about those except resting or exercising more, depending on the latest symptom.

During this visit to his office I told him about the blood. He said he'd call another doctor who did colonoscopies and see if he thought this could just be internal hemorrhoids. When he returned to the room he looked stricken and said the doctor would set me up with an appointment tomorrow. It might be nothing, but it would be best to have "it" looked



into now. He was sorry about my having to have the colonoscopy, but there really was no other way. I'd been dreading this physical invasion since I turned 50 a few years ago, but up until now my doctor had not required me to have one. That evening I began a binder in which I continue to keep all papers and images related to my cancer.

## CANCER DIAGNOSIS

On the way to the university hospital where the colonoscopy was to take place, I told my husband Tony that I was sure they would find cancer and I wanted him to be prepared. I also said that I would not get a colostomy—I'd rather die! This was a quality of life issue and I wanted this control.

As I expected and forecast, the colonoscopy doctor said I had cancer. Colon cancer—what I have always thought of as an old man's cancer! It was in two sites and he showed us photographic images that had been taken of the cancers—they looked organically sculptural, colorful, and wicked. However, they were not benign aesthetic objects, they were malignant tumors. I already knew the doctor thought I had cancer because I had woken up during the procedure when the medical staff were all talking excitedly about what they were seeing during the procedure. This was at OSU's university hospital—a teaching hospital in which there are always crowds of student doctors around during procedures. I had asked what was up on the television screen that they were all fixated on. One of them told me it was cancer and someone else made a crude joke about the image and then the doctor told a nurse to put me out again. After I was in the colonoscopy recovery room I remember asking him in a drugged haze if he was really sure about his cancer diagnosis or if there were a chance of a mistake. In answer to my question, the "C" doctor repeated that he was 100% sure it was cancer. However, the cure rate for colon cancer was impressive and he would arrange for me to see the best surgeon he knew. Tony volunteered that I did not want to have a colostomy. The "C" doctor answered that he couldn't see any other options since I had the cancer in two sections of my large intestine, but I should see the surgeon before I made that decision.

Within two days I had the promised appointment with my cancer surgeon. The cancer surgeons' shared waiting room was a real trip—really sick looking men, women, and children crowded into it. I tried editing my graduate students' research papers but couldn't help staring at the other people with parts of their faces missing, many without hair, and some talking to their partners using voice vibration machines. Was I really one of them? Did my questioning of this positionality mean I bought into a sense of normality that did not include cancer patients? Have I been socially and politically constructed to oppress or demean seriously ill people in ways that I resent others doing concerning race, ethnicity, gender, sexuality, or social class (Davis, 2006; Stuhr, Petrovich-Mwaniki, Wasson, 1992; Ballengee-Morris & Stuhr, 2001). At the onset of my clinic appointment with the colon/rectal surgeon, I repeated my mantra that a colostomy was not an option. After another mortifying, embarrassing, and painful examination he said he thought he could surgically fix things and that a colostomy would probably not be needed. He then sent me for a battery of further tests including an MRI, which yielded more bad news. The MRI showed a spot on my liver. My surgeon explained if that spot was cancer too, I would die shortly after the surgery. This surgeon was not known for his bedside manner, but I appreciated his forthright professionalism. He handed me a packet of papers to fill out before the surgery including a will and organ donor forms. He also said I should arrange for someone to stay with me or for care in a nursing home for a few weeks after the surgery.

I called Debbie and told her the news and I thanked her for giving me the motivation to face this cancer reality. I was surprised that I never cried or felt bad about the possibility of dying. I reasoned that I had a great life, better in so many ways than I ever thought it would be. If my life had to end, so be it, just please not too much more pain! I did feel bad about how terrible my cancer made other people feel and often found I had to do the consoling. The Department Chair, Jim Hutchens, acted kindly toward me and gave me an off quarter to work on developing my online course so that I didn't have to use many sick days. I had told all of the colleagues with whom I was close about my cancer and upcoming surgery. I asked Jim to tell the others.

### CANCER SURGERY

I waited for the surgeon's office to call me back with a surgery date. I continued to wait for another month, and then I called the colonoscopy doctor, because he told me to do so if I didn't have an appointment scheduled for surgery right away. The surgeon's office called back the same day with a date and a 6:00 a.m. appointment for the surgery; I'd simply slipped through the cracks so they were getting me in before usual surgery hours. My niece, who had gone to OSU's law school a few years before, came to be with Tony and me during the surgery and she also helped me with the will and living will. I had arranged for two of my sisters to come in week-long intervals after I was released from the hospital.

Because I had to go in for another colonoscopy to be done by my surgeon (he likes to know exactly what he is getting into, he explained) and I couldn't eat for a day before the surgery, I had gone without food for over three days and with mega doses of antibiotics, I felt deathly ill by the time I walked through the hospital doors that morning. My niece said by comparison to the morning I checked in for surgery, I looked like the picture of health when I came out of recovery that afternoon, even though I had tubes going in and coming out of numerous parts of my body. The surgeon was in my hospital room sitting on the other side of the room staring at me when I came to. He reported all went well, no colostomy, no liver cancer, the x-ray spots were only calcium deposits, and I'd be in the hospital another ten or eleven days or until I was able to pass gas. For at least the next nine days, I was in a drugged state and my stomach was continually pumped. My body was not really my own but a Harawayesque (1991) hybrid bionic version of me. During this time I had nothing except a few ice chips to eat and nothing to drink. I had asked that no visitors except for one friend and my immediate family be allowed to visit me. I do not like people to see me weak. The third day after surgery I asked my husband to bring up my laptop because the summer and fall course schedule needed to be put up for the department and no one else knew how to do this. I noticed an icon on my desktop that had not been there before. I clicked on it and the pictures of my cancers in vivid living color popped up and covered the screen. I was dumbstruck! How had these images (see Figure 3) gotten there?

FIGURE 3



*Patricia Stuhr, Cancer Site 1, December 16, 2002.*

The eleventh day after my surgery I finally, painfully expelled gas. Then the last intravenous tube was removed and I was allowed to go home. At home I slept downstairs because I was not supposed to climb steps more than once a day. I had to shower with plastic wrap enveloping the entire length of my incision from the end of my chest cavity to my pubic bone. My incision was like a ragged mountain range with ugly black stitches. The incision looked like the kind of thing an alien might pop out of. It seeped pink watery liquid, which was considered normal, but I was to call the hospital if the discharge turned yellow. It later turned in to a purplish pinkish red lumpy scar. The doctor assured me the bumps would wear down with age. I never showed anyone my scar, which signified the damage of cancer.

## RECOVERY

After I came home from the hospital, I gave myself one day to feel sorry for myself and then I promised myself that I would start on the road back to good physical and mental health. I could not drive for six weeks because of the surgery and the pain killers I was on. My sisters, taking turns as caregivers, chauffeured me around to doctor appointments and the Lancaster mall and Circleville cemetery where I walked to keep my digestive system in working order. In my effort to reclaim my body I was soon up to walking four miles a day. Both of my sisters also lost weight during the time they spent with me.

The most surprising thing that happened once I was back at home was the number of letters, notes, prayers, flowers, and plants that were delivered from friends, colleagues, and relatives. The hospital had not allowed live plants on the cancer ward. Now they took over my entire dining room table and every available end table and coffee table. The house smelled like a funeral home with all of the blossoms. Many of the cards and letters were from art education friends and colleagues from across the nation and globe. They often expressed how much my work meant to them and how they admired me as a person or friend. I realized that their personal notes of friendship and caring meant more to me than the notes describing the impact of my scholarship on them or their work, although I appreciated that too. I also realized how much I owed to the OSU Department of Art Education. Being a part of this renowned department gave me the opportunity to meet and work with renowned art education colleagues across the globe.

At the end of the six weeks of house confinement, I was back in the office. I was supposed to start with a few hours a day and then add more time as I was able. Within the week I was back full-time. I had applied for a sabbatical for the following year before I went in for surgery and had also made plans to teach courses at the University of British Columbia.

Jim Hutchens had just been promoted to associate dean in the college and the faculty were making plans for hiring a new department chair. I could not attend that meeting, but I left notes with my colleague Vesta Daniel, because I had decided earlier to take a trip to Wisconsin to assure my aging parents that I was alive and doing well. While I was in Wisconsin, my colleague Sydney Walker called to ask on behalf of the faculty if I would consider filling in as chair for the following year until they could fill the position. I explained my sabbatical and teaching plans and said that I would not be interested in filling in for a year. She then asked me if the faculty were to consider me for the position for a full chair term of four years, would I then be interested in the position. Without thinking I said, "probably," because then I could get something done and not simply be a placeholder.

Within a day she called back to say the faculty and dean wanted to discuss the full term chair position with me. I don't think I ever would have considered being a department chair if I had not had cancer. It was no blessing, but it did give me an opportunity to rethink my priorities. I decided it was time to give back to the department that had given me so much. I wanted to make the lives of everyone in the department better. Life I now realized was very short! I wanted faculty, students, and staff to enjoy the work place and have whatever they needed to take advantage of their work, research, teaching, and service possibilities.

Besides, I thought, if I ran into a snag, Jim was just downstairs in the dean's office. But he was not to be for long. Stomach cancer claimed Jim after only five months into his new position. I had just visited him in the hospital with Vesta the week he died. I was asked to give a eulogy for Jim at a campus memorial service, but the day before it was scheduled, I decided to ask Bob Arnold to do it instead. Why had he gone so soon and I remained? I was suffering survivor guilt and didn't think I could go through with a service presentation. It took me over four years to remove his personal belongings from the chair's desk, which he had left behind. Perhaps I thought if they were removed, his spirit would go with them too.

Shortly after Jim died, I ended up in the hospital with adhesions and bowel obstructions. Tissue from the surgery adhered to parts of my insides and caused my intestines to twist up. I had earlier been to my physician's office several times that month trying to get relief from the pain. The last time I went to the clinic, my physician was not in and a fill-in woman doctor asked me to rate my pain from one to ten. I said, "twelve." She brushed it off, saying that I was probably under stress at work and this caused my intense stomach pain. By 8:00 p.m. that evening I was in the Circleville hospital's emergency room telling my husband I just wanted to die to stop the pain, and by 6:00 a.m. the next morning I was back at the OSU hospital in surgery. This time the emergency surgery (done by my original cancer surgeon) left a scar that was clean and neat, and repaired the damage from the adhesions. Another eleven days in the hospital without food or water, more dedicated sister care, and another six weeks of recovery from this surgery. This time I was angry at the woman doctor who had told me my pain was caused by stress, or in other words, in my head. After I was home but still on pain drugs, I called the clinic to complain to her. She was not in, so I told the nurse that his doctor should not be so quick to chalk symptoms up to stress. I said I was angry that I ended up in the hospital vomiting so strenuously that I was bringing up fecal matter, and that I had to undergo another intestinal surgery because of her misdiagnosis. Perhaps I would have had to have the surgery anyway, but I felt resentful of her callousness. I was also troubled because I wondered if I would have reacted this way if it had been a male doctor's diagnosis.

Since this last surgery I have had to repeat the emergency room experience and another midnight ambulance ride to the OSU hospital for another eleven-day stay, one more time. Never again, I hope, but the experience, scars, and fear remain. I have been able to share and exchange these and other parts of my cancer stories with Terry and Debbie. Sometimes this is emotionally difficult and at other times we look at our experiences with humor and laughter. I continue to live my life, sometimes limping and sometimes galloping, but always dragging my visible and invisible scars along.

## CONCLUSION

### TERRY

To live is to become. After I was “cured” of my kidney cancer, I felt fairly invincible again, or at least strong enough to continue everything that the unexpected surgery and recovery had temporarily interrupted. I was in a kind of denial, again aware that life is fragile, but I did not consciously make many changes. Scans of my “granular” lymph nodes every six months were worrisome intrusions into my chosen sense of normalcy. They produced anxieties during the days preceding the scans and anxieties about what the scans might reveal to the oncologist. After three years of scans during which my lymph nodes were determined to be stage 4B cancer rather than harmlessly granular, denial was no longer possible. I felt perfectly healthy when I began chemotherapy, but chemotherapy quickly became my illness rather than cancer. During and after chemotherapy I could no longer minimize the threat to my life. How do I want to become?

Now (hopefully) in remission, there are some changes of which I am aware. I am struggling to rebuild an identity with which I am comfortable. I am faced with remapping a future, very aware of not knowing its length. I am again examining my purposes, distinguishing what seems important from what seems not. I am now drawn to people’s true stories. Everyone has them and I want to hear them. I want to tell my own. I am more honest with my students. I want to hear their stories. I am more selective about students and I try to expend energy only with those who want to work. When students choose to come to me, I eagerly respond to them. I want to be encouraging, challenging when necessary, but kind and helpful. I especially enjoy mentoring. I want to smile more.

### DEBBIE

I no longer enjoy the rush of adrenalin that goes with pushing myself to the limits of my emotional or physical endurance when dealing with just about anything. I seek joy. I am intolerant of negativity and injustice and I suspect that this shows during my dealings with students, colleagues, and especially administrators. I’ve got nothing to lose by being honest, open, and sometimes abrupt when it might be useful. There’s no time to waffle around and what’s the point anyway? I try to be generous with my students and colleagues by sharing time, ideas, and strategies for success. I try to make each minute count and consider both destinations and detours sites for deconstruction, reflection, research, and artwork that express my verbally unavailable feelings and issues. I am hooked on autoethnographic exploration because I can’t get far enough away from myself to avoid the personal, so I might as well be part of all the stories.

### PAT

No one, it seems, really recovers from cancer unscarred. These remnants and traces of cancer remain as memories of pain and humiliation (St. Pierre & Pillow, 2000). If I ever think I can forget the cancer experience, there is another six or twelve month doctor check-up to remind me. Probing tests and body scans continue. I do not like being referred to as a cancer survivor. I accept that I have post-traumatic stress and I live with the continuing reality of possible reoccurrences. My journey in art education as a chairperson, professor, advisor, mentor, and writer is significantly changed by my encounter in cancerworld. I believe that by sharing my story, I can open the door to discussions about the cultures of cancer and illuminate its emotional, spiritual, and embodied potentials for art education



research and pedagogy. As the cancer center's holiday card implies, the culture of cancer includes all of us, in one way or another, and like any other cultural phenomena, cancer can be used as a subject for visual and verbal interrogation.

## FINAL WORDS

In our autobiographical narrative exchanges, sometimes gender lines blurred and sometimes stood out in stark contrast. We passionately and dispassionately referred to and discussed body parts. At times we interrogated and revealed the stigma of illness and imagery attributed to women and men. Most often, gender roles played out in our narratives in taken for granted socialized ways, as they do in life. Our doctors were mostly men except for the one female doctor who made a misdiagnosis. Caretakers were primarily female: a wife, a daughter, sisters, a niece, and nurses. However, we attributed kind acts to both male and female colleagues, department chairs, mentors, a granddaughter, and the prayerful. Insensitivity crossed gender lines too. Narratives such as ours provide opportunities to freeze-frame snapshots of gender, age, and social relationships, and those snapshots allow us to contemplate aspects of their social construction and possibilities for change.

The imagery we encountered, made, and remade during and after our cancer experiences produced understandings about illness, death, life, and afterlife. They helped us discover and face what was an unimaginable cancerworld. These images are also barometers that forecast our moods and engagement with life and our relationships with others. We had been conditioned through our lifelong engagement with and in the arts to rely on these informative and intelligible voices of our pain, despair, and joy.

*Authors' Note:* We dedicate this article to our family, friends, and colleagues whose lives have also been forever changed by cancer, and especially to those whose lives were taken by the disease.

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