

My Easy Year:

Breast Cancer, Narrative Reckoning, and the Art of Creating a Dissertation

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In memory of Mariel Carla Q. de Jesus

Abstract

A serious illness acts as a break to one's routine and wrecks a life's narrative (Frank, 2013). A serious illness can force one to examine the weave of their life—past, present, and future—in unexpected ways (Lorde, 1980/2020). I learned this firsthand when, late in my doctoral studies, I was diagnosed with breast cancer after a routine mammogram screening.

The diagnosis, treatment, and on-going side effects left me with one question: How am I supposed to get through *this* (creating a dissertation) after going through *that* (cancer)?

To answer that question, I turned to arts-based research practices (Leavy, 2015; Loveless, 2019; Springgay & Irwin, 2005). In this non-traditional “braided” dissertation (Miller, 2021), I use creative writing (personal stories, journal entries, and doctor's charting notes), textile arts (knitting, felting, weaving, and quilting), and photographic practices (black-and-white darkroom work and the cyanotype process) to examine my past, present, and future.

At the same time, I incorporate research and theory from medical sociology to ground my personal experience in a larger cultural context. I explore the illness narratives I tell (Frank, 2013) and consider how they align with or resist American breast cancer culture and the expectation that women are made “better” by having cancer (Ehrenreich, 2001; Sulik, 2011). I argue that there is no conclusion to breast cancer, even though the broader culture may call for one.

Ultimately, this dissertation resists dominant breast cancer culture and adds nuance and complexity to breast cancer stories. It also demonstrates how artistic practices

and academic research can be used to make sense of the existential crisis that a serious illness can trigger in one's life.

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Preface: My Easy Year

July 7th, 2021, afternoon

“I’m sorry, I have to interrupt you—” The nurse from the Cancer Center had just told me I had cancer. It was *estrogen positive* with *many good treatment options*, but I wasn’t hearing her because I was distracted by the scene outside my window. “—a giant peanut just drove past my house.”

“A giant peanut?” the nurse repeated.

“Yeah, like the Oscar Mayer Weinermobile, except it was a giant peanut. I live on a busy street, so we see all sorts of things, but that’s new.”

I started laughing.

I had cancer. And legumes had become cars.

* * *

Even though my biopsy had only been two days prior, I’d expected this call for two weeks.

I wasn’t worried when I got a callback after my very first routine screening mammogram. I had been told by the mammogram technician that first-timers often got callbacks since they had no baseline images. I was only forty, and as far as I knew, there was no history of cancer in my family, even with a half dozen aunts. A few of the women in my family had been called back for additional images, but anything found had been a nuisance at best. I was sure it would be the same for me.

After two more mammograms, I got called to a different room for an ultrasound. I still wasn’t worried—even though my best friend, Cynthia, had been diagnosed with

breast cancer only two months earlier. She was older than me, she had baseline images. The breast center simply needed to learn what my baseline was. Besides, Cynthia and I couldn't have breast cancer at the same time. That would be too weird.

And I truly believed this, even when the ultrasound wand was jammed into my armpit, even when I was wondering if I'd have a bruise because they were pushing against my skin so hard.

I only became worried when the room grew oppressively silent. The ultrasound tech, the nurse, the radiologist, and her resident—none of them looked at me. Or each other. Instead, they all stared at the screen.

And then the numbers started coming. “Twelve centimeters from the nipple, nine o'clock. Maybe ten...” Dr. Steeple^a held a small, flexible ruler against my skin. “About one-point-five... one-point-six centimeters...” *Click*, a screengrab. *Click*, another screenshot. *Click, click, click, click*. Digital photo after digital photo.

“Nine or ten o'clock?” someone asked.

“Mmmm, let's say nine-thirty.”

Finally, Dr. Steeple—while I was still on my back, bare breasted, with my right arm wrenched behind my head—started talking. *Sometimes people get callbacks after mammograms, and then they need more mammograms and maybe an ultrasound, and sometimes the ultrasound can show you if it's a benign cyst or not—*

I felt like I was underwater. Her voice sounded very far away, and I already knew

^a My doctors' names are pseudonyms.

all of this, why was she telling me—

“I want you to get a biopsy.”

“OK.” My heart pounded in my ears; tears welled in my eyes. I started bargaining. “But don’t most biopsies come back normal?”

“Out of all biopsies performed?” Dr. Steeple made a big circle with her hands as she spoke. “Yes, most come normal.” She held my gaze. “But I will be very surprised if this comes back normal.”

Well. She was the expert.

I blurted out, “I don’t have time for this shit, I’m supposed to be writing a dissertation.”

“I know. But this has to come first.”

* * *

The day after my You Have Cancer call, I found myself sitting in my surgical oncologist’s office. Dr. Xie had examined me and spent over an hour and a half reviewing what little we knew about my tumor. It was estrogen and progesterone positive—good. It was small—good. We didn’t know if it was HER2 positive or not—triple positive breast cancer is rare, but when you’re young at diagnosis—and at forty years old, I was considered twenty years young for breast cancer—“weird things are more common.”

I’d almost certainly have radiation. I might need chemo.

I was young and we should consider genetic counseling and genetic testing; it would help us decide which surgery to get. The tumor wasn’t *in* my chest wall, but it was *touching* my chest wall, and that might make getting negative margins hard.

It was good I had gotten a screening mammogram.

We'd plan on surgery in August, maybe a consultation with a plastic surgeon. It would depend on the test results we didn't have. Did I have children, was I concerned about fertility, and did we need to discuss freezing my eggs? Oh, and was I interested in a research project about vitamin A? What about my tumor, could they use it for medical research purposes?

"I don't care what you do with my tumor, as long as you don't put it back inside of me."

Finally, near the very end of the visit, Dr. Xie asked me what I did for work and what my work schedule was.

"I'm a doctoral candidate at the U. I work twenty hours a week right now, but I'm quitting that job..." I wasn't even sure what to say. "I landed a super competitive fellowship *and* another competitive external scholarship for this next school year, so I don't have to work. I'm supposed to graduate in May, I'm supposed to be writing my dissertation." I gazed at the white linoleum floor in the examination room. "This was supposed to be my easy year."

I've since repeated this speech, nearly word for word, with at least a dozen medical providers—my radiation oncologist, my medical oncologist, two ER doctors, residents, medical students, my radiation therapists, my lymphedema specialist, nurses, the phlebotomists who draw blood and make small talk, whoever else happens to be in the room. Sometimes I've cried while saying it. Other times it's come out with a bitter edge. Sometimes it's just been a matter-of-fact monologue.

This was supposed to be my easy year.

I don't remember how I said it to Dr. Xie. I only remember her pragmatic response: "I wouldn't want to be writing a dissertation right now."

Part I: Context

I am talking here about the need for every woman to live a considered life. The necessity for that consideration grows and deepens as one faces directly one's own mortality and death.

—Audre Lorde, *The Cancer Journals* (1980/2020, p. 50)

I'm trying to tell you something about my life
Maybe give me insight between black and white
The best thing you've ever done for me
Is to help me take my life less seriously
It's only life after all, yeah

Well, darkness has a hunger that's insatiable
And lightness has a call that's hard to hear
And I wrap my fear around me like a blanket
I sailed my ship of safety till I sank it
I'm crawling on your shores
—Indigo Girls, "Closer to Fine"

Chapter 1: A Moral Problem

This is not the dissertation I wanted to write.

It's certainly not the dissertation I *expected* to write.

I passed my oral exam and proposal just weeks before COVID shut everything down. When it was clear COVID was going to drag on, I found ways to adjust my proposal—I was researching teacher identity development of first-generation graduates—to the realities of Zoom and remote teaching. I adjusted my graduation timeline.

A year later, I felt like things were going as normally as they could, considering I'd been working at home during a pandemic. I'd lined up all of my participants. I had most of my data collected, transcribed, and even analyzed. I'd applied for and received two financial awards and was looking forward to the last year of my work. In mid-June, I finished a three-week dissertation writing retreat; I had a huge chunk of my dissertation drafted.

But then I went in for my routine mammogram screening.

I

For months, before my official diagnosis and throughout most of my active treatment, I Googled variations on “getting cancer in graduate school.” I wanted to know how other people got through graduate programs—especially the dissertation writing process—after a diagnosis. How did people manage all of the appointments, the fatigue, the fear and uncertainty of what was next?

What information I found was extremely limited. As Cheung (2019) says about the illness experiences of doctoral students, “almost no scholarship on the topic [of

doctoral students with chronic or serious illnesses] exists” (p. 232). What I could find seemed to focus on managing coursework, working in a lab, and making sense of a university’s policies (e.g., Arubala, 2016; Dalmaijer, 2016; Madhusoodanan, 2017; Miller, 2013a; The Samfund, 2016). I was in an extremely privileged position, since I was done with my coursework and my fellowship included my health insurance.

I also read stories from and about people who found comfort in their research (e.g., Cheung, 2019; Flumer, 2020; Madhusoodanan, 2017; Ridgway, 2022). For these people, illness gave them a reason to keep working, and work gave them a welcome distraction from their illness.

I couldn’t relate.

I didn’t have to deal with teaching, coursework, qualifying exams or other milestones, or any external work obligations. My health insurance and funding were safe. And even with those advantages, I had a difficult time going through my breast cancer treatments while being a doctoral student.

Even though the cancer was “only” Stage I, and the tumor was “only” a centimeter on the long edge, and I “only” needed a lumpectomy and radiation (and no chemo), and active treatment “only” sucked up six months of my life—even though my cancer was caught early—everything changed.

I couldn’t focus on anything except my cancer. If I wanted to think about anything else, I zoned out with Netflix and some mindless knitting or Candy Crush.

Maybe something was wrong with me. Maybe this was a sign I didn’t belong in the academy. Because I certainly found no shelter in my dissertation.

II

The wounded storyteller has lost what were possibilities of acting as and feeling like the body in which his or her point of view has been grounded. The problem of storytelling goes well beyond who gets to tell the story, important as that is.

The underlying problem is how people can tell any story after losing the point of view that their previous narrations depended on. Without a point of view, there is no story to be told—the lifeworld would have no voice. (Frank, 2013, p 210)

III

I mostly put my research aside during my active treatment; I finished my data collection, did some transcription and gave myself permission to get through treatments without worrying about my dissertation. And I adjusted my graduation timeline. Again.

Near the end of my active treatments, I told a few people I didn't know what to do with myself. "I have had to think about cancer since June 24th. I don't know what I'm supposed to think about when I'm not thinking about cancer. What am I supposed to do when every day isn't a cancer day?"

I remember several friends saying, "Well now you can get back to normal."

That's what I wanted, too.

But it was impossible. There was no getting back to normal. Normal was *never cancer*, and I would never get that back again. Now it was *once cancer*.

I gave myself time and space, knowing that the end of treatment isn't the end of healing. I took six nights away and went on a solo, silent retreat (see Chapter 6). And that's where I realized that although I still cared deeply about my participants and their stories, surviving cancer had caused such an internal shift that I didn't know where to go

next. I found myself distracted by a new set of questions, ones that felt more personal and more urgent. More important.

I wrote in my retreat journal:

But here's the thing: How do I get through this dissertation when my schedule is still being interrupted by multiple doctor's appointments each month? How do I come back to this work? What do I do now that cancer has shifted my priorities so much? How am I supposed to do this when I don't care about it anymore? How come I can't stop thinking about my cancer? How do I see myself as a survivor? How can I be an artist, a researcher, a teacher *and* a survivor? I still haven't "worked through" my cancer diagnosis and how it upturned my life, how am I supposed to work through this? How do I finish this dissertation when I'm *not* the same person I was only a year ago?

What I'm asking is... How am I supposed to get through *this* after going through *that*?

IV

Cancer diagnosis radically alters autobiographical perspective; every aspect of life narrative—past, present, and future—looks different. (Couser, 1997, p. 64)

V

Creating this dissertation—researching, writing, creating art—was not a linear, straightforward activity. For several months, I resisted changing my topic, and I thought I might be able to include one brief chapter about dealing with my cancer diagnosis, almost as a researcher interlude.

I was, in fact, thinking deeply about my dissertation, my participants' stories, and the literature I'd read about first-generation college students. I kept returning to the literature, and thinking about my own college and career choices. Why did I make the college decisions I made? Why didn't I stick with my intended major? Why *didn't* I pursue art, either photography or creative writing, in college? How did my decisions relate to my own identity of being a first-generation student?

I thought of these questions over and over, digging deeper into my own schooling and teaching history. As I did this, my questions started to shift. Why did I choose to start a doctoral program? What did I want to do with my doctorate when I started? What do I want to do *now*, after cancer? Why didn't I pursue art? Why have I always seen art as a hobby and not a possible career choice?

And: What am I supposed to do now, after cancer, now that I feel like all of my priorities have shifted? What am I supposed to do now that I don't care about the same things? And why can't I get over cancer? I was only stage I; I should be able to get over this... right?

VI

No matter how we abject our bodies, particularly in the academy, they come back to haunt us. They make their claims on us/for us/in us/outside us. (Banks, 2003, p. 28)

VII

I wrestled with these questions and reached out to friends. Over coffee, my friend Abby and I tried to figure out how I could get back to my dissertation. I had my research journal, a calendar, notes about everything I'd already done, and a loose outline of what I'd already written.

No matter what we thought of, I couldn't find a way in.

Frustrated, I finally said, "I don't think I can write my dissertation without *just* writing about my cancer."

I was hoping Abby would respond with some magical advice, some statement that would make everything click into place. I just needed more time—that's what she'd suggest, right? That was common, normal, reasonable advice.

"You're right. You can't," Abby said. "You write and make art to process things, and that's what you need to do here."

Abby's response was the support and validation I needed. I knew she was right. I needed to pivot my dissertation. But changing my topic so late still felt risky, possibly unwise. I wrote in my research journal:

I talked to Abby about this tension I'm feeling today, and she said what I secretly hoped—and was afraid!—she'd say. She thinks I should shift my topic.

That feels wild, and stupid. And like a lot of work.

But it also feels like the only thing I can possibly do. I know I need to do this.

My friends keep calling my brave—am I?

Cancer had changed everything for me. Was I brave enough to let it change my dissertation topic, too?

VIII

Although I didn't know it at the time, I was grappling with what medical sociologist Arthur Frank calls a moral problem. As Frank (2013) says:

Illness is not presented to the ill as a moral problem; people are not asked, after the shock of a diagnosis has dulled sufficiently, what do you wish to become in this experience? What story do you wish to tell of yourself? How will you shape your illness, and yourself, in the stories you tell of it? (p. 159).

This moral problem comes about, in part, because illness disrupts memory (Frank, 2013). This isn't a disruption of remembering things, but *of* memory. "The memory that is disrupted is a coherent sense of life's sequence: what the philosopher David Carr calls 'the whole which comprises future, present, and past' " (Frank, 2013, p. 60). The present (ill) person has to face a past that wasn't supposed to include illness, and the present (recovered) person has to manage a past that "never received its due telling when it was happening" (Frank, 2013, p. 60). Quoting Carr's work, Frank says that this disrupted memory becomes a *moral* problem with two aspects: "one to live out or live up to a plan or narrative, large or small, particular or general; the other to construct or choose that

narrative. The first is constrained by the choice of the second” (David Carr, as quoted in Frank, 2013, p. 60).

This was the moral question I grappled with as I tried to “get back” to my dissertation work seven months after my cancer diagnosis had interrupted it. Should I go back to my original topic, with all of its collected and processed data? A large chunk of my dissertation was already drafted, after all... And was I obligated to stick to my original topic because I’d landed a fellowship and scholarship to complete that work?

Or should I honor the fact that writing about and making sense of my cancer experience felt more pressing and more important? The few grad-student-with-cancer stories I’d been able to find all told the same story—one I didn’t identify with or connect to. Could my dissertation help a future grad student facing a cancer diagnosis? Could my dissertation help *me* process what I’d just gone through? Could I use my dissertation to reshape and reform the self I wanted to be going forward?

In the end, I decided that living up to my post-cancer self was the best way to honor my commitment to myself as a researcher.

When I finally accepted this truth, I considered the questions I wanted to use to guide my work. I wondered: How can I use artistic practices to make sense of the narrative wreckage that my breast cancer diagnosis brought with it? How can the process of creating a dissertation be used as a tool of emotional processing?

In short: How do I get through *this* after going through *that*?

Chapter 2: Philosophical Underpinnings

Archaeologists love finding rats' nests in the walls of a building. Rats usually live in one area for their whole life, and they tend to gather materials from a fifty-foot radius. This means that the bits they steal from their surroundings represent a very small slice of life. Additionally, because they don't discriminate, rats collect things that usually aren't saved over time, such as forks or bits of paper. And then rats urinate on their nests; the urine acts a preservative, turning the rat's nest into a time capsule. Rats' nests can show how an environment changed over time, and they raise more questions: Where did that button come from, how did that teacup break? An enslaved family lived in this home—who wrote on the bit of paper, and how did he learn to read? What happened to his life after that?¹

As an artist, a researcher, and a teacher—as an a/r/tographer (Irwin & Springgay, 2008; LeBlanc & Irwin, 2020)—I feel like a theoretical packrat. I pull bits and pieces from different places, make new connections, and link together disparate ideas. The ideas layer one on top of another, making a home for my work. This is great, artistically, because so much of artmaking is bringing together disparate ideas. But it does make it difficult to describe my exact research practices and philosophy to a reader.

My philosophical beliefs influenced every aspect of this work, including why I pivoted my topic from teacher identity development to my personal experience with breast cancer, how I used artistic practices, how I viewed the materials I interacted with throughout this process (physical materials such as my medical records or yarn and film, but also abstract materials such as the stories themselves), and how I chose to represent

and present this dissertation. The “how” of research can’t be separated from the theory or thinking of research (LeBlanc & Irwin, 2020; Ravelli et al., 2021; Springgay & Truman, 2018).

Researchers frequently position themselves according to three *-ologies*: *ontology*, or beliefs about what we can know and how we view reality; *epistemology*, or how we can know what we know; and *methodology*, or how a researcher goes about their research, including the ethical choices they make. Although these are three separate terms, they’re interlinked (Ingram, 2021; Springgay & Truman, 2018). For this reason, some researchers use the terms *onto-epistemology* or *ethico-onto-epistemology* to draw attention to the ways that ethics, knowing, and being are interlinked (Springgay & Truman, 2018). In what follows, I will describe the philosophical underpinnings that are essential to my research practices and researcher identity. First, I briefly discuss arts-based research as a research orientation and Robin Wall Kimmerer’s idea of non-human animacy (agential realism). Next, I describe the ethical tensions I faced in creating this dissertation; I also explain some of the ethical choices I made, and I share how I envision the reader interacting with this dissertation. Finally, I provide a brief overview of the remaining sections of the dissertation.

Arts-Based Research

I ground my research practice in an arts-based research orientation, one which recognizes artistic practices can be used to make sense of and understand the world (e.g., Chapman & Sawchuk, 2012; Ingold, 2010; Irwin & Springgay, 2008; Leavy, 2015; Loveless, 2019). Arts-based research practices go by many names, including research-creation, creative research, practice-led research, or artistic research.² No matter the term

used, this research orientation usually includes a creative process, conscious aesthetic components, and/or an artistic work as key parts of the research process (Chapman & Sawchuk, 2012). This research orientation leads to diverse research practices, processes, and products (Chapman & Sawchuk, 2012; Ravelli et al., 2021).

In their work, Chapman and Sawchuk (2012) describe four common, overlapping “families” of arts-based research (which they refer to as research-creation). Some arts-based researchers situate themselves heavily in the artworld, and written output is secondary to artistic output (this could be thought of as *research-for-creation*); other researchers use artistic practices to do research, but favor traditional academic writing as their primary output (*research-from-creation*); other arts-based researchers use creative and experimental forms of writing to resist traditional academic writing (*creative presentation of research*).

Finally, there are researchers whose artistic and research practices span multiple disciplines equally, and theory and practice are so interwoven they can’t be teased apart (Chapman & Sawchuk, 2012; Loveless, 2019). This research contributes to “knowledge in a profoundly different way from the academic norm,” and the product created will not follow or adhere to the norms of academic products such as journals, book articles, or research reports (Chapman & Sawchuk, 2012, p. 21).

A/r/tography

Within the world of arts-based research, I am heavily influenced by ideas arising from a/r/tography (Irwin & Springgay, 2008). *A/r/tography* embraces an artist-researcher-teacher lens, seeing these roles as deeply intertwined. A/r/tographers create renderings, or theoretical spaces where artistic ways of knowing can be explored and researched

(Springgay & Irwin, 2005). These theoretical spaces emphasize the importance of creating circumstances where on-going inquiry can be used to create and produce knowledge; these spaces also de-emphasize the importance of reporting or finding knowledge (Irwin & Springgay, 2008). A/r/tographers make, change, and understand meaning through their practices and roles as artists and researchers and teachers (Springgay & Irwin, 2005); importantly, the emphasis is on practice and process (Irwin & Springgay, 2008; Springgay & Truman, 2018).

A/r/tography, as a practice, does not rely on proceduralism (Springgay & Truman, 2018), or a belief that certain procedures must be followed for something to be considered a/r/tographic research. This can make describing what a/r/tographers *do* difficult, because it's a "living practice of art making, researching, and teaching" (Springgay & Irwin, 2005, p. 902). To best understand what a/r/tography is, a researcher must plunge into the messy middle of research (Springgay & Truman, 2018), and they must be willing to sit in uncertainty, allowing for "discomfort, frayed edges, and holes" (Springgay & Irwin, 2005, p. 901). At the same time, a/r/tographers must be attentive to "the sensual, tactile, and unsaid aspects of artist/researcher/teachers' lives" (Springgay & Irwin, 2005, p. 899). This is "research that breathes. Research that listens" (Springgay & Irwin, 2005, p. 899).

And it's a research methodology that's especially well suited for this dissertation. I am a process-oriented artist and researcher rather than a product-oriented artist and researcher. In other words, I do not consider the product of doctoral work (the dissertation, new research) the most important outcome; I believe the process of doing doctoral work (learning to become a researcher, positioning myself philosophically,

doing research, and so on) is the most important outcome (see Herman, 2010, for a brief discussion on this topic). A/r/tography's focus on process is in line with this worldview.

But beyond my own passion for process, a/r/tography is especially well suited for this dissertation—specifically this *topic*—because a/r/tography may “engage emotional, intuitive, personal, spiritual, and embodied ways of knowing—all aspects of one’s private, public, and/or professional self” (Springgay & Irwin, 2005, p. 901). A/r/tography (specifically) and arts-based research (generally) honor and respect bringing the whole self into research. In fact, bringing the whole, embodied, subjective self into research is seen as a positive for arts-based researchers (Ravelli et al., 2021).

Non-Human Agency

Artistic ways of knowing—that knowledge can be generated and understood through artistic practices—are an essential part of my research. So is Robin Wall Kimmerer’s description of agency among non-human beings. And it was an idea I came to by accident.

The first winter of COVID, I watched a Zoom talk Kimmerer, an Indigenous scholar and author, did for the Minneapolis Institute of Art (MIA) titled “Learning the Grammar of Animacy: Subject and Object” (Minneapolis Institute of Art, 2020).

I’d heard rave reviews of Kimmerer’s work before attending the talk, but I had not read any of it. She started the talk by explaining the three ways of knowing she was working with—Indigenous knowledge, plant knowledge, and scientific knowledge. When she went to forestry school, she wanted to study botany to find out why goldenrod and asters looked so beautiful together. She was told, by her predominantly white institution, that those questions were not scientific, and weren’t related to botany. From there,

Kimmerer talked about how non-human beings have agency, purpose, reason for existing that is outside of human-centered beliefs.

She talked about how animals, plants, water, soil, and rocks are subjects, not objects.

I was listening to her talk, and I wanted to understand. But I was having a bit of a difficult time.

I have always “appreciated” nature, and it was easy for me to see how animals are agentic beings—my cat most definitely has his own agency and reasons for doing things. But even though I was somewhat aware of the “scientific” evidence regarding how plants and fungi communicate with each other (Katz, 2018; Sheldrake, 2020; Simard, 2021)—and even though I gardened, tended to my water garden, and helped my parents with their vineyard—it was hard for me to see plants as having agency. And if it was difficult for me to imagine living beings as being agentic (let alone believe that they are), it was impossible for me to see how rocks and water could be agentic (even if things live in water or under rocks); those didn’t seem alive to me.

My upbringing, and the things I’d been taught about human’s place in the world, were getting in the way of my understanding.

At the end of the talk, Kimmerer took questions from the audience, and from employees of the MIA. Here is part of that transcript:

57:16 (Jill Ahlberg Yohe, Associate Curator of Native Art at MIA): So much resonates that I see these connections between museums and your understandings of ecology and what you were taught, this idea of objects, art museums thinking of art as objects, and ecology, something to be collected, something to be studied,

to be owned, to be researched, rather than the subjectivity of—of the art objects which reside in MIA. And, um, the ways in which we re-imagine and learn with our Indigenous partners and collaborators, to understand that these artworks that we think of as objects are actually filled with subjectivity and involve our own relationships, reciprocity, and restoration. And your thoughts about directions that we take at MIA to [*unintelligible*] restoration and to move forward, recognize the agency and personhood of the objects themselves.

58:29 (Robin Wall Kimmerer): Hmmm, it would be presumptuous for me to say what MIA should do, I don't know enough about what you *do do* [*laughter*], but the recognition of works of art as verbs rather than nouns... Um, that they are... they are... they have their own life and their power and agency in the world that we're not in charge of or in, in control of, right? So, I would imagine that this poses really interesting challenges in how you tell the story of the... of the artwork. I'm trying not to say objects [*laughter*], because it's so much how—objects—how we think about them in museums.

Um, but a way of honoring the agency of works of arts, I suppose, is to really let them speak for themselves. And speak to one another. I think about, you know, how sad it feels when you go to the Smithsonian and see living beings like drums or beautiful beadwork that are in a glass case, where they are reduced to objects. Beautiful, iconic objects.

But I think of how lonely they must be. How lonely they must be in the way that they are being treated, not only *because* of the way they are being treated, but that they can't be in relationship. That the drums can't sing when they

are in a box, for example. So those are just some thought about—that might prove useful as you think about your exhibits as verbs, as a way to make relationship, not as aesthetic objects. (57:16–1:00:38)

“That the drums can’t sing when they are in a box” acted as a spark of electricity. I dashed to my research journal to scribble that phrase down.³

Finally, things started to fall into place.

That one phrase unlocked a new world of thinking for me. This wasn’t just about non-human beings having agency. It was about non-human beings being in community with each other, with humans, with the world and environment around them. This wasn’t about reciprocity with other humans, but reciprocity with *all* other beings. This was about viewing “objects” as verbs, not nouns (see “Learning the Grammar of Animacy” in Kimmerer’s *Braiding Sweetgrass* for a longer discussion about the grammar of animacy).

I started asking myself: How am I in relationship with [_____]? How am I in relationship with stories? My garden? Art materials? The neighborhood I live in and walk through every single day? How can I view [_____] as a verb and not a noun? How is 35 mm film a verb? What does my wool want to *do*, as a verb? How can I make relationship?⁴

How does [_____] sing? And how can I shut up and listen to its song?

Learning and Unlearning

I am not claiming I have a deep, consistent understanding of non-human agency.

I don’t.

I am steeped in Eurocentric/settler colonial philosophical and academic traditions, and they are hard to see, let alone overcome. As Rosiek et al., 2020 say:

The material-semiotic architecture that both enables and constrains our practices of scholarship, knowing, and civic responsibility in Western settler colonial societies is very old and runs deep. [...] We can critically question one part of this matrix, but the others remain as ballast that draw us back into past practices that are networked with other cultural and material aspects of the world.

Consequently, as new materialist scholars invent ways to enact agentially realist inquiries, there is a significant risk that proposed innovations will be superficial and will be interpolated back into deeply ingrained practices of knowing and being. (p. 335)

For me, this learning (and unlearning) is on-going, and I know I'm going to get things wrong.

Speaking frankly, I'm afraid I will try to write about non-human beings/items/things/nouns/agents having agency and still position myself as the enlightened spectator (Rosiek, 2020), instead of a being in—rather, understanding how I am in—community with non-human beings.

I am afraid of unintentionally appropriating the work of Indigenous scholars (Rosiek et al., 2020; Tuck & Yang, 2012), especially because this dissertation does nothing to support projects of Indigenous sovereignty or land reclamation.

I am afraid I might be reading the work of Indigenous scholars “extractively, for discovery” (Smith et al., 2019, as cited in Rosiek et al., 2020), furthering settler colonialism.

I'm afraid I won't ever completely understand the depth of Indigenous scholarship, which makes me wonder if I should cite it at all—even though I don't feel that same tension with other (white) scholars (see Rosiek et al., 2020).

In fact, I *could* avoid this discomfort entirely. I could cite non-Indigenous scholars.

This philosophy of non-human agency goes by many names, including agential realism, “new materialism, new feminist materialism, posthumanism, new empiricisms, post-qualitative research, feminist technoscience studies,” or “the ontological turn” (Rosiek et al., 2020, pp. 331–332; see the article for scholars associated with each term). And work around those terms is being done primarily by white scholars.

But I didn't gain an understanding of these concepts from the (primarily white) scholars who coined those terms. It wasn't “metaphors from particle physics” (Eglash et al., 2020) that sparked a new way of thinking for me. It was the work of Indigenous scholars (e.g., Kimmerer, 2015; Kimmerer via Minneapolis Institute of Art, 2020; Simpson, 2014; Wilson via IAS UMN, 2021).

So I recognize that this work feels uncomfortable to me as a white settler scholar. I recognize I am going to make mistakes. I recognize this process of learning and un-learning is on-going.⁵

And I recognize that this has an ethical and philosophical impact on how I present this dissertation.

Moving, Breathing, Doing, Practicing Theory

The two core philosophies—that artistic practices and processes are ways of understanding and sensemaking and that non-humans have agency and purpose outside of

human desires and are in relationship—influence every aspect of this dissertation. This includes, but isn't limited to: how I entered the messy middle of research (Springgay & Truman, 2018), who and what I can cite, how I decided to “write up” this dissertation, and how I hope you, Reader, will be in relationship with it. Those are the issues I explore in this section.

By sharing some of the decisions that I've made about the dissertation and the writing of it, I hope the reader will understand deep theoretical and ethical work, the tensions and joys of it all, that I faced in creating it.

Gathering Materials

“Research begins in the middle” (Springgay & Truman, 2018, p. 206), but I suppose much of this work began with gathering materials.

My cancer treatments caused fatigue, and I didn't entirely trust my memory. But no matter how tired I was, I journaled every single day. These journal entries helped me remember exactly what I was thinking and feeling during treatment, and I could even remember what I felt but left out of the journal entries.⁶ I also collected Facebook posts, emails, text messages, and WhatsApp chats with friends. I reviewed my day planner to make sense of a timeline; I reviewed my medical records.⁷ I asked friends and family members what they remembered about my cancer diagnosis and treatment. I collected photos I'd taken of my body during various points of treatment. I examined my mammogram images.⁸ I gathered together my hospital wristbands and the piles of medical supplies I'd been given or had been forced to purchase—thick foam tape; ACE bandages; medical packing material; compression sleeves for lymphedema. I collected mailings I'd gotten from the cancer center, ones that were sent to me as an individual and

ones that were sent to me because I had crossed over from the “kingdom of the well” to the “kingdom of the sick” (Sontag, 1978).

I put the materials in a tidy pile, I spread them out; I ignored them, I played with them; I rearranged them, I held them; I added new materials, removed old materials, put them back.

I wrote.

I wrote up decades old memories that cancer had unearthed. I wrote fresh, angry words about cancer screwing things up. I wrote whatever needed to spill forth (Richardson & St. Pierre, 2005). I kept writing, figuring I would find a way to blend this disruptive experience together later.⁹

And I started reading. I sought out narrative research studies about breast cancer survivors. At first, I was trying to answer specific questions. I wanted to know why I resisted the term “survivor.” I wanted to know why I didn’t seem to have the optimistic attitude other breast cancer survivors had. I wondered why my radiation center had a giant bell on the wall. I wanted to know if I was the only one who felt like cancer—even stage I cancer!—had caused an existential crisis. Once some of my immediate questions were answered, I shifted my focus to broader questions. What sorts of stories did cancer survivors tell? Why did they tell them? I read classic books about breast cancer culture (e.g., Lorde, 1980/2020; Sulik, 2011) and illness narratives (e.g., Couser, 1997; Frank, 2013, 2016; Sontag, 1978). Sometimes I sought out certain research articles to make sense of a question I had. Other times, a research article would appear—or reappear at the perfect time, just when I needed to read it.

As this reading, writing, and thinking was going on, I also made art. I spent time

in the darkroom and I worked with the sun to create cyanotypes. I spun yarn, I knit, I wove. Tacit knowledge comes from making things by hand (Ingold, 2010; Porter Lofaro, 2017), and the artmaking helped me make sense of what I'd gone through with my treatments, how I was feeling emotionally, and how I wanted to shape and form cancer's meaning in my life. The artmaking—and sensemaking through art—also gave rise to more writing and more reading, usually outside of the field of medicine or narrative research.

As happens, the more I read, the more connections I made; the more I wrote, the more questions bubbled up; the more connections I made, the more art ideas I had; the more art I made, the longer my reading list became. The more I worked, the more settled¹⁰ I started to feel (slowly, in fits and starts).¹¹

My work ebbed and flowed.¹² There were times I was more focused on one aspect than another, but most of the time two or three things were happening in conjunction with each other. And the three activities (artmaking, writing, and reading)¹³ fed each other. This was an intuitive, embodied practice.

And I kept returning to my pile of materials and the stories I was writing. How did seeing these things in one space spark new ideas, new connections, creative wondering (Kleon, 2019)? But also, what did the materials tell me? What did I learn from them? How could the materials lead me (Ingold, 2010)? How were they in relationship with each other, with me, with my experience, with my dissertation? What might these materials tell me about getting through *this* after going through *that*? I returned to these questions frequently. It was all part of my effort to unlearn what I'd culturally believed about non-human beings.

Citing and Explaining

As the stories and artwork and reading and writing started to take on some sort of shape, some sort of form, I faced the question of citation. Citation is a crucial part of scholarship, and it's easy in some cases: academic journal articles, books, government websites.

But what about all of the *other* things I learn from and through? Learning comes through all sorts of “non-academic” reading, including blog posts, poetry, narrative non-fiction, non-fiction, and fiction; videos, films, documentaries, music, and other forms of artwork; conversations with others—including overheard snippets of conversation gathered from public locations; the land, including plants, animals, seasons, water, and air; dreams and nightmares; artistic materials I work with, such as my camera, film, fabric, wool, felting needles, my sewing machine, and my spindles.

Citing these materials and sources—many of which would not be considered appropriate in an academic paper—is crucial. As Chapman and Sawchuk remind us, “intuitive ways of knowing may underpin all discovery, yet, this is often systemically unacknowledged within traditional research paradigms” (2012, p. 12). Learning from a variety of sources is part of community and reciprocity. I'm in relationship with these sources and materials, and pretending otherwise, or limiting my academic citations is dishonest.

This personal knowledge is usually impossible to cite. In those cases, I try to explain. I try to share my thinking, drawing a thread from X to Y to Z so the reader can follow along. I am most interested in the processes people go through when they make art

or research or write or problem solve, so sharing my own process seems like a natural choice.

Yet, most of these “uncitable moments” occurred when I was making art, and explaining the thinking about my artwork raised a new set of ethical concerns. As Sontag says, “In most modern instances, interpretation [of art] amounts to the philistine refusal to leave the work of art alone” (Sontag, 1966, p. 5). More recently, Kimmerer reminds us to “really let them [artwork] speak for themselves, and speak to one another” (Kimmerer via Minneapolis Institute of Arts, 2020).

The desire to: acknowledge ways of knowing that are frequently ignored in academic work; think deeply about process; honor relationships and agency of non-human beings; and let artwork and stories speak for themselves has been a site of ongoing tension for me. I suspect this will continue to be a source of exploration throughout my future research work.

Making Rhetorical Moves

Of course, there’s also the issue of the reader. I need to consider what my reader needs and how they should be in relationship (Kimmerer, 2015) with this dissertation. Reading and writing are social acts, and you, Reader, have an active role in making meaning of this work. A/r/tography makes meaning not through text alone, but through the encounters that take place between reader, writer, and text/images. (Springgay & Irwin, 2005). In this section, I explore some of the rhetorical and aesthetic moves I made in order to create a dissertation that felt authentic and ethical to the work, how I structured this dissertation, and how I intend for you to interact with it.

Hermit Crabs and Braided (Interrupted) Narratives

The stories in this dissertation were written as stand-alone stories, so each story takes on its own voice, form, and content. I haven't attempted to use one consistent voice or structure across all of the stories. Some of the stories are very straightforward. Others use flashbacks or interrupted narratives. Some of the stories include photographs. These photos may act to illustrate the text, or complement the text, or they may act as breaks between sections of text. Sometimes I've captioned photos, and other times I haven't. This choice—to do what was needed for each individual story—was intentional (how I approached the inclusion of photographs in this dissertation was heavily influenced by Harper, 2003, 2004; Holm, 2014; Marín & Roldán, 2010; and Vellanski & Davesar, 2020).

As I wrote, I drew on two forms of creative non-fiction described in Brenda Miller's book *A Braided Heart* (2021): the hermit crab essay and the braided essay.

Much like a hermit crab uses the shell from another creature to protect its soft abdomen, a hermit crab essay borrows the form and style from another genre to provide the writer with a level of protection. For example, writers may use rejection letters (Miller, 2013b), a multiple-choice test (Wallace, 2018), or a crossword puzzle (Easter, 2018) to tell a story. Hermit crab forms can provide protection to the writer by giving them a framework to write about sensitive or emotional topics; at the same time, the stolen genre can help shape, reveal, and illuminate meaning that might otherwise remain hidden in a traditional narrative essay (Miller & Paola, 2019).

In this dissertation, I use doctor's charting notes as a hermit crab shell. These notes, which are fashioned off of and heavily borrow the language from the notes I could

see in my medical chart, gave me space to address issues that came up during active treatment.

I've also tried to "braid" my work together (Miller, 2021; Miller & Paola, 2019). In a braided essay, multiple strands weave around each other to form a braided narrative, and outside voices add meaning to the writer's voice (Miller & Paola, 2019). Of the braided essay, Miller (2021) says:

The braided essay [...] offers a slightly different form of armor when venturing into dangerous or risky territory. In these essays, strands form, disappear, and reappear at strategic moments, creating a lively, interactive structure in which one's personal material now can find the way its threads interweave with material the world offers. The personal and the more "impersonal" can play off one another to create new meaning. (p. 68)

In this braided dissertation, I wove together stories, artwork, and charting notes to make sense of the wreckage a cancer diagnosis left behind. And I wove in the voices of academics, artists, musicians, friends, and family members.

I did this in an effort to add more texture and meaning to this work, but a braided narrative also allowed me to tell the "interrupted narrative" (Frank, 2013) that my cancer diagnosis caused. A braided narrative let me interrupt my own narrative similar to the way the breast cancer diagnosis interrupted—and continues to interrupt—my own personal narratives.

This interrupted narration style shows up in this dissertation in several ways. Some interruptions are explicit, such as the Artistic Interruptions that pepper this dissertation. But this interrupted and braided narrative shows up throughout this

dissertation in more subtle ways, too. Photos interrupt short stories in chapter 6. In Chapters 1 and 8, thoughts are picked up and dropped, interrupted by quotes from other people.

I've approached this work as an artist first and foremost. The stories and artwork come first. I don't mean that I created them first—as described above, this was a messy, intertwined, relational process. I mean that ethically, I've prioritized artistic and aesthetic decisions involved in creating stories and artwork over conventional research moves such as incorporating research literature, thinking with theory, and interpretation.

Writing compelling stories, creating meaningful artwork, and letting these things “sing” were the most important things I could do, according to my philosophical and ethical beliefs.

But once I decided on creating a braided narrative, I had to decide how to bring in the voice of other researchers. I also knew I needed to show I was familiar with the literature, could think with theory, could interpret the stories, and could make ethical research decisions. And of course, I also wanted to prioritize the stories and artwork.

What I Didn't Do; What I Did

I considered starting each chapter with a story, then inserting a division line, then providing theory, literature, and interpretations of the story. I also considered clustering stories together and then doing separate chapters for analysis and interpretation. For example, I could have presented all of the stories about my life before cancer and then presented the literature, theorizing, and interpretation in a large chunk (see Boehm-Turner, 2020 for an example). I considered weaving theory and analysis throughout stories (see Quillien, 2019; Sameshima, 2007).

I rejected these ideas because each of them risked making the research literature, theory, and interpretation seem as important as the stories and artwork. I was concerned that no matter how often I said I was privileging stories and artwork, they would be deemed less important.

I considered writing stories and using footnotes for the literature, theory, and interpretation. I considered how text boxes, italics, or parallel texts would work. These choices have been used as a way to resist the norms and expectations in conventional academic work, and to encourage the reader to make their own decisions about how to read the text (see Balbuski, 2017; Beaton, 2014; Beaton Zirps, 2016; Boehm-Turner, 2020; Quillien, 2019; Sterner, 2019 for examples).

Ultimately, I rejected these ideas for aesthetic reasons, and because I didn't want to burden the reader with reading decisions. I wanted them to be able to sink into the stories, at least for as long as it takes to read each one.

What I have done is present each story—and I use the term “story” loosely, inclusive of charting notes, artistic pieces, Facebook posts, etc.—without any explanation or interpretation. Each story has “room to breathe” (Frank, 2012); the reader also has room to make their own connections to, and ask their own questions about, each story. At the end of each chapter, I've included endnotes. In this space—which is separate from the main text and written in a different font—I incorporate literature, theory, and interpretation into the dissertation as a whole.

I recognize that endnotes create their own set of reading considerations. The primary problem for me was that endnotes often read as disjointed. To avoid this, I've attempted to make each endnote a complete unit, but I've also tried to create an endnote

order where one note flows into the next. I've made every effort to structure the endnotes so they can be read in order, after reading the story. Although this hasn't been possible in every instance, I think I've made it so that the reader won't have to flip back and forth repeatedly to see what part of the story the endnote is connected to.

I've also included a few footnotes. I use footnotes to interrupt the text, and my hope is that the reader embraces the interruption.

I created the dissertation this way so that the stories and artwork are foregrounded and privileged. Literature, theory, and interpretation are set in the background. I am consciously and purposely *emphasizing* the importance of stories and *de-emphasizing* the importance of interpretation. This is my act of resistance against conventional academic writing; it's also how I ethically enact my research in a way that aligns with my onto-epistemological beliefs that making and experiencing art are ways of making sense of the world.

Dissertation Overview

I am being transparent about my writing process in an effort to build a relationship of care and reciprocity with my reader. Academic writing is usually structured so that a reader can skip from section to section in search of specific information (Sword, 2012). This braided dissertation calls for you to read this dissertation differently; I ask you to treat this dissertation as a holistic piece of writing that must be read through completely. Still, I want to give you an overview of what you can expect from the rest of this work.

Stories, and experiences of illness, are shaped by culture. In the next chapter (Contextualizing Breast Cancer Narratives) I provide a brief overview of American breast

cancer culture and the ways stories of illness are told. This chapter highlights the work I think a reader should know before reading the stories themselves. It is the most conventional chapter in this dissertation, and it rounds out Part I (Context) of the dissertation. I hope this literature review will help the reader think through illness and breast cancer narratives as they read the rest of the dissertation.

A serious illness changes how you see your past, present, and future (Bury, 2001; Frank, 2013), and I explore these three things in Part II (The Body) of this dissertation.

In Chapter 4 (Before), I re-examine the stories I'd told about my past, before cancer. Drawing on stories from throughout my life I reconsider why I chose teaching as a career path; I also consider why I *didn't* choose other paths.

Chapter 5 (Active Treatment) is about the immediate aftermath of my breast cancer diagnosis. Told primarily through medical chart notes, I examine some of the "active treatments" I went through; instead of providing a detailed account of what happened, I let you fill in gaps and make inferences. In this section, I also discuss the emotions that arose as I found myself with an identity I never wanted: "cancer survivor."

In Chapter 6 (Rest), I visit Pacem in Terris, a Catholic hermitage retreat center in Minnesota. Although Pacem in Terris was not part of my "active treatments," this part of my healing felt the most important to me personally. This was the only part of my treatments that I felt like I had full control over. I chose to go, I decided for how long, and every day, every single thing I did was under my control for the first time in nearly six months.

In Chapter 7 (Recovery), I briefly turn toward the future. This chapter shows how I continue to explore healing the body and self: the "body-self" (Frank, 2013).

Finally, dissertations are expected to have conclusions. In Part III (~~Closure~~ Composure), I explain why this one doesn't—can't, actually—have a conclusion. Instead of providing any grand answers in Chapter 8 (There Is No Conclusion), I leave the reader with an ambiguous ending.

My Dream Reader

Lastly, I'd like to discuss the question of audience. When I taught my fifth-grade students about writing for an audience, they'd stare at me blankly. Since I was their teacher, I was their audience, obviously. "No," I'd explain, "forget about me. Pretend I don't exist. Who would be your dream reader for this story?"

Who am I writing this for? The obvious audience for a dissertation is "my committee," and more broadly "peers, other researchers." But none of those people are my Dream Reader.

My Dream Reader is the doctoral student who finds their life in complete upheaval after a major event—one their peers haven't had to experience. I'm writing for the student who wonders how they can finish their dissertation when everything around them has changed. I'm writing for the doctoral candidate who isn't sure if they should stay in their program or quit.

I'm writing for the student who is looking for a bit of hope, some proof that they too can get through *this* after going through *that*.

Endnotes

¹ Researchers in Colonial Williamsburg found a rat's nest in the wall of the house an enslaved family lived in. In that nest they found a scrap of newspaper dating back to 1833, as well as part of a reading primer page. This was a huge find, because learning to read or write was illegal for enslaved people at the time (Kessler, 2020).

² These terms are, in part, influenced by geography. Yet, some scholars also see those terms as having important, granular distinctions. I use the phrase arts-based research as an encompassing term.

³ I find it interesting that it was a drum—a non-living thing—that helped me understand Kimmerer's idea. But as she said in the same talk (Minneapolis Institute of Art, 2020) at 1:01:08:

I don't know that I got to say that when I was talking about it, but this notion of the honorable harvest, which comes from harvesting the land, I think is applicable to everything, *everything*. Everything in our lives comes from the earth, *everything*. Even though that—that chain may be remote and hard to see, that's where our attention comes in, is to be able to pay attention, to know that this thing that you've been sold as a thing is in fact a gift from the earth. And, and manifesting that in an art setting, ahh [*sigh*]. I think that would be breathtaking. (1:01:08–1:01:58)

Everything comes from the land.

⁴ At first, Kimmerer's use of "in relationship" and "make relationship" confused me. I wanted to say "in a relationship" or "make a relationship." After thinking about these phrases, I realized that using the article "a" turns "relationship" into a noun. It becomes a *thing*. The way that Kimmerer speaks, using "in relationship" or "make relationship," makes "relationship" a verb. It becomes an *action*. This is a striking difference.

Endnotes—continued

⁵ Dualisms, such as the Cartesian mind-body split are deeply ingrained in our culture, and it's impossible to pretend they no longer influence us (Hopwood & Paulson, 2012).

⁶ Written documents don't give access to authentic experiences—they are always mediated; this includes diaries, which record only what the writer chooses to include (Reissman, 2015).

⁷ In her seminal work, *Illness as Metaphor*, Sontag (1978) compared the historical perception of cancer and tuberculosis. She says, "TB patients may see their X-rays or even possess them [...] Cancer patients don't look at their biopsies" (p. 12).

That may have been true forty years ago, but only months before my diagnosis, the 21st Century Cures Act made it so all patients in the United States had access to their medical information in their electronic records (Blease et al., 2021).

I could read all my charting notes, my test results, and my lab results in MyChart. At my biopsy, I asked if I could have my mammogram images. "I'm an artist," I said, "I might want to use them in my art." A few minutes later, I had three CDs in my hands—with all of my mammogram and ultrasound images.

I didn't get to see my core needle biopsy under a microscope, but on the ultrasound images, I can see the biopsy needle entering my breast, sampling tissue, and being removed. I can see the metal marker they left in my breast at the site of the tumor—it looks like a spaceship.

From my surgical pathology report, I know that my tumor tested high in nuclear positivity for estrogen receptors (95%) and even higher for progesterone receptors (99%). I know the tumor's exact measurements, and exactly how wide the "margins" of healthy, non-cancerous tissue around it were. I know the "specimen" that was surgically removed from my breast was stained a different color on each side and sliced into nine pieces.

The spaceship was in slice #4.

Endnotes—continued

⁸ This unfettered access to my chart came with its own problems. I couldn't stop researching my breast cancer. As I said to my doctors—all of them—when they begged me to stop using Dr. Google, “I have access to my medical chart, Dr. Google, institutional library access to every article ever written about breast cancer, and the false belief that I can read and understand them since I'm a doctoral candidate. It's the worst of all worlds.”

We'd chuckle about it, but it was an awful habit. And perhaps it was an occupational hazard, because Cheung (2019) found her research participants, all doctoral students who had been diagnosed with serious illnesses during their doctoral programs, engaged in the same behavior. She writes:

To cope with the uncertainties stemming from their diagnoses, many participants engaged in a strategy that apparently took advantage of their occupational skills: they plumbed deep into reading about their medical conditions, including possible causes, treatments, and medical advancements. In particular, participants read scholarly and peer-reviewed literature, though not exclusively. (p. 85)

Some students found this empowering behavior, but it could also be detrimental, “especially when it involved internet research” (Cheung, 2019, p. 86).

I was researching in an effort to feel better, but it only made me more anxious. My friend Cynthia, who (somehow!) wasn't lured in by Dr. Google's charms, told me I was trying to get answers that the internet didn't have for me.

She was right.

I wanted to find assurance that my cancer would never come back, and I wanted to know what I could do—what I could control—to make that happen. My doctors, and Dr. Google, agreed that I should eat lots of fruits and veggies and get exercise. But beyond that, my medical team could only give me highly educated guesses on whether or not the cancer would return; I was never going to be able to find the answer to my question on the internet.

Endnotes—continued

After a horrible Saturday night when I mistakenly thought another tumor had been found—it was a benign “incidental” finding as part of a routine non-breast related screening—I had my chart adjusted so lab and test results weren’t released until a provider had reviewed them first. This was good for me (because I wasn’t Googling terms I didn’t know or understand), good for my doctors (who wanted to interpret results for me), and good for my relationships with friends and family members (who were supportive of me, but also frustrated at how I could manage to wind myself up before even hearing from a doctor.)

Still, I couldn’t fully resist the allure of doing research. But for research to be beneficial, I needed to tamp down my academic ego, and become much more realistic about what I could read and understand. Scientific articles about the molecular subtypes of breast cancer? No, at least not without a lot of interpretation from my medical team. General quantitative articles? Accessible, with some caveats. Qualitative, narrative, and sociological articles about women’s experiences with breast cancer? Ah, absolutely, yes.

What I only realized after digging into the narrative research is that I wasn’t only questioning if my cancer would come back. I was questioning how I was supposed to live after being diagnosed with cancer. I was looking for examples of other people who had gone before me. I was looking for proof that eventually cancer would no longer feel like the most important thing in my life.

⁹ “Like all narrators, I made choices about what to include, what to emphasise, what to ignore [...] I recognise these choices are significant ones” (Reissman, 2015, p. 1056).

¹⁰ Making decisions about what to include, or not, in this dissertation also helped me feel a sense of control. As Reissman (2015) says about writing about illness in an academic setting, “Omissions are one way to exercise control over the uncontrollable: private confessions are another” (p. 1062).

Endnotes—continued

¹¹ One issue that frequently comes up in narrative research is the issue of truth. What if the storyteller is lying? Arthur Frank (2013) beautifully describes my stance on this issue:

The stories we tell about our lives are not necessarily those lives as they were lived, but these stories become our experiences of those lives. A published narrative of an illness is not the illness itself, but it can become the experience of the illness. The social scientific notion of reliability—getting the same answer to the same question at different times—does not fit here. Life moves on, stories change with that movement, and experience changes. Stories are true to the flux of experience, and the story affects the directions of that flux.

If calling stories true requires some category of stories called false, I confess to being unsure what a “false” personal account would be. I have read personal accounts I considered evasive, but that evasion *was* their truth. The more reconstructed the story, the more powerful the truth of the *desire* for what is being told, as the correct version of what was lived. Hearing the desire in the story takes me back to the need for a different level of attention to stories. (p. 22)

¹² “Deep inquiry into our lives requires a/r/tographers to make meaning through their senses, bodies, minds, and emotions. It is a research process that is fluid, uncertain, and temporal” (Springgay & Irwin, 2005, p. 908).

¹³ And I moved. I took a lot of walks, I stretched, I lifted weights, I gardened, I chopped vegetables, I picked grapes, I hiked. These activities reminded me I’m not a head attached to a body, but a being moving through and with the world.

Chapter 3: Breast Cancer Culture and Illness Narratives

Individuals experience illness, yet illness is not only an individual experience, but also a cultural one (Bury, 2001; Ehrenreich, 2001; Frank, 2013, 2016; Segal, 2007; Sulik, 2011). Experiences, identities, and stories are intertwined with cultural norms, expectations, and constructs (Clandinin & Connelly, 2000; Holland et al., 1998). This is also true for disease and illness.¹⁴ Disease and illness are culturally constructed (Couser, 1997) and the stories we tell about illness generally, and breast cancer specifically, are culturally constructed (Bury, 2001; Couser, 1997; Ehrenreich, 2001; Frank, 2013; Sulik, 2011).

In this chapter, I will examine American breast cancer culture, specifically, as well as how we talk about illness generally. I draw primarily from the work of medical sociologists Gayle Sulik and Arthur Frank. These are the primary theories and concepts I worked with as I thought through my cancer experience and cancer stories, and I reference them frequently in the remainder of the dissertation.

In the first part of this chapter, I will first give a very brief history of how breast cancer, and women with breast cancer, have been viewed in American society over the past two centuries. Then I will discuss the rise of “pink ribbon culture” (Sulik, 2011) before considering what makes a woman a “good breast cancer patient.” (Spoiler: Optimism is a key ingredient.)

In the second part of this chapter, I will shift my focus to illness narratives (Frank, 2013). I will explore the body-self’s need to tell stories during and after illness. Then I will explore the three common illness narratives (restitution narratives, chaos narratives,

and quest narratives) before considering how these illness narratives function culturally. I will also explore the benefits and drawbacks of each type of narrative.

Next, I will consider the individual, collective, and cultural work that illness narratives do. I will also examine how the generic subgenre of the breast cancer narrative makes it difficult for women to tell stories that counter pink ribbon culture.

Finally, I will argue for the importance of being a witness.

A History of Breast Cancer in the United States

Historically, breast cancer has been deemed a private matter (Sulik, 2011). Victorian American culture saw breast cancer as related to a woman's feminine fragility and her personal failures. As such, breast cancer was hidden away in the private sphere that women belonged to according to the norms of "proper" Victorian society (Sulik, 2011).

In the 1930s, the Women's Field Army of the American Society for the Control of Cancer was created (Sulik, 2011). The Women's Field Army recruited women, who were organized into a vertical structure like that of the military, into volunteer positions. Their mission? To encourage others to get regular breast cancer screenings and to take part in the conventional breast cancer treatment of the time (Sulik, 2011).¹⁵

As World War II ended, the American Society for the Control of Cancer became the American Cancer Society, and the organization relied heavily on war metaphors to describe the fight against cancer. This language forced the general public to choose sides, and women who were bad soldiers—who didn't "aggressively us[e] the weaponry of breast examination and medical science"—were blamed for their cancer (Sulik, 2011, p. 74). Throughout this time period, and the next several decades, women who did get

breast cancer were expected to remain as visually pleasing as possible, and maintain a “normal” looking figure, even after being subjected to the Halsted radical mastectomy (Sulik, 2011).¹⁶

The 1970s brought change with the women’s, patients’, and consumers’ rights movements. These movements resulted in increased medical knowledge for lay people, increased patient advocacy and empowerment, and decreased isolation as patients and cancer survivors shared information with each other (Sulik, 2011). The women’s health movement also tried to remove the stigma of breast cancer and bring it into the public eye. Notably, this was a patient-led movement, and patients were trying to connect with, and make life better, for other patients (Sulik, 2011). Changing attitudes about breast cancer was a steep hill to climb. “When post-mastectomy patients first proposed meeting in support groups in the mid-1970s, the American Cancer Society responded with a firm and fatherly ‘no’ ” (Ehrenreich, 2001, p. 47).¹⁷

For breast cancer, this was a feminist-led movement (Ehrenreich, 2001; Sulik, 2011). Unsurprisingly, this provoked a backlash.

During the 1970s, in response to the women’s health movement, “traditional feminine image and self-presentation became a touchstone for helping women to face breast cancer with greater confidence”; instead of viewing women as frail, “traditional femininity would be cast as an empowering coping strategy” (Sulik, 2011, p. 39). Wigs,

makeup, and prosthetics were used to create the socially desired appearance, and women who didn't conform were harshly judged.^b

During this time period, high society became an important part of the breast cancer movement (Sulik, 2011). Teas, luncheons, fashion show, galas, and balls were frequent methods of fundraising, and the public image of breast cancer was white, upper-class, and heterosexual. These breast cancer survivors created a non-threatening public image (Sulik, 2011). (Surely, these women wore their lambswool prosthetics while at the golf club.)

By the 1990s, the breast cancer movement had become more public, and with publicity came clout (Ehrenreich, 2001; Sulik, 2011). Non-profit organizations, and eventually corporate entities, became the center of the breast cancer movement (Sulik, 2011). Breast cancer organizations, coalitions, and networks tried to become more racially diverse, although they still leaned into heterosexual and upper-class imagery.¹⁸ Breast cancer culture started becoming more homogenized as larger organizations swallowed smaller, local organizations. Although patients and survivors had a seat at the

^b Audre Lorde's powerful book *The Cancer Journals* (1980/2020) is an excellent introduction to how women were expected to behave during this time. Lorde writes about her life after a breast cancer diagnosis and mastectomy. She discusses the expectation, from her doctors and nurses, that she wear a prosthesis whether she wanted to or not. When she refused to wear a fake pink lambswool breast, she was scolded and told that her body was upsetting other people. "The emphasis upon wearing a prosthesis is a way of avoiding having women come to terms with their own pain and loss, and thereby, with their own strength" (Lorde, 1980, p. 41).

table, the breast cancer movement was no longer centered around patients and survivors (Kaiser, 2008; Sulik, 2011). “The movement become pro-woman, but not pro-feminism” (Kaiser, 2008, p. 79).

The 1990s saw a dramatic rise in breast cancer awareness by the public and by corporations. Breast cancer became reclassified as an epidemic (Sulik, 2011), and the pink ribbon was invented. October was fashioned as Pink Month, Pink October, Pinktober, or Breast Cancer Awareness Month. Corporations also became involved in breast cancer philanthropy; supporting breast cancer was a way for corporations to signal their support for women (Ehrenreich, 2001; Sulik, 2011) without actually being feminist (Ehrenreich, 2001).¹⁹

Since the 1990s, breast cancer culture—what Sulik (2011) calls *pink ribbon culture*—has developed into a well-oiled machine, one that has become a clear part of American society. Built on the back of the breast cancer movement of the 1970s and 1980s, pink ribbon culture is “sustained by mass publicity, the cancer industry, corporate and political interests, and a steady revenue stream” (Sulik, 2011, p. 62). Feminists want to know the *causes* of breast cancer so they can *prevent* it (Ehrenreich, 2001; Lorde, 1980/2000; Sulik, 2011), but pink ribbon culture is not interested in identifying causes.

Even though the breast cancer movement was started by feminists, “aside from the dilute sisterhood of the cyber (and actual) support groups, there is nothing very feminist—in an ideological or activist sense—about the mainstream of breast cancer culture today” (Ehrenreich, 2001, p. 47). In contrast to the feminist call for prevention and addressing environmental and causal issues, pink ribbon culture claims eradication of breast cancer will come through consumption, capitalism, and the collection of money

from corporations²⁰ that traffic in carcinogens.²¹ In pink ribbon culture, people who want to “do something” about breast cancer are encouraged to “get mammograms, participate in pink programs, and buy pink consumer goods” (Sulik, 2011, p. 63).^c

The Good Breast Cancer Patient (and Unrelenting Optimism)

Within pink ribbon culture, there is also a specific way to be a good, acceptable breast cancer survivor, and to tell stories of breast cancer (Ehrenreich, 2001; Flanagan, 2021; Frank, 2016; Sulik, 2011). Whole books have been written about this (e.g., Sulik, 2011), but in short, breast cancer survivors need to be *she-roes* (“she heroes”) (Sulik, 2011). Early detection through mammograms²² is a key component of breast cancer awareness and pink ribbon culture; good breast cancer she-roes “behave” and trust science, so their cancer should have been caught “early.” Breast cancer survivors should be brave warriors who muster up courage and strength to fight breast cancer. These

^c Barbara Ehrenreich’s article “Welcome to Cancerland” (2001) provides an excellent introduction to pink ribbon culture. After being diagnosed with breast cancer, Ehrenreich muses on both the childish pinkness and the consumerism that infuses the breast cancer spaces she’s expected to participate in. After listing over a dozen pink breast cancer awareness things to buy, Ehrenreich says: “‘Awareness’ beats secrecy and stigma of course, but I can’t help noticing that the existential space in which a friend has earnestly advised me to ‘confront [my mortality]’ bears a striking resemblance to the mall” (2001, p. 46).

See Segal (2007) for a brief discussion about how Ehrenreich’s “renegade story” failed to have the impact she wanted it to have.

women must treat the whole thing with lightheartedness and humor—and hopefully, they’ll look good doing it (Sulik, 2011).^d

Breast cancer survivorship is also governed by three “feelings rules” (Sulik, 2011), and the good breast cancer survivor will feel a blend of guilt, selfishness, and—most importantly—optimism.

Breast cancer survivors should feel guilt if they don’t live up to pink ribbon culture’s heroic survivor ideal, but they should also feel guilt for losing their feminine body, and for disrupting gender roles (Sulik, 2001; see Chapter 5 of this dissertation for further discussion about survivor’s guilt).

Breast cancer survivors also need to be selfish in the right way. They should be selfish enough to take care of their health, certainly, but they should also show an ethic of care for others, and they should be sure to manage other people’s emotions and make an effort to not upset or worry other people. This selfish behavior can be constructed as a rational (and therefore masculine) coping method, or can be a confession of violating the gender norms of being a woman (Sulik, 2011; see Chapter 6 for further discussion about gender norms in breast cancer survivorship).

Finally, breast cancer survivors must be optimistic (Sulik, 2011).

^d “Cancer is a rare and still scandalous subject for poetry; and it seems unimaginable to aestheticize the disease,” Sontag wrote in 1978 (p. 20). Yet, with its emphasis on pink clothing, makeup, head scarves, lipstick, and the attractive breast cancer patient, pink ribbon culture has attempted, if not managed, to make breast cancer a “sexy” disease.

Optimism is the most important trait the cancer hero brings with them. “She-heroes successfully display optimism by normalizing their experiences, avoiding complaints, and using breast cancer as a catalyst for empowerment” (Sulik, 2011, p. 231).

Women with breast cancer expected to be grateful for being alive, and must tamp down complaints (Ueland, Dysvik, Hemberg et al., 2021; Ueland, Dysvik, Rørtveit et al., 2021). Women should also view cancer as an opportunity to become a better person: A better wife, a better mom, a better friend, a better daughter, a better sister. The implication is that a woman before breast cancer isn’t good enough, and that breast cancer will make her better—for *other* people (Sulik, 2011). But in order to reach this ideal, she must be optimistic.

The she-ro model of survivorship “creates the impression that diagnosed women should feel proud of their experience and use it for transformative purposes. Pride and transformation require optimism, the cornerstone of survivorship” (Sulik, 2011, p. 16).^e

This relentless optimism does cultural work too. “The effect of this relentless brightsiding is to transform breast cancer into a rite of passage—not an injustice or a tragedy to rail against, but a normal marker in the life cycle, like menopause or graying hair” (Ehrenreich, 2001, p. 49).

^e Sontag (1978) described cancer as: “Cancer—a disease which nobody has managed to glamorize” (Sontag, 1978, p. 35). Again, pink ribbon culture has attempted to, if not managed to, glamorize breast cancer.

A woman who fails to display never-ending optimism^f is a bad cancer survivor. In breast cancer culture, “cheerfulness is more or less mandatory, dissent a kind of treason” (Ehrenreich, 2001, p. 50).^g

As we will see later, this expectation for optimism also creeps into the way women are expected to share stories about breast cancer.

Arthur Frank’s Illness Narratives

The stories we tell about breast cancer are situated within the larger context of stories we tell about illness. Arthur Frank, author of the seminal work *The Wounded Storyteller* (2013), is best known for his work around illness narratives. A sociologist who was always interested in how people could live an ethical life, Frank turned his attention to illness narratives after he was treated for prostate cancer.

^f Caitlin Flanagan’s essay “I’ll Tell You the Secret of Cancer” (2021) explores the public expectation that cancer survivors have cheerful, upbeat, positive attitudes. Her essay was published less than two weeks after my surgery, and when I read it, I felt like someone understood the pressure I was feeling to be upbeat. Flanagan writes: “When I began to understand that attitude doesn’t have anything to do with survival, I felt myself coming up out of deep water. I didn’t cause my cancer by having a bad attitude, and I wasn’t going to cure it by having a good one” (paragraph 22).

^g In 1885, a doctor advised “those who have apparently benign tumors in the breast of the advantage of being cheerful” (Sontag, 1978). Sontag writes, “Today [1970s], this would be regarded as encouraging the sort of emotional dissociation now thought to predispose people to cancer” (p. 53). Much has changed in just forty years. Now, women with *malignant* tumors in the breast are encouraged and expected to be optimistic.

To better understand Frank's work, it's important to contextualize the time period his work was written in. *The Wounded Storyteller* (2013) was originally published in 1995. The patient's, women's, and consumer's rights movements had only started two decades before (Sulik, 2011). The shared decision-making model of medicine, where doctors and patients work together to make treatment decisions, was still in its infancy and hadn't been widely adopted (Elwyn et al., 2012). The red AIDS awareness ribbon had been invented only four years earlier (Wrench, 2003), with the pink breast cancer ribbon following a year later (Fernandez, 1998).

Perhaps most indicative with regard to Frank's work, the Health Insurance Portability and Accountability Act of 1996 (commonly called HIPAA) wasn't in effect, allowing patient records to be disclosed without patient permission (Moore & Frye, 2019). Although Frank's work (2013) focuses on patients' stories, the book as a whole implicitly acts as a critique of the medical profession and the way they controlled stories of illness. In the preface to the 2013 edition, he writes, "My intent was to write a book that kept health-care workers generally, and physicians specifically, in the background. Even criticizing doctors makes them central" (p. xvi). Ultimately, Frank argues that patients must be in charge of their own stories.

Frank (2013) uses the phrase *medical colonization* to describe a situation where medical providers need the bodies of ill people to conduct their work, but refuse to acknowledge the individual within those bodies. As Frank saw it, medical providers were able to tell the stories of their patients; patients didn't get their own voice. According to Frank, people who are experiencing illness or disease of some sort need to tell their own stories in their own voices to reclaim their lives from the shock of a serious diagnosis, as

well as the loss of control that comes with illness. “Turning illness into a story is a kind of meta-control,” he writes (2013, p. 30). Frank argues patients need to be able to tell stories that go beyond what technical, medical language allows for. Frank believes that telling stories is important practically, existentially, and communally.

Frank (2013) uses the phrase “remission society” to refer to people who have faced serious illness. Members of the remission society, people who have visited or remain in Sontag’s (1978) “kingdom of the sick,” have returned to a “normal” life, “but obligations are never again what used to be normal” (Frank, 2013, p. 9).

Members of the remission society tell stories about their illness and their lives, and Frank (2013) is interested in how these stories are part of an ethical stance of living. In his book, Frank explores three key concepts related to illness narratives. First, he explains why ill people (his phrase) need to tell stories; second, he explores how these stories of illness are embodied and told by and through the body; finally, he considers which stories people share, and how those stories are told. An illness story is a story of the body and the spirit. It’s a story of the *body-self* (Frank, 2013). The body and the self both need to tell stories.

The Body’s Need to Tell Stories: Four Problems of Embodiment

First, Frank (2013) addresses the body’s need to tell stories. He argues that ill bodies face four action-oriented problems of embodiment. I reference these problems of embodiment throughout this dissertation. I specify when I most grappled with these issues, and I discuss how storytelling and artmaking helped me tackle these problems of embodiment.

The first problem of embodiment is *control* (Frank, 2013). Can I control my body, or depend on it to be reliable and act in a predictable manner? What do I do when my body is subject to forces that can't be controlled? "Illness is about learning to live with loss of control" (Frank, 2013, p. 30).

The second problem is *body-relatedness* (Frank, 2013). How do I relate to my own body? Do I view my body as separate from the essence that makes me *me*? Do I have a body or am I a body? The way that medicine is practiced, with its emphasis on measurable numbers and metrics, can also add to a feeling of being separated from one's own body. Drawing on the work of Zygmunt Bauman, Frank points out the inherent contradiction of the body: all bodies will eventually die. "As long as the body is healthy and mortality is beyond the horizon of consciousness, associating the self with the body comes easily. The recognition of mortality complicates this" (Frank, 2013, p. 34).²³

The third problem of embodiment is *other-relatedness* (Frank, 2013). Do I view my body as isolated and alone, or do I see myself as existing with and for others? My illness is mine alone, but there have been people before me with the same illness, and there will be people after me with the same illness. How do I interact with them? How do I interact with healthy friends and family members?

Finally, there is the issue of *desire* (Frank, 2013). "What do I *want*, and how is this desire expressed *for* my body, *with* my body, and *through* my body?" (Frank, 2013, p. 37, emphasis in original). Defining desire as "wanting more," Frank says that bodies (especially ill ones) can experience a lack or loss of desire or can continue to produce desire. But illness can also bring along with it a greater exploration of desires. Drawing

on the work of Anatole Broyard, Frank says serious illness can be “like a great permission” (Frank, 2013, p. 39).²⁴

People react to these four problems of embodiment in a variety of ways (Frank, 2013). For example, one person may control their body through diet and exercise in an effort to regain predictability. Another person might respond to desire through increased consumption of goods. Another might unleash rage and anger onto others. Or people may experience a great desire to connect with others.

Although I’ve presented these reactions with either-or extremes for clarity, the ways people grapple with and respond to these problems of embodiment are complex and varied. How people react is in flux and falls along a continuum (Frank, 2013).

The Self’s Need to Tell Stories: Narrative Wreckage

The body lives in and through stories, and illness stories are not just about the body but told with and through the body. The way that an ill body grapples with these problems of embodiment is one way the body tells stories (Frank, 2013).

The ill *self*—however you view that in relation to the *body*—also calls for stories in two ways (Frank, 2013). There is an external, immediate demand for stories; someone calls and asks how the surgery went or what the test results were. A doctor asks you (for the thirty-ninth time, it feels like) when your symptoms started, whether or not you need to discuss freezing eggs before a procedure, or how your skin is doing with radiation treatments.

Those are stories about the illness itself. But stories are also needed so that ill people can repair the *narrative wreckage* that a serious diagnosis or illness leaves behind (Frank, 2013). Narrative wreckage refers to the fact that the illness often destroys the

stories that people have told about their own lives, and their plans for the future, leaving people feeling like survivors of a shipwreck. Illness creates a rupture in a person's biographical sense of self (Bury, 2001): "The illness story is wrecked because its present is not what the past was supposed to lead up to, and the future is scarcely thinkable" (Frank, 2013, p. 55). The essay I opened this dissertation with, "My Easy Year," is a perfect example of how I found myself adrift in the immediate aftermath of my diagnosis.

People form their sense of selves through stories they tell (Clandinin & Connelly, 2001; Frank, 2013; Shields et al., 2015), and telling illness stories is a way of re-forming the self (Couser, 1997; Frank, 2013). Sharing illness narratives with others is one way for an individual to reaffirm who they are and that they still live and have a story to tell; the listener's willingness to listen affirms the teller's value and the importance of relationships (Frank, 2013).^h

After cancer treatment, cancer survivors need to relearn who they are; they must reconsider their character, their history, their roles (past and present), and their new identities (Yang et al., 2010). In order to make sense of the narrative wreckage, cancer survivor must be allowed to tell their own true stories after cancer treatment (Ueland, Dysvik, Rørtveit et al., 2021). "Stories have to *repair* the damage that illness has done to

^h "Every attempt I made to examine or question the possibility of a real integration of this experience into the totality of my life and my loving and my work, was ignored by this woman [a breast cancer survivor from a local volunteer organization], or uneasily glossed over by her as not looking at 'the bright side of things.' I felt outraged and insulted, and weak as I was, this left me feeling even more isolated than before" (Lorde, 1980/2020, p. 49).

the ill person's sense of where she is in life, and where she may be going" (Frank, 2013, p. 53).

Illness acts as a life interruption, and medical treatment is a series of life interruptions. Even if one is "in remission," life continues to be interrupted by illness (Frank, 2013). For example, at the time of drafting this paragraph, I feel like my life is medically in a (welcomed!) lull. Yet even in these slow months, I've been interrupted by a quarterly monitoring appointment with my medical oncologist, by prescription refills for medicine that helps reduce chances of my cancer returning, and by a phone call from a close family member who needed to update her family medical history before a mammogram. This interrupted life calls for new types of narratives, ones that aren't necessarily tidy or clean; Frank says that an illness story "faces a dual task. The narrative attempts to restore an order that the interruptions fragmented, but it must also tell the truth that interruptions will continue" (2013, p. 59).

Restitution, Chaos, and Quest: Types of Illness Narratives

Frank says that the stories people tell about illness, orally and in written form, tend to fall into three illness narrative types: restitution, chaos, and quest. Although one narrative type may be favored, illness stories usually have aspects of each of these narrative types.

*Restitution narratives*²⁵ are the ones we are expected to tell and hope to hear, culturally. They are "I got sick, I got treated, I'm better now." It's a back to normal, miracle of modern medicine story (Frank, 2013). Frank says that over-the-counter cold and flu medication commercials are a perfect example of a restitution narrative. These stories are ultimately about health. Even when restitution is difficult to come by, there's

always the *hope* that a new treatment or medication will appear. In the restitution narrative, the body can be restored and mortality can be held off for another day. Unsurprisingly, this narrative is used the least often by people who have chronic illnesses (Frank, 2013).

In restitution narratives, the doctor and patient can both be heroes, but the doctor—and modern science—is the primary hero. The story is “told *by* a self, but [is] not *about* a self” (Frank, 2013, p. 92). Restitution narratives are about modern medicine. But restitution isn’t guaranteed, and when the restitution narrative feels difficult to obtain, people may shift their attention to trying to figure out why they got sick.

*Chaos narratives*²⁶ are anti-narratives. In these narratives, the body is the primary storyteller, because narrative structures can’t be laid over the chaos narrative. The body-self telling the chaos narrative is trapped in the present and can’t see a way out of the chaos. When people do try to give these stories narrative structure, they often fall into an “and then... and then... and then...” pattern of storytelling, where one idea piles on top of another. The problems faced by someone in a chaos narrative seem insurmountable, and these problems are both physical and emotional. As Frank (2013) says, “emotional battering is fundamental to chaos” (p. 101).

When a person is living in a chaos narrative, they have no voice and can’t tell their own story; “the body-self that is immersed in a chaos lives out only in immediacy” (Frank, 2013, p. 109). Only after time has passed, and chaos has subsided, can the person put narrative order on their story.

People who use *quest narratives* to describe their medical experiences “meet suffering head on; they accept illness and seek to use it” (Frank, 2013, p. 115). Quest

narratives are the most frequently published medical narratives, although people can turn their quest narratives into embodied action, such as through volunteering for a cancer organization or changing their careers to something that fits the new person they've become. Notably, quest narratives are the only narrative where the teller is the hero and narrator of their own story (Frank, 2013).

Frank (2013) compares the quest narrative to Joseph Campbell's popular Hero's Journey. Generally speaking, in quest narratives the ill person has a call to action that they can't hide from (e.g., a diagnosis). After being challenged with a series of tests and trials (e.g., treatment), the hero returns, not as "normal," but as changed by the experience of illness. Finally, the hero seeks to share whatever they've learned with other people. According to Frank (2013), in an illness narrative, the hero becomes heroic not through acts of heroism such as slaying a dragon, but through acts of *perseverance*.

Quest stories can further be subdivided into three types, although there is considerable overlap between the subtypes (Frank, 2013). *Memoir* quests are the gentlest quest story. In these narratives, an autobiography is interrupted by illness; this illness is then accepted and incorporated into the writer's life. The primary insight in these stories is the acceptance and incorporation of illness in a lifetime.

Another type of quest narrative—one that is not gentle—is the *manifesto* (Frank, 2013). A manifesto quest narrative usually includes a call for political or social action. Audre Lorde's *The Cancer Journals* (1980/2020), first published in 1980, is one example of a manifesto quest narrative. In her book, Lorde demands that breast cancer patients be in charge of how they present themselves publicly and whether or not they choose to hide their mastectomy under a prosthesis. Authors of manifestos "do not want to go back to a

former state of health, which is often viewed as a naive illusion. They want to use suffering to move others forward with them” (Frank, 2013, p. 121).

The third quest type, *automythography*, also calls for some sort of change, although it’s usually at a personal level rather than a political one (Frank, 2013). In an automythography, the author has survived their medical issue but has also been reborn. According to Frank, these aren’t minor post-illness changes, but large, sweeping changes. This doesn’t mandate that the storyteller has become a completely different person; often, the storyteller has developed a deeper sense of who they’ve always been. The author of this narrative has reinvented themselves, or connected to who they have always been but have been able to enact in their life before an illness. Automythographies turn a “specific illness into a paradigm of universal conflicts and concerns” (Frank, 2013, p. 126).

Quest narratives are very common in American illness stories (Bury, 2001) and, as we will see later, American breast cancer narratives (Couser, 1997; Segal, 2007; Sulik, 2011). Yet, we should remember that a quest story does not mean the teller is thrilled to have quested. In fact, people who do find illness transformative in some way often feel a sense of ambivalence about it (Frank, 2013), although I’m not sure how often that ambivalence is clearly stated or heard.

How Culture Responds to Illness Narratives

Stories are cultural. Stories are shaped by culture, and stories help shape culture (Clandinin & Connelly, 2000; Couser, 1997; Frank, 2013) Because stories are cultural, Frank’s three illness narrative types have different impacts on culture. Each story has its benefits and limitations.

Restitution narratives are the ones that the majority of people feel most comfortable hearing. In fact, “medicine’s hope of restitution crowds out any other stories” (Frank, 2013, p. 83). Notably, pink ribbon culture, with its promised early detection, depends on restitution narratives (Sulik, 2011).

Restitution stories benefit the individuals who tell them, emotionally (Frank, 2013). They also benefit society, supporting the idea that the contingency of the body—the fact that our bodies are going to break down—can be fixed with modern science. Unlike the chaos or quest narratives, the restitution narrative allows the ill person to return to their normal pre-illness life. Of course, the limitation of the restitution narrative is that mortality will still come for each one of us in the end.

As individuals and as a society, chaos stories are difficult to listen to (Frank, 2013). These stories make listeners anxious. These stories remind us that chaos can come for any one of us. When people hear chaos stories, they often respond by describing how *they* would have a solution in the same situation. Listeners may also try to rush the teller into moving on, or getting over the chaos. “But attempting to push the person out of this wreckage only denies what is being experienced and compounds the chaos” (Frank, 2013, p. 110). Complicating matters, medical providers may diagnose a person trapped in a chaos narrative with depression. This diagnosis then allows doctors and society to replace a chaos narrative with a restitution narrative (Frank, 2013). As you can imagine, these responses don’t affirm the ill person telling the story, nor do they build a relationship of trust and respect between teller and listener.

The benefit of chaos narratives is that they expose the hubris in restitution and quest narratives. The limitation to the chaos narratives is that living in chaos is a miserable experience (Frank, 2013).

Finally, Frank (2013) makes it clear that he believes the quest narrative is the “best” way for an ill person to respond to their illness. He claims the person who tells a quest story is addressing the four problems of embodiment in an ideal manner. This person has accepted that mortality is certain. They live in relation with their own body, recognizing that the body-self is one whole, embodied being rather than a brain that simply has to be carried around by a body. Quest storytellers do not avoid discussion of their physical body in their writing, but “write of their own bodies, including pains and disfigurements, in sensuous detail” (Frank, 2013, p. 127). Finally, these authors cultivate a desire for connection. They reach out and share their stories in an attempt to connect with other people and possibly change their lives (Frank, 2013). Narratives are shaped by culture, and the questing storyteller has been affected by their culture’s narratives; but the listener also has a role of shaping the questing story.

As positive as Frank (2013) is about quest narratives, he also recognizes the limitations of quest stories. “Falling into the hubris that one’s own voice can ever be entirely one’s own” (p. 135) is one of the risks questing storytellers face. Because of this, the quest tale risks becoming a hero rises from the ashes story, used to “reassure the healthy that just as the author has risen above illness, they too can escape” (Frank, 2013, p. 135). To help prevent this, chaos narratives must be told and given room to exist; culture needs to be reminded that chaos is part of living.

Quest stories can also present the reinvention of the self as a clean, complete process (Frank, 2013). Frank uses the common story of a Phoenix rising from the ashes. The Phoenix doesn't remember anything from its former life; people who have lived through trauma remember. Furthermore, these stories can unintentionally deprecate people who don't rise out of their own ashes.

Finally, quest stories may romanticize illness (Frank, 2013). Restitution stories, with their reminder that "any sane person would rather be healthy, and most of us need the help of others to sustain health" (Frank, 2013, p. 135), can help counter this romanticization.²⁷

Critique: What Frank Misses

I find a lot of value in Frank's work (2013), and it provides a helpful framework for reading this dissertation. I read Frank's book more than six months after I'd completed my active treatments, and his work helped me understand why I thought it was so important to discuss the existential crisis that my cancer diagnosis brought upon me; his work filled in gaps and gave me a greater understanding of what happened to me. I *had* to tell this story in order to process what had happened to me, physically and emotionally. Frank's work also helped me understand the tension I was feeling about changing my dissertation topic, and that it was, indeed, a moral dilemma. Frank's argument that testimonies are given in bits and pieces, and that interrupted narratives require new types of narratives helped me feel secure in my choices about the format and structure of this dissertation. Overall, I find his work extremely helpful in my thinking. Still, I'd like to discuss some limitations and assumptions I've noticed in Frank's work.

First, Frank (2013) makes no mention of a storyteller's race, gender, or socioeconomic status, and how some people may find their stories listened to and accepted more easily than others because of their identities. I'm also unsure of where he did his research, although I believe it was in English-speaking North America. Frank repeatedly says that narratives are shaped by culture while shaping culture, but he doesn't explicitly ground his work in the culture he worked within.

Frank (2013) also doesn't discuss how having access to medical care is complex and nuanced. For example, health care coverage, financial ability to cover co-pays and deductibles, the ability to access doctors in a wide network of providers, the resources to travel if necessary, and living in a rural vs. urban area all impact the medical care someone receives in the United States (U.S. Department of Health and Human Services, n.d.). All of these factors matter in how people experience illness, but Frank doesn't discuss them, even in passing.

Another limitation to Frank's work (2013) is that he focuses on adults, with no mention of children and their stories. He also focuses only on physical illness, with no mention of mental illness. Frank gives few examples of people with chronic illnesses, and he doesn't include any examples of people who have disabilities and also deal with illness.²⁸ Frank does briefly address some of these limitations in the afterword to the second edition (2013), primarily through the brief introduction of three additional narrative types.²⁹

I understand that Frank's focus was on physical health, but this points to the biggest issue I saw in *The Wounded Storyteller* (Frank, 2013), one which is hinted at in the term "remission society." There are a few unstated assumptions in Frank's work: that

everyone is born with the same level of “health,” that health is “normal,” and that health can *usually* be obtained partially or fully. Even though Frank argues against the simple narrative of restitution (admitting that restitution can be hard to come by), or the idea of staying in a state of chaos (saying it is an unlivable state), or the transformative nature of quest narratives (arguing some people can’t rise from the ashes), Frank’s work still focuses on creating a *post-illness* person, a new way to live as a member of the “remission society.” There seems to be an implicit assumption that everyone *can* go into “remission.”

Frank (2013) is careful to argue against binaries, but also unintentionally creates a binary related to the healthy versus the ill. Each of his three narratives is ultimately related to the idea of starting in and returning to a normal state of health: the restitution narrative is normal to normal via illness; the chaos narrative is chaos versus a sense of normal; and the quest narrative is shaping a “new normal.” With Frank’s three types of illness narratives, there are limited options for people who can’t return to a state of normal. People with chronic illnesses or metastatic cancer, for example, can’t use the restitution narrative as intended. The chaos narrative is, as Frank says, no way to live. That leaves some sort of quest narrative. But what story is there if the ill person doesn’t want to go on a quest?

Despite this critique, I believe Frank’s work (2013) is valuable. Frank (2013) gives an excellent overview of three primary types of illness narratives, applicable to many (not all) people and illnesses. The phrase “illness narrative” makes it seem like there is *one* illness story, but multiple discourses shape narratives (Frank, 2016), including the discourse that arises from pink ribbon culture (Sulik, 2011). The three

narratives that Frank offers align with pink ribbon culture (Sulik, 2011) and the stories breast cancer survivors are expected to tell about their experiences. In the United States, when it comes to breast cancer, the master narrative about breast cancer relies on restitution. We *do* expect a return to “normal”—especially if the breast cancer is “found early.”

Sharing Stories

Telling and hearing of illness narratives is beneficial to ill people, non-ill people, and society as a whole. Still, narratives are not value-neutral, and uncritically experiencing stories can reinforce negative cultural norms.

The Benefits of Sharing Stories

As described above, people *need* to tell stories to help make sense of, and reconstruct, the narrative wreckage illness brings with it (Frank, 2013). Narratives help the self heal (Couser, 1997; Frank, 2013; Segal, 2007).

Illness narratives also help others understand what the person dealing with illness went through, and teach others how to respond to ill people (Couser, 1997; Frank, 1993). Through the sharing of illness narratives, we can learn how to encounter our own illness, resist medical colonization of the body, and ultimately create a sense of solidarity and relationship with each other (Couser, 1997; Frank, 2013).

These stories do cultural work, too. Illness narratives teach us that our bodies aren't under our control, and create and shape how we see bodies (Couser, 1997). For example, in the 1980s and 1990s especially, breast cancer and AIDS narratives tended to “be conscripted into ongoing struggles over the bodies of women and gay men” (Couser, 1997, p. 289). Illness narratives can help us, individually and as a society, understand

disrupted life experiences, and how identity and experience interact in our culture (Bury, 2001).³⁰

The way that we tell and listen to stories is cultural and relational (Clandinin & Connelly, 2000; Connelly & Clandinin, 1990; Frank, 2013; Segal, 2007). Stories expose dimensions of lives lived when people are not being patients (Frank, 2013). These stories help us shape ourselves as human beings, and thinking with stories means the self is in relationship with stories. Some of these stories even become touchstones that we return to, over and over again, as we continue to make sense of ourselves in different contexts (Frank, 2013).

But this truth—that stories shape us, and we shape them—carries with it inherent risks.

The Risks and Drawbacks of Sharing Stories

Stories hold a bundle of assumptions in them, whether told by ingroup or outgroup members (Delgado, 1989). Yet, the way we frame and (re)tell stories—the genre we use—can reinforce dominant social narratives (Goodson, 1995).

This is especially true when “the accepted discourse of pink ribbon culture—solidly lodged in war metaphor, triumphant survivorship, pink consumption, and narratives of quest and transcendence—limits the words, plotlines, and imagery available to communicate women’s varied experiences of breast cancer and ways of coping” (Sulik, 2011, p. 317).

Breast cancer stories have been told (and published) enough that they are no longer radical. In fact, they now have an established genre (Couser, 1997; Frank, 2016; Segal, 2007).

In an article about the breast cancer subgenre of illness narratives, Frank (2016) argues that there are discourses at play. There is the illness experience (an individual's experience), the discourse from institutional medicine (framing medical treatment in a restitution narrative), and the "pink-ribbonism" discourse.

Participants who act within the pink ribbonism discourse must believe three intertwined truths put forward in the search for "the cure" (Frank, 2016). These are: that mass participation in events, such as marathons, walks, or balls, is a form of public witness; that acting as a public witness and participating in these events funds medical research; and that corporate sponsorship of these events has positive outcomes. "In the staging of the events, these truths are mutually implicated: the telos of 'the cure' compromises all three" (Frank, 2016, p. 15).

These three discourses each offer their own form of truth, and come with their own forms of capital (Frank, 2016). The medical narrative comes with economic capital, scientific cultural capital, and professional prestige. The illness experience narrative has low economic capital, but high humanistic and cultural capital, including an ethical need to live an "examined life." The pink-ribbon narrative, unsurprisingly, is backed by massive economic capital in the form of corporate money (Frank, 2016).

But even if a woman wants to avoid pink ribbonism discourse, and instead lean into an individual story, there is a "master plot" at play.

The master plot of a breast cancer narrative is one that is autobiographical, comic/humorous, and ends "happily." And "without exception then, the narrators are, or claim to be, better off at the end than at the beginning" (Couser, 1997, p. 39). This master plot is enacted in a very similar story, one told time and time again: the narrator discovers

a lump or tumor, is diagnosed with cancer, undergoes treatment, receives favorable health reports and reaches peace of mind (mostly, at least) (Couser, 1997).

Couser (1997) bases his arguments on published breast cancer narratives. These stories are generally written by middle- and upper-class white women, who have access to prompt and thorough medical care, are treated with respect by medical providers, and who have time and support to write their breast cancer narratives (Couser, 1997). (In other words: Published breast cancer narratives are generally written by people like me.)

Yet this breast cancer genre applies to unpublished stories and imagery. As Sulik says, “the common image of the breast cancer survivor in pink ribbon culture overwhelmingly represents the normalizing feminine aesthetic—a survivor/medical consumer who is happy, whole, restored, and better than ever” (2001, p. 45). No matter how the story is told, “in the breast cancer drama that dominates pink ribbon culture, the story line is one of emotional upheaval, ultimately ending in triumph and happiness” (Sulik, 2011, p. 96).

The cultural edict of a positive, optimistic, bubbly breast cancer survivor—an individual survivor, a she-ro superhero—reigns supreme. “The norms and values of survivorship and support instill the message that there is a single way to speak about, and therefore experience, breast cancer” (Sulik, 2011, p. 100).

That is a problem.

Breast cancer narratives can be therapeutic for the women who tell them, can provide “thick description” of illness, and can be forms of activism (Segal, 2007)—all positive things! Yet, the standard breast cancer story that has become part of dominant cultural discourse also encourages ignorance about breast cancer (Segal, 2007). Pink

ribbon culture makes it so that women should make others feel good, and this means hiding the difficult and often un-pretty realities of breast cancer (Sulik, 2011).

Furthermore, the way that breast cancer stories are told, the onus is on the individual to prevent and treat cancer (Segal, 2007; Sulik, 2011). “How irresponsible should we feel if we do not eat quite well enough or do not exercise—or, in the particular case of breast cancer, if we delay having children, or do not have children at all?” (Segal, 2007 p. 7).

Telling individual cancer stories ignores the fact that breast cancer is not an individual disease, but is a disease of a population (Segal, 2007). How would the story look if individuals were not the focus? What would it look like if we talked about environmental factors—like carcinogens? As Segal (2007) says, looking for “the cure” distracts the public from campaigns looking for “the cause.”

Illness narratives, especially ones of upheaval and transformation, can run the risk of being romanticized (Bury, 2001). When a positive narrative is expected—as it is from breast cancer survivors (Couser, 1997; Ehrenreich, 2001; Segal, 2007; Sulik, 2011)—suffering and pain can be hidden from sight; researchers may unwittingly encourage this when they uncritically focus on narratives and ignore cultural expectations (Bury, 2001).

How Should You Counter a Counterstory That’s Become Conventional?

We tell stories about breast cancer, and those breast cancer stories tell a story about us (Segal, 2007). In a time when doctors were in charge of patients’ stories (Frank, 2013) and women were encouraged to feel ashamed and hide their breast cancer diagnoses (Couser, 1997; Lorde, 1980/2020; Sontag, 1978; Sulik, 2011), telling illness narratives—being open about experiences with disease and illness, including breast

cancer—was a revolutionary act. These counterstories (Delgado, 1989) radically questioned, resisted, and interrogated cultural norms of the time.

But what do you do when a counterstory becomes, well, conventional? What happens when the counterstory becomes the new masterplot?

The current subgenre of a breast cancer narrative, and its dependence on generic plot,³¹ gives an author (or breast cancer survivor) a structure to build on, and is comfortably predictable for the reader (Couser, 1997). But these standard stories, with their generic plots and generic genre expectations, make counternarratives harder to tell (Segal, 2007).³²

Couser (1997) believes that authors can subvert, tweak, and change the subgenre, defying, complicating, or refining its conventions. Not all researchers agree. Segal says: “The conventional features of the personal narrative are so well established that even those authors who try to write against the standard story often, in the end, just end up writing it again” (2007, p. 15).

Creating this dissertation is my way of making sense of my breast cancer diagnosis and treatment. It’s also my way of questioning, resisting, and interrogating the dominant cultural norms I faced when I was diagnosed with breast cancer in 2021.

Have I done that?

I hope so.

Witnessing as an Act of Resistance;

Witnessing as an Act of Solidarity

It may seem that I am unwavering in my criticism of breast cancer culture.

Although I am critical of breast cancer culture, I also know that untangling oneself from

cultural norms is difficult. Furthermore, I respect any woman's right to tell her breast cancer story as she sees fit. As Couser (1997) says:

We should not overlook the political significance of the act of autobiographical narration in the case of breast cancer. Whatever the choices these women make regarding treatment, prosthesis, or breast reconstruction, all have chosen to own their illnesses rather than to pass as healthy or physically intact. All enact narrative alternatives or complements to prosthesis and breast reconstruction— candid exposure of scars, literal or metaphorical, and the reconstruction of identity in all its fullness. In telling their illnesses they also tell their lives and those of others to whom they are related. (p. 77)

Telling a story about breast cancer is a political and personal act. The personal is political.

The personal is also social.

People who have been diagnosed with cancer are *cancer survivors*. Frank (2013) suggests that instead of being called cancer survivors, we should seek to be cancer witnesses. "Survival," Frank says, "does not include any particular responsibility other than continuing to survive. Becoming a witness assumes a responsibility for telling what happened" (2013, p. 137).

"Cancer survivor" is a contentious term (I explore this more deeply in Chapter 6), and I personally like the idea of witnessing better than surviving. Still, I wonder if people who have lived through serious illnesses are responsible for being witnesses for the rest of their lives.

I am willing—eager—to tell my cancer story right now, because doing so has helped me personally. As you’ll see in the remainder of this dissertation, thinking deeply about my cancer diagnosis and experience continues to help me make sense of what I want to do with myself after this and what kind of life I want to live.

I am also telling this story in the hopes of connecting with someone else. I hope that another person—someone who doesn’t identify with the “I found out I had cancer and poured myself into my work because it gave me meaning” narrative—finds this work and feels less alone than I did.

At the same time, I really hope that this (undesired, unasked for) identity of being a cancer survivor and witness fades in importance over time. I hope as I gain chronological and psychological distance, this whole experience takes up less and less space in my life, my heart, and my psyche.

I want to share my story, when it’s necessary, to connect with others, yes. But I hope that I will feel less of a need to share my story *for me*.

I hope that, in time, I enact a life made up of narrative *reckoning* rather than narrative *wreckage*.

An Invitation

Witnessing, unlike surviving, is a communal act. One becomes a witness by sharing a testimony with another person or listening to another person’s testimony (Frank, 2013). Witnesses don’t think *about* stories, but instead think *with* stories (Frank, 2013). And one doesn’t need to be sick to become a witness; a reader or listener who hears an illness narrative and then shares it with others is also a witness (Frank, 2016).

In the previous chapter, I invited you to be in relationship with this dissertation.

Now I'm inviting you to become a witness of this dissertation.

I had no choice in becoming a witness. Illness forced it upon me. Becoming a witness was the only way I could solve the moral problem my cancer diagnosis brought with it (see Chapter 1).

You, however, have a choice.

I hope you will accept the invitation

Artistic Interruption: *Three (One) Dimensions*



Figure 1: *Three (One) Dimensions*, 2022, wool and tussah silk.

At the very beginning of COVID, back when the university sent us home for two weeks to “help flatten the curve,” I went for a walk. I went for a walk the next day, and the next. Then I decided I’d go for a walk each day I was home due to COVID. It seemed like a good way to take a break from my house, get some exercise, and inhale some fresh air.

Of course, two weeks became two months and then two hundred days...

And still, I kept walking.

I went for some hikes and I visited some local parks. But most of my walks were done in my neighborhood. Over time, I found loops ranging from one mile to three.

Walking the same loop every day sounds boring, but I found that the repetitive nature of the activity was soothing and eye-opening. We'd lived in our house for more than three years when COVID began, and we'd taken plenty of walks. But there was so much I had never noticed or paid attention to: quirky houses, spring flowers, which trees turned first in the fall, and the sections of sidewalk that never, ever got shoveled.

My daily walk became an essential part of my day; I found I worked better after I'd taken my walk. But the walks also helped ground me, physically, in my neighborhood, and in the greater universe.

* * *

These walks helped me see, in tiny ways, how people and places are connected to each other. Watching the seasons repeat made me think of time and question how I'd experienced it.

I was developing a non-linear sense of time, and seeing how humans, non-humans, and processes are in relationship with each other; my walks were cultivating within me a true "sense of place" (Harwell & Reynolds, 2006).

About 400 days into this daily walking practice, I was thinking of the gifts my walks had given me. I was on a walk, of course, and I suddenly froze, mid-stride. My feet were planted to the ground.

In their seminal book *Narrative Inquiry* (2000), Clandinin and Connelly describe the metaphorical, three-dimensional working space used in narrative inquiry research. This research space is made up of interactions (personal and social; inward and outward), continuity (past, present, and future), and situation (place and context). For simplicity's sake, I thought of these dimensions as relationships, time, and space/place.

I had never questioned this three-dimensional space. The idea made sense to me, since stories have a setting (place and time) and characters and materials who interact with each other (relationships). I imagined these dimensions existing in the Cartesian XYZ-coordinate grid I used to teach to my fifth graders. Or I thought of them as the three points on a triangle; if one particular aspect—relationships, time, or space—were more important, the triangle would skew, becoming an isosceles or scalene triangle.

But on this walk—a walk I'd taken hundreds of times, almost the exact same one, daily, for over a year—I realized Clandinin and Connelly (2000) were wrong.

Time, place, and relationships aren't three different dimensions. They're one thing, described in three different ways.

And it wasn't just stories that included place, time, and relationships. Those aspects—the one dimension—were in *all* of my artistic practices. These were key parts of photography, textile arts, and writing. In fact, I couldn't think of any artmaking behaviors, in any medium, that didn't involve all three things—place, time, and relationships between human and non-human beings.

But I now understood—because I learned it from the land (Simpson, 2014)—that these three dimensions were actually one dimension.

* * *

Once I came to this understanding, I wanted to find a way to represent it. How could I show that these three things were *one* rich dimension that had multidimensional depth? Every representation or model I thought of flattened the concept. All of my ideas—overlapping circles, a triangular prism, a list of interacting ideas—became one flat

dimension (figuratively speaking) on a two-dimensional (mathematically speaking) sheet of paper.

The solution came when I was listening to They Might Be Giants. Their song “Particle Man” started playing.

Is he a dot, or is he a speck?

When he’s underwater does he get wet?

Or does the water get him instead?

Nobody knows, Particle Man

(Flansburgh & Linnell, 1990, stanza 2)

Those lyrics sparked a few half-formed memories from books—*Flatland* (Abbott, 1884) and *Flatterland* (Stewart, 2008)—I’d long forgotten I’d even read. The solution fell into place: The one dimension could be represented as a sphere.

* * *

Felting is one way to make animal hair, such as wool, into fabric. When wool is felted, the scales covering the shaft of hair become tangled together. This creates a dense fabric, one that can be cut but can’t be pulled apart. Felted fibers become so intertwined that no single strand can be pried free from the rest.

For this piece of art, I created a felted sphere. I used layers of wool to create the base sphere, then used hand carders and a blending board to lightly blend three colors of wool together. These three colors, each representing one of the dimensions, have become so matted together that they can’t be separated. The three dimensions have become one.

To add a bit of depth and texture to the sphere, I also included some pieces of white tussah silk. These strands of white silk, embedded in the work, are there for

aesthetic rather than philosophical reasons. The silk adds depth and texture to the wool, and it reflects light that the wool would otherwise absorb.

Endnotes

¹⁴ There is a difference between “disease” and “illness,” although lay people may use the phrases interchangeably (Bury, 2001; Cheung, 2019). Disease is situated in and defined by the world of medicine, while illness is culturally and socially created outside of the world of medicine (Bury, 2001; Cheung, 2019; Frank, 2013).

¹⁵ Throughout this dissertation, I use “woman” and “women” when referring to breast cancer survivors. I recognize that this term is neither as inclusive nor as specific as it could be.

Cisgendered men can and do get breast cancer, but breast cancer is overwhelmingly a cancer that affects cisgendered women, and breast cancer has been treated throughout the literature as a (cisgendered) women's disease (Sulik, 2011).

In all of the research that I read, I never saw any mention of cisgender men, transgender women or men, or non-binary people having breast cancer. This doesn't mean that cisgendered men, transgender men or women, or non-binary people don't get breast cancer. They do (de Blok et al., 2019; Grady, 2016; Richards, 2016a, 2016b; Susan G. Komen Puget Sound, n.d.). What I mean is that they are excluded from the vast majority of the published literature about breast cancer.

It would be more inclusive to write “people with breast cancer,” but the research cited in this dissertation was not inclusive. This applies to the sociological literature (e.g., literature about individual experiences, breast cancer narratives, and breast cancer culture) as well as the medical literature (e.g., literature about the disease itself, such as historical treatments or incidence and disease rates).

Perhaps unsurprisingly, the literature I read did not *specify* that it only included cisgendered women; instead, cisgendered womanhood and femininity were unstated assumptions. This is in line with how breast cancer is medically and culturally treated as a women's disease (Sulik, 2011).

Endnotes—continued

There is very limited research on the experiences of cisgendered men, transgender men and women, and non-binary people with breast cancer (de Blok et al., 2019; Grady, 2016; Richards, 2016a, 2016b; Susan G. Komen Puget Sound, n.d.). What literature does exist suggests the medical and social experiences of being a breast cancer survivor are gendered. I experienced breast cancer as a cisgendered woman, and this dissertation is centered around that experience.

For these reasons, I feel comfortable using the words “woman” and “women.” Still, I want to be clear that the use of this term assumes cisgendered womanhood.

¹⁶ The Halsted radical mastectomy removed the entire breast, all the lymph nodes under the arm, and the chest wall muscles under the breast. It left women with awful complications, including severe lymphedema, decreased function of the arm, loss of sensation, and general diminished quality of life. It is only used in limited cases today (Nathanson et al., 2017).

¹⁷ Susan Sontag’s *Illness as Metaphor* (1978) provides a short, but depressing history on how illness in general—and tuberculosis and cancer specifically—have been viewed in Western culture over the past several hundred years.

In the nineteenth century, cancer patients were thought to develop cancer because they were too full of emotions and activity that needed to be tamped down; in the twentieth century, this flipped, and cancer patients developed cancer because were “empty of feeling and devoid of self” (Leshan, 1977, as cited in Sontag, 1978, p. 51).

No matter what, a cancer diagnosis was treated with secrecy. “Since getting cancer can be a scandal that jeopardizes one’s love life, one’s chance of promotion, even one’s job, patients who know what they have tend to be extremely prudish, if not outright secretive about their disease” (Sontag, 1978, p. 8).

Endnotes—continued

Envelopes sent from cancer centers didn't include any identifying information about the sender, and more shockingly, some doctors didn't even tell their patients they had cancer (Sontag, 1978). And the 1966 Freedom of Information Act specifically cited cancer treatment as something exempt from disclosure; "It is the only disease mentioned" (Sontag, 1978, p. 8).

I remember the first time I got a postcard from the cancer center. It advertised their "survivorship" workshop series. I did think, for a brief moment, *Oh, I guess the mailman knows I have cancer now.*

¹⁸ In the United States, non-Hispanic white women have the highest incidence rate of breast cancer, but black women have a higher mortality rate from breast cancer (Jatoi et al., 2022). This is likely due to a host of issues, including barriers in accessing healthcare (Jatoi et al., 2022), medical racism (Gehlert et al., 2021), and the fact that breast cancer is frequently seen as a white women's disease (Moore, 2001).

Although women of all races can get breast cancer, I noticed almost all of the participants in the qualitative articles I read about breast cancer survivors were white women. The breast cancer experience is a racialized one (Corvin et al., 2013; Davis et al., 2016; Gehlert et al., 2021), and this showed up in the studies I read. There is narrative research about how women who are not white experience and view breast cancer (e.g. Corvin et al., 2013; Davis et al., 2016; Gehlert et al., 2021; Jatoi et al., 2022; Moore, 2001; Patel et al., 2014; Whitten et al., 2011), but that's not a topic I explore in this dissertation since this is an autoethnographic piece and I'm white.

I know that my experience with breast cancer was a racialized experience. American breast cancer culture has centered the bodies of white women like myself.

¹⁹ Breast cancer was also an attractive cause to support because it was a "safe" disease to support. Corporations worried that supporting the growing HIV/AIDS movement would offend customers and the public (Ehrenreich, 2001).

Endnotes—continued

²⁰ AstraZeneca is a common sponsor of breast cancer month, breast cancer walks, and other breast cancer “awareness” activities. AstraZeneca created tamoxifen, a failed contraception that is now widely used in breast cancer treatment (Quirke, 2017). But before a corporate reorganization in 2000, AstraZeneca was a leading manufacturer of pesticides, including ones that were classified by the United States government as “probable human carcinogens” (Ehrenreich, 2001; Sulik, 2011).

²¹ The Susan G. Komen foundation has been the target of extensive criticism regarding the companies they choose to work with. For example, in what the organization Breast Cancer Action (2014) called an incredible act of “pinkwashing,” the Komen Foundation teamed up with the Baker Hughes company to create pink drill bits during October (Abrams, 2014). These drill bits were used in the fracking industry, which has been tied to cancer-causing chemicals (Nobel, 2018; Vogel, 2017).

Baker Hughes’ advertising slogan? “Doing Our Bit for the Cure.”

²² One big issue in breast cancer culture, although Sulik (2011) doesn’t explicitly address it, is that breast cancer culture’s focus on early prevention and early-stage cancers makes it so metastatic breast cancer is largely ignored (Jacobson, 2018).

I remember seeing a post on Twitter, which I’ve unfortunately been unable to source and thus can’t cite, that referred to metastatic breast cancer as the “ugly stepchild” that the breast cancer community doesn’t want to attend to.

When looking for journal articles about narrative stories of breast cancer, I found article after article that excluded women with stage IV cancer from telling their stories. If I wanted to find the stories of women with metastatic breast cancer, I had to explicitly seek them out. Metastatic cancer doesn’t fit into the mold of breast cancer survivorship (Jacobson, 2018).

Endnotes—continued

Since I wasn't diagnosed with metastatic breast cancer, I fit perfectly into the mold that breast cancer culture is designed for. This dissertation focuses on my experience with early-stage breast cancer, and an in-depth discussion about metastatic breast cancer is beyond the scope of this dissertation.

²³ According to Bickel (2005), “The body has not been a valued location of learning and knowledge creation in our western society” (10). Yet, artmaking with my unfamiliar, alien, foreign body—the body of a cancer survivor—was one of the ways I came to value my body when I struggled with the problem of body-relatedness. I consider this in Chapter 6.

²⁴ As you can tell, I am very critical of the idea that breast cancer survivors must express optimism. Many times, this optimism is expressed by referring to cancer as a gift or a blessing (see Chapter 6 for a discussion about this). But Frank's (2013) use of “a great permission” dovetails nicely with a brief point Sulik (2011) makes, and together they add nuance to the idea of optimism. Sulik (2011) writes:

In my conversations with breast cancer survivors, women frequently captured the optimism embedded within their stories in the word “blessing.” If we had stopped the conversation there, I might have thought they were referring to a miracle or stroke of good fortune. This was not what most women meant. Instead, the blessing was about permission: breast cancer permitted women to take on a new and valued identity. (p. 236)

²⁵ The desire to tell restitution narratives is so strong that I preemptively used the restitution narrative before the tumor was removed. “I've been diagnosed with breast cancer, I'm going to be OK, it's only stage I.”

I continue to use this narrative when cancer comes up in passing, when I don't want to dwell on or discuss it. For example, I ran into an acquaintance I wasn't close to, and she asked

Endnotes—continued

me if I'd graduated. The restitution narrative popped out of my mouth. "Well, I was supposed to graduate in May, but I was diagnosed with breast cancer last summer, and that threw things off—it's OK, I'm fine now." (But am I, really?)

In the past, I've expected—and wanted—to hear this narrative from others who disclose their health stories. I remember a student's parent sharing with me that she'd had breast cancer treatments the year prior, and it had affected her child academically and emotionally. I thanked her for telling me and immediately asked, "But you're OK now?" (I won't ever knee-jerk ask that question of anyone again.)

²⁶ If I had to choose a time when I felt like I was most in the chaos narrative, it would be the period between my surgery and my radiation treatments. My friends and family members were very supportive of me during this time. Still, I felt like I had to rein in my complaining. I felt like I was making others uneasy.

Now that I am past my chaos period, I can see the experience with more clarity. Yet, writing about this time period now that I'm past it and through it makes me uncomfortable. I don't want to remember it even happened. I want to gloss over it. But Frank (2013) writes that "to deny a chaos story is to deny the person telling the story, and people who are being denied cannot be cared for" (p. 109). I discuss the chaos narrative—and how being in chaos was actually beneficial in one way—in Chapter 5. Telling my story, with the benefit of space and distance from the chaos story, is a way of caring for myself.

²⁷ Frank (2013) says that restitution stories can help counter the romanticization of illness. But I'd argue that the focus on quest stories in pink ribbon breast cancer culture, and the view that breast cancer is a rite of passage (Ehrenreich, 2001) that will make you a better person (Ehrenreich, 2001; Sulik, 2011), is one way of romanticizing breast cancer. When it comes to breast cancer,

Endnotes—continued

the restitution narrative doesn't counter the romanticization, because the restitution narrative is *embedded* in the commonly available breast cancer story.

Relatedly, see Sontag (1978) for a discussion about how tuberculosis was romanticized by nineteenth century authors.

²⁸ Frank was writing *The Wounded Storyteller* at roughly the same time that disability studies—and the social model of disability—was becoming more widely known and accepted (Bickenbach et al., 1999). So it's possible that he doesn't cite scholarship from the field because of the time he was writing in.

Even though I critique Frank (2013) for not drawing on the scholarship from disability studies, I also don't draw widely on that scholarship. I view my cancer diagnosis as an acute event and not a chronic illness, which is why I have read primarily from medical sociology rather than disability studies.

²⁹ Frank (2013) introduces three new narrative types in the afterword to the second edition: borrowed narratives, broken narratives, and life-as-normal narratives. I didn't find these narratives applicable to my work, so I don't reference them further. However, these narratives do start to address some of my concerns over not having any information about children or people with disabilities.

Frank (2013) draws on anthropologist Cheryl Mattingly's work with chronically ill children to discuss *borrowed narratives*. Borrowed narratives choose other stories and use them to tell their own story. Although adults may incorporate borrowed stories into their narratives, they do so in subtle ways. Children, as well as their medical providers and family members, borrow stories liberally and overtly, calling on characters and heroes from cartoons and movies to make sense of an ill child's experiences. In her work, Mattingly shares the example of a child who needed to wear a mask over his face to help minimize scarring; he first saw himself as Batman when he put

Endnotes—continued

on his mask. Later, he identified with Buzz Lightyear, who didn't take off his helmet in the *Toy Story* films. Using these narratives can be especially beneficial in learning how to communicate difficult medical concepts (such as "keep this tight-fitting face mask on day and night") to children. These borrowed narratives also allow for "perpetual reinvention through co-construction" (Frank, 2013, p. 199).

Health psychologist Lars-Christer Hydén, who works with "people who seem incapable of telling stories" (Frank, 2013, p. 201) coined the term *broken narrative*. These narratives can be used by "people whose physical or mental capacities make it difficult or impossible for them to tell the sort of stories that fill *The Wounded Storyteller*" (Frank, 2013, p. 201). Frank (2013) reminds the reader that stories are not only told through writing or speaking, but that the body also tells stories, that "their bodies give their stories their particular shape and direction" (Frank, 2013, p. 27). But to tell the story the body doesn't explicitly tell, the primary storyteller (the person with a disability) will need a co-collaborator. The storyteller and co-collaborator work together to share the storyteller's story; the co-collaborator does not tell a story *for* the patient, but *with* the patient. Frank argues that these narratives "uphold the *moral personhood* of people whose limited mental capacities put the recognition of their personhood in jeopardy" (Frank, 2013, p. 202, emphasis in the original).

Finally, there is the *life-as-normal* narrative. People who live out a life-as-normal narrative do not share their diagnoses or health matters with others; they may even actively work to hide their illnesses, treatments, and any side effects from others. This narrative preserves other parts of the patient's life, which continues on with the illness story waiting to be told.

Frank (2013) explains that he purposely omitted this narrative type from the first edition of *The Wounded Storyteller*, because by the 1990s, people were learning how to tell illness stories in ways they hadn't been able to previously. He also expresses concern that it may be easier for healthy people to act like life is normal around an ill person, and the ill person may be coerced

Endnotes—continued

into acting like life is normal. According to Frank, the life-as-normal narrative makes it harder for people to talk about illness when they eventually do need to talk about illness. “Talking about illness takes practice,” says Frank (2013, p. 197).

Ultimately, Frank (2013) says this life-as-normal narrative “runs counter to the [book]’s overarching themes of the individual, relational, and communal responsibilities to witness suffering” (Frank, 2013, p. 195). Frank argues that a life-as-normal narrative, even if it seems important to a patient or their family, risks doing more harm in the long run by encouraging silence.

I have one problem with Frank’s take on the life-as-normal narrative. Frank seems to value communication with others, and storytelling, over the ill person’s agency. He wants ill people to reclaim their stories from medical professionals, and from expected social silence. But it feels like he judges people who choose to use their agency to remain private.

³⁰ In this chapter, I am focusing on what medical sociology says about illness narratives, and how they can benefit individually and society. I also want to point out that telling stories about the body is beneficial to the academy, an institution which has historically ignored embodied experiences in favor of “rational” ones. As Banks (2003) says:

Regardless of how distant we can get ourselves from the embodied experiences of our lives, if we do not find our way back to those bodies, those experiences, we run the risk of impoverishing our theories and pedagogies. More specifically, when we ignore the “embodied” in discourse, we miss the ways in which liberation is always both social and individual, a truly symbiotic relationship. (p. 22)

³¹ “In the harshest judgment, the breast-cancer cult serves as an accomplice in global poisoning—normalizing cancer, prettifying it up, even presenting it, perversely, as a positive and enviable experience” (Ehrenreich, 2001, p. 53).

Endnotes—continued

³² Segal (2007) also argues that the breast cancer narrative allows for only one genre: that of the personal narrative. She believes the personal narrative, because it focuses on the individual, can be dismissed as being a story about an individual rather than society or culture.

I believe that personal writing—writing *about* the personal—can be meaningful. The following quote from Banks (2003) speaks to my beliefs about writing and reading personal stories. In this quote, he explores the use of personal stories in academic writing:

Just because the writing seems “personal,” that doesn’t mean it isn’t “critical” or “rigorous” as well. [...] “Personal” writing often disrupts our simplistic notions of thinking, of arguing, or (re)presenting as utterly linear [...] Likewise, such writing, particularly when it is presented to a professional reader, bears the responsibility of making “personal” knowledge into “social” knowledge that others can use, of adding to a very specialized “body of knowledge.” (p. 33)

Part II: The Body

This event called upon me to reexamine the quality and texture of my entire life, its priorities and commitments, as well as the possible alterations that might be required in the light of that reexamination.

—Audre Lorde, *The Cancer Journals* (1980/2020, p. 54)

Pain from pearls, hey little girl

How much have you grown?

Pain from pearls, hey little girl

Flowers for the ones you've known

Are you on fire

From the years?

What would you give for your

Kid fears?

—Indigo Girls, “Kid Fears”

Chapter 4: Before

Becoming a First-Gen Teacher

When anyone asked me why I became a teacher, I said I wanted to teach because I had some great teachers, and I wanted to inspire students like those teachers inspired me. I might say something about how I was the first in my family to attend college,³³ and education was important to us. It makes for a great American dream success story.³⁴

That was the truth, but not the entire story.

I started my college career as a high school junior attending a local community college full time.³⁵ The college courses I took counted toward my high school diploma, and I walked across a stage to get my associate's degree several weeks before walking across another stage to collect my high school diploma. I transferred my credits to a private women's college in the south, feeling prepared to double major in chemistry—the major that would snag me a decent career, according to my parents—and philosophy—the subject I fell in love with while fulfilling a requirement for my associate's degree.

Transferring as a new high school graduate with two years of credits left me in this bizarre space where I was treated as both a first-year and transfer student by the college. Although I felt academically prepared for most of my courses, I found myself in a much wealthier community than I had grown up in, one which was infused with the Southern culture that I was not familiar with. I felt intense pressure to hide my family's working-class roots.³⁶

It all came to a head when I took organic chemistry. I had to study for the first time in my life, and I had no idea how to do so. I also didn't know where to turn for help—not that I was going to ask for any!³⁷

During this time, I also participated in a research project that brought undergraduate science majors, education majors, and practicing K–12 teachers together to do geological research. I found the work interesting, but I realized I didn't want to work in a lab. Rather than explore non-lab career options, or even science majors other than chemistry, I dropped my chemistry major and focused on graduating with a bachelor's degree in philosophy.

Philosophy is an esoteric major, and it's hard to see how it's useful in real life. If someone asked me what I was studying, their follow up response was almost always the same: “Philosophy, that's interesting. What are you going to do with philosophy?”

One of the upperclasswomen in my program came up with the perfect response to that question, and I started using it.

“As little as possible.”

I'd say it with a chuckle, but the truth was I had no idea what I could do with a philosophy degree. Shortly before I graduated, I was admitted to an alternative teacher preparation program. Now I could use the same answer and chuckle, but I could also tack on “But seriously, I'm going to become a teacher.”³⁸

The preparation program I was admitted to focused on “urban” education. We were specifically and consciously taught to teach in local Title I schools, which were majority Black students, using the work of scholars including Lisa Delpit, Gloria Ladson-

Billings, and Paolo Freire. As part of that work, we dug into our own racialized experiences with schooling and discussed why we wanted to become teachers.

My cohort was racially diverse, especially compared to the general teaching population of the time, and about half of the students were career switchers. It made for a group of students across a span of ages with varied life experiences.³⁹

Yet, that diversity didn't seem to apply to our reasons for wanting to become a teacher. As I remember it, the reasons given for wanting to be a teacher fell along racial lines, with very little variation. The white students tended to talk about love of children and wanting to make a difference for "needy" children in "those schools." The people of color tended to talk about wanting to be a role model for students and making a difference specifically for students of color; I remember one Black classmate saying, "I want to teach in 'those schools' because I'm from 'those schools.'" Across the board, students talked about the importance of education.

And I fell in line with it, talking about the importance of education and mentioning a favorite teacher, and how I wanted to be like him.

I didn't feel comfortable saying that part of why I wanted to become a teacher was because it was a stable career. That wasn't a "good" reason. And it didn't fit in line with the image of the altruistic teacher. I also thought teaching would be something I could do until I decided what to *really* do with my life.

But truthfully—and I'm hesitant to admit to this, even twenty years later—I also chose it for financial reasons. I had watched my mom work very hard in hourly jobs her whole life. I didn't know what *salaried* meant, but I knew that teachers were paid consistently and had regular daytime hours. I also knew that teachers would always be

needed. Finally, teachers could get jobs anywhere; I had moved often throughout my life, and I liked the idea that I could live wherever I wanted. To state it simply: I wanted an easier life than I'd witnessed my mother have, and I saw teaching as a way to get that easier life.⁴⁰

I started teaching in a Title I elementary school outside of Atlanta, and I struggled with the typical first-year teacher concerns. I was too focused on classroom management to reflect on how much my K–12 educational path influenced my teaching decisions. At the time, I also didn't explicitly connect my career choice with my parents' careers or my family's socioeconomic status.

My second or third year as a teacher, I read a newspaper article about the issues first-generation college students faced at college. Although I was briefly in a TRIO program, a federal initiative aimed at getting low-income, disabled, and/or first-generation students into college, I'd never heard the term "first-generation college student" before. The details are hazy now, but I remember being surprised at how many of the stories I identified with: applying to only one college, the financial aid office not being helpful, not being able to afford to travel on breaks, working part-time in addition to my work study job, not wanting to ask for help with academics, and hiding details about my family's life in order to fit in. I finally had a term to identify one of the roles I had in my family, that of a college student who was "breaking away" (London, 1989), and I started thinking more deeply about my college experiences as well as how my first-generation status influenced my choice of a career and the way I approached it.⁴¹

I was able to view my teaching practice with a more discerning eye; I was finally able to start deeply reflecting on my teacher identity and teaching practice, and how my

identity and practice was influenced by my own school experiences. In some ways, these teaching decisions were private moves, such as a one-on-one interaction with a parent or student. Sometimes these choices were more public, like talking to the whole class openly about how my parents didn't have college degrees. Other times, these decisions put me in awkward situations with my administrators, like when I showed no interest in collecting Box Tops from my students.

In big and little ways, my lived experiences mattered.

In my ninth year of teaching, I started hosting student teachers, and eventually I became the lead mentor teacher in my school. Through these roles, I met prospective and practicing teachers with a host of backgrounds and interests, and I started to wonder how the life histories of my friends and colleagues influenced their teaching. For this reason, I dug into the research on teacher identity work and teachers' lived experiences.⁴²

As I explored my original dissertation topic (the experiences of K–12 teachers who are also first-generation graduates), I was better able to understand why teaching was such an attractive career option for me. I asked myself: Why did I choose teaching? How did I teach? Why did I teach that way? How did my first-gen identity impact my major, my career choices, and my teaching?

These questions suited me well. Until I was forced to deal with the narrative wreckage (Frank, 2013) that the cancer diagnosis left behind.

During this time, I realized that all of my questions had been operating under an implicit assumption: teaching was a given.

But... What if teaching *wasn't* a given? What if the question wasn't "Why did I choose teaching?" What if it was actually "Why *didn't* I choose something else?"

49 Minutes

This essay is excerpted from an article (Shopa, 2020b) published in the Journal of Artistic and Creative Education and is used with permission. In that article, I explored my photographic studio practices through four stories that span three decades. Since photography is intrinsically linked to time, each story was based on a different unit of time (1/125th of a second, 49 minutes, Monday–Thursday and Friday, and indefinite). I've made very minor edits to spelling.

49 minutes; the length of my physical education class in eighth grade

Two facts about my life as an eighth grader: first, I was exempted from some outdoor physical education units for medical reasons and was sent to the school library to write reports. Second, the library had a two-book checkout limit. If either of these hadn't been true, perhaps I wouldn't have become a book thief.

While some of my classmates occasionally brought their point-and-shoot cameras to class, my SLR could always be found in my backpack or hanging from a woven strap around my neck. I took photos most days, during lunch and recess, but also in class. I don't remember asking my classmates or teachers for explicit permission. Some teachers were supportive; my homeroom teacher let me use class time to take double exposures of my friend John near the lockers, and the art teacher let me turn some painting assignments into photography assignments. Other teachers simply ignored me, and I took their silence as tacit approval and universal permission. In a school of approximately 700 students, I saw myself as—and felt seen by my peers and teachers as—a photographer.



Figure 2: *John Wheeler*, ~1994, color photograph.

This photo shows a middle school friend of mine, John Wheeler, next to the locker. I double exposed it, which is something I was very interested in experimenting with at the time. On the back of the photo, I wrote the reason I'd taken the photo: "Because it's John, that's why!"

One snowy day, I had to write a report about ice hockey. I read a single encyclopedia articleⁱ and then started browsing the stacks. There, I discovered the library's dusty cache of photography books from the 1960s and 1970s, books that hadn't been checked out since at least 1983 according to the due dates stamped inside the back covers. I'd reached my checkout limit, but I knew nobody else in the school would want those books.

ⁱ The only fact I remember from the encyclopedia article was that there was no 1918–1919 Stanley Cup winner due to the 1918 Flu Pandemic. I thought it was incredible that the flu made them cancel such a large event.

One of the boys in my homeroom class had once told me he didn't think the library's back exit—the one tucked between two tall bookshelves—had sensors on it. I studied that exit, trying to figure out if the librarian could see it from her desk. We weren't supposed to use that door, but we'd never been told we *couldn't*. And it didn't have a red fire alarm bar on it ...

I decided to steal the books.

The next physical education period, I greeted the librarian with a nod. I headed to the photography section, chose two books and shoved them in my backpack. I sat down at a table with my back to the librarian and pretended to do my math homework.

When the bell rang, I walked to the back exit, my heart pounding.

No alarms went off, and the librarian didn't stop me.

For months, I stole library books, returning them when I was finished reading them. I learned how to make pinhole cameras out of coffee cans and tennis balls. I read that kitchen twine and an eyebolt could make a decent substitute for a tripod and that overexposing film was better than underexposing it. I also discovered ways I could manipulate images by smearing Vaseline on a filter or stretching a piece of nylon mesh over the lens.

I was most interested in the instructions for building and using a darkroom. The family I babysat for had an abandoned darkroom in their basement, and they said I was welcome to take it apart, but my mom and stepdad wouldn't let me. They argued that I'd have access to one in high school.

In between rounds of being a book thief, I dropped off rolls of film at the local photo lab, paying for the one-day processing with my babysitting money. One book said

short negative strips could make loading the negative carrier difficult and suggested leaving them uncut, so I started writing “please do not cut negatives” on the drop-off forms.

It felt good to be seen as a photographer by my classmates, but it could also be lonely. Taking and sharing photos can strengthen relationships and create individual and group identity (Gye, 2007); certainly, the act of taking photos helped form my socially constructed identity (Holland et al., 1998) as a photographer. Yet although my personal identity was strong, I lacked a community of photographers to talk with and learn from. In retrospect, those books became part of a self-created community that reached through the decades to show me what was possible through photography.

Discovering those books broadened my studio practice to include some historical perspectives. More importantly, I discovered a whole field of photographic possibilities. I was limited by my lack of a darkroom, and I found that out one book at a time.

Arts High School

I also wrote about my darkroom time in the Journal of Artistic and Creative Education article (Shopa, 2020b). Although this is not an excerpt, some bits of this essay overlap with the Monday–Thursday & Friday section of that article.

My freshman year of high school, I took Photography I and II. My teacher, Mr. Nelson, taught us the basics of photography: how to photograph action shots, how to apply visual composition rules to photography, and the relationship between film speed, shutter speed, and camera aperture.

He also wanted us to learn the basics of darkroom work. How to develop film, how to make contact prints and a test strip, how to dodge and burn to bring out a crisp, clear print.

The problem was that I had been using my camera for years. The internal light meter didn't work, so I had to meter everything using the Sunny Sixteen rule of thumb^j—I understood the relationship between film, shutter, and aperture. And if I wanted perfect prints in the darkroom, I could get prints done at the corner store in an hour.

I wanted to try the medium format camera (the “4x5 camera”). I wanted to make my own pinhole cameras and solarize prints and try layering single-exposure prints into

^j On sunny days, set the aperture to f/16 and the shutter speed to the nearest reciprocal of film speed. From there, the aperture or shutter speed can be adjusted to account for weather conditions or additional light being reflected off of reflective surfaces. For example, on a sunny day, with 400 ISO film, at f/16, you'd set the shutter to 1/500th of a second.

double- or triple-exposure prints.

Mr. Nelson wanted us to make technically beautiful prints; I wanted to play.

One day, Mr. Nelson called me to his desk. He flipped through the photos from my last assignment, which I'd turned in late. He pointed out the places where my prints were dusty and where the colors were muddy. He asked me if I'd noticed the border around a print was off kilter. I'd put the paper in the easel crooked (which was easy to do in the dark) and I hadn't trimmed the print cleanly after it dried (which was easy to do with the paper cutter in the light). "I know you want to experiment, but you need to do better work," he said. "And you can use the 4x5 to do your assignments, not just your 35mm camera."

I nodded solemnly and slunk back to my enlarger, my head down. I'd been scolded by teachers for talking too much in class. But doing sloppy work? In a *photography* class? When I felt like a photographer? I could feel Mr. Nelson's disappointment in me, and I was ashamed.

Mr. Nelson kept after-school darkroom hours, which I was finally able to use in the wintertime, when Debate season ended. I spent nearly every day in the darkroom. I tried to put my work for class first, and save the experimentation.

I didn't want to leave when Mr. Nelson did, and eventually he let me stay in the darkroom—alone—after he went home. I cranked up the radio and worked for hours in quiet peace. Solarizing prints was my favorite experiment. A solarized print is partially developed and then exposed to white light. The white light exposure creates a silvery glow between the highlights and shadows, and I was never sure how the final results would look.

After some more time passed, Mr. Nelson showed me how to mix the chemicals for the classes—both stock solution and working solution. I knew I'd reached a new level of trust with him. I could mix new chemistry, work in, clean up, and close up the darkroom. Alone.^k

Friday was the only exception to this rule. Mr. Nelson wanted to be the one to close the classroom for the weekend so nothing would be forgotten.

Well, that made sense.

* * *

My sophomore year, I took photography as an independent study. In the fall and early winter, Debate team limited my after-school time, so my darkroom time was limited to school hours. But I had learned how to make a very basic pinhole camera using an old coffee can and photographic paper as a negative. I'd also helped Mr. Nelson take photos at the harvest festival dance in November.

One day Mr. Nelson asked me if I was going to apply to the state's Arts High School. The Arts High School, which included only eleventh and twelfth graders and focused on a variety of art forms, was difficult to get into. You applied to a specific strand of artistic study and created a portfolio of work; there was an interview involved.

He wasn't the only person who asked me if I considered it. My creative writing teacher had brought it up, as had a few of my classmates. I usually laughed it off and said I couldn't decide which program to apply to: creative writing or photography.

^k I'm not sure this would ever happen nowadays, but at the time I sure appreciated the trust I was shown and the independence I was given.

But really, deciding which program to apply to was unnecessary. I never even discussed it with my parents. I knew full well that the Arts High School wasn't an option for me.

Transportation was part of the issue (although students did carpool); I didn't have a license and couldn't drive, and I didn't have the financial ability to get my own car even if I could.

But the bigger issue was that the Arts High School was financially out of reach.

Even though the Arts High School was a tuition-free, public school, I knew that I was going to do Minnesota's Post-Secondary Enrollment Option (PSEO) during my junior and senior year. The PSEO program gave high school students the opportunity to attend college up to full time on the state's dime—tuition, fees, and books were all covered.

I already had what I needed to have for the PSEO program: Strong grades, a decent rank in my class, and my guidance counselor's recommendation.¹ I could attend the local community college, where my mom was earning her nursing degree, and where several of my friends were also going to do the PSEO program. I could ride with them or take the public bus—it only took one transfer to get there.

Also, I wasn't going to major in photography or writing in college, because going to college was for the purpose of getting a degree so I could get a job. I couldn't see any clear path for earning money, and finding a stable job through photography or creative

¹ There may have been more to the application than that, but unlike the Arts High School, I didn't have to compete for a spot.

writing. I knew I should major in the sciences. That's where jobs and money were.⁴³

There was also the more immediate issue of *spending* money. I could attend high school for two more years or attend college for two more years—the price to my family would be the same.

But with careful planning, I could complete my associate of arts degree *and* high school at the same time. This would save thousands, if not tens of thousands of dollars on college costs. That made staying in high school cost more in the long run. The cost of staying in high school felt too great.⁴⁴

Since I didn't want to talk about my family's finances with anyone, I shrugged off their suggestions and changed the subject.

The Arts High School might be out of reach,⁴⁵ but at least I had the rest of my sophomore year to use the darkroom. I'd even been given permission to stay in the darkroom on Fridays, as long as I kept "closing everything up the right way."

What I'm Going to Do

“You know you need your PhD, right?”

I furrowed my brow at my vice-principal, Felicia. It was a Friday in mid-September. The students had gone home and we'd been shooting the breeze in her office for quite some time. The conversation had meandered, flowing between personal and work-related topics. We'd been discussing the district's budget issues when she had abruptly changed the topic.

You know you need your PhD, right?

She wasn't the first person to tell me I should get a PhD. I'd had other administrators, instructional coaches, and fellow teachers suggest it to me. “Have you ever thought about getting a PhD?”

I'd always laughed and said, “I don't want my PhD. And if I do get a PhD, it will be in something like [...]” Knitting in Scandinavia in the 19th century. Quilting as a form of feminist resistance. The rise of craftivism. My answer would change depending on the day, but it was always related to craft⁴⁶ and “women's work.”

I planned to cut Felicia off in a similar way. I shook my head. “I don't want to be an administrator.⁴⁷”

“I didn't say you needed your administrator license,” Felicia said. “I said you needed your PhD.”

I was confused. “Why do I need a PhD?”

“For what you want to do, you need a PhD.”

I leaned back in my chair and crossed my arms over my chest. “Oh? And what is it I *want* to do?” My voice was tinged with sass and disbelief.

Felicia leaned forward, looking directly at me. “Fine. For what you’re *going* to do, you need your PhD.”

I blinked at her, speechless.

Surely she was kidding.

I was a teacher. I had a dozen years under my belt. I was teaching in a full-time gifted education class—fifth grade, my absolute favorite age—and I had a student teacher. I was math lead teacher and lead mentor; I’d spent the prior summer working on curriculum guides for the math office and the gifted education office. I’d been slotted into several leadership roles, and I was comfortable and confident as a teacher; I was excited to repeat some projects and try new ones. I had consciously chosen to stay at my school instead of pursuing a position as a pull-out gifted ed teacher, because I liked the school and community I was teaching in. I was a *good* teacher.

Teachers don’t need PhDs.

And even if I wanted to get a PhD, I couldn’t. I didn’t want to quit my job, and teaching and earning a PhD would be miserable. And besides, there was no way my husband and I could afford tuition for a PhD program.⁴⁸ Frustrated with her suggestion, frustrated that she thought *I* was the type of person who had access to that sort of education, I scoffed. “I don’t need my PhD.”

“Yeah, you do.” She waved her hand at me dismissively and picked up a stack of papers on her desk. “It’s late. Go home, Shopa.”

I left her office, and walked back to my car, rolling Felicia’s words around in my head.

I tried to figure out what she saw that I ~~didn’t~~ couldn’t see.

For what you want to do, you need a PhD... For what you're going to do, you need a PhD.

I didn't know what she meant by that, but my whole body tingled, as if I could feel every nerve ending firing.

What if she was right?

Weeping Over Sushi

What follows is an excerpt from my research journal; it has been lightly edited for clarity. When I wrote this entry, I'd just completed a three-week long dissertation writing retreat, and I was knee deep in my original dissertation topic. I met with a member of my committee for lunch. It was the day after my first mammogram.

I don't remember if I cried before or after [she] told me she was proud of me. I think my crying had to do with my existential crisis more than anything else.

What do I want to do? I don't know. What sort of job do I want? I don't know. What do I want? To not work full time. To make art. To garden. To hike. To cook. To be outside. To write.

She asked me if I'm in my dissertation, if my story is included and woven throughout. In narrative inquiry, the researcher and the participants form a new story, a research story. I have three participants, but I'm a fourth; I'm a first-gen teacher. Or at least I was, five years ago, before I gave it up for this.

What am I now? A teacher? Teacher educator? Teacher researcher? Do I even want to be any of these things anymore? (And can I be an artist-researcher-teacher if I'm not teaching?)

"What's your 'why'? Remember your 'why.'" That's the advice given to grad students when they're struggling. Except I'm not sure I ever had my own why. Felicia told me "for what you're *going* to do, you need your PhD." And it made sense at the time. But there was nothing logical about it, it was all a gut reaction.

And what am I *going* to do? Or what do I *want* to do?

I want to work less and hike, make art, cook, knit, garden, sew, photograph more. Those are things I enjoy. If I could find some job combining outside time, artmaking, photography, writing and maybe a little teaching? It'd be a thrill. Or editing. I love reading people's work and making it better, and there's teaching in that work, especially when you work closely with an author.

But saying you don't want to work full time, or don't want some high-powered career, seems counter to the whole point of getting a PhD.

So that's one reason I cried. But it's worse than that.

When [she] said I should write about this, she also said I should take photos, make art. "You're taking photos of this, aren't you?"

No, no I'm not. I'm not taking photos, I'm not sewing.

I'm seventeen days behind on my scarf (eighteen if you count today) and the days I do have done? The ends are ragged and need to be woven in. I can't remember the last time I took any film photographs. I think it might have been last year's camping trip? I used to carry my camera around *everywhere*, but now I have rolls and rolls of undeveloped film and a camera that's been in the repair shop since October (although I have multiple cameras, so...). Oh, October, that may have been the last time I took photos with film. My knit sweater (also started in October) isn't done. I don't think I can finish it by the State Fair. My small quilt I was working on before the pandemic? I haven't touched it since then. It hangs around me like an albatross.

I went through my blog last weekend, deleting old posts. I used to write. I used to write so much, and I had a community of writers. I haven't written creatively in ages. I'm not making. I'm not doing art.

I am getting outside. There's that. I do have that going for me. But hiking? Nope. I'm walking, but I'm not hiking. Our state park pass expired in January. It's *June* and we haven't renewed it.

The things I want to do? I'm not doing them.

Part of the problem is I'm still waiting for data. Part of the problem is that the tentacles of positivism run deep, and it's hard to completely break free from it, even when I want to. Part of the problem is I wonder if it would just be easier to do a "traditional" dissertation and forget about the artmaking. Part of the problem is I keep learning new, big, distracting ideas! Part of the problem is that the academy wants words, not art, which means it's easier to focus on the words and not the art.

And then I feel this extra pressure, entirely internal, to do Something Grand for this dissertation since I landed those scholarships and since I have the gift of time staring me in the face.

And part of the problem is that I want to shift toward artmaking, freelance work, creative writing, editing, something—anything else—but that is terrifying. Admitting it is terrifying. Not having a backup plan or regular income or health insurance or any of those other things that you need in America—the things that are *success* to a first-gen student (!)—it's all just plain terrifying.

(This may be the Biggest Problem, really.)

And even if I can work through that terror, I still don't know how to get there.

I'm not sure how PhDing fits into that shift.

The Heart of It

When I won a fellowship for my final year of dissertation work, I was excited and relieved. A whole year to focus on only my dissertation! But I was also unsure what to do with all of that time. The COVID pandemic had thrown off my sense of time (Takayama, 2020), which was an issue.

But the bigger issue was that I had worked, either full or part-time, though every single college class I'd ever taken. As an undergraduate, I'd worked off campus and done work study. When I was a first-year teacher, I was taking a full-load of graduate courses to complete my masters. My doctoral program, where I worked twenty hours a week for a project or program related to the University and didn't do any other paid work, was the first time I had done a degree the way it was "supposed" to be done.

I didn't know what to do with myself or the luxury of time I was given. Should I work at least a few hours a week? It would feel really weird not to work. But hadn't I applied for those awards hoping for time?

I turned to my friends for advice.

"Don't work," they all said. (The ones who had worked regretted it.)

"Take the time to rest, take long walks," another said.

"You'll need the time to find a job," someone else said.

Several friends also said it didn't really matter what I did for the first semester. According to them, "You'll write your dissertation in the last semester."

If I wrote my dissertation in the spring semester, what would I do in the fall?

Well... There was that *one* topic I was avoiding thinking about...

For years, when someone asked what I wanted to do with my PhD, I'd remember my undergraduate answer—"as little as possible"—and make a joke. "I'm not sure, I've got five [four, three, two...] years to figure that out."

Even though COVID added a year to my graduation clock, I still hadn't figured out what I wanted to do. And I was down to my final year.

Now I was facing unstructured, unscheduled time, and I would figure out what I wanted to do with my life.

Shortly after deciding this, I found out about an artist residency in the Brittany region of France, The HEART.^m They were inviting creators, researchers, and "seekers" (people who needed to answer a personal question during a time of crisis) to spend time together studying love. As I said to a few friends, "As an arts-based researcher who's having an existential crisis about what to do with my life, this is perfect!"

On the application, I needed to choose if I was applying as a creator, a researcher, or a seeker. Applying as a researcher felt like the safest choice. I could back up my researcher identity. But I didn't want to apply as a researcher. Instead, I decided to apply as a creator. In the application, I wrote:

Discussing my career was the last thing I wanted to do though, because I'm not applying to The HEART as a researcher. I'm applying as a creator, because that's the area where a residency—especially a residency focused on love between self, others, and the

^m A pseudonym.

environment—would help me grow and develop the most personally, emotionally, and spiritually.

I want to come to The HEART to connect with (love) myself as an artist. I've been a creative person my whole life. Sewing, knitting, taking photos, creative writing—these are some of my creative practices and hobbies. But even though other people see me as an artist, I don't see myself as one.

I went on to detail what I wanted to do at The HEART. In my proposal, I was brutally honest and reflective about my hang-ups over seeing myself as an artist. As part of a longer answer about exactly what my project would be at The HEART, I wrote:

I'd like to use my daily practice of walking the land and my creative practices to connect to myself, other human and non-human beings, and the environment. Through this, I'll work to overcome my perfectionism and insecurities.

I come from a craft background, and craft and arts are often seen as being divided. That is part of why I have a difficult time seeing myself as an artist, but shame and perfectionism are also issues. I have no formal art training, and I feel uncomfortable claiming status that I don't feel like I've "earned." And perfectionism? Coming from a craft background, I

was taught that the ultimate goal was handmade perfection—neat backs of embroidered pieces, and exquisite, perfectly exposed, dust-free photographs. Even though I don't expect myself to be perfect in other areas of my life, I do when it comes to creative activities, which is... stifling. (It's also not loving behavior.)

Although I struggle to call myself an artist, I do call myself an arts-based researcher. However, I have a hard time putting my personal art making before research art making. I'm applying to The HEART as a creator, rather than a researcher, so I can use this residency to focus on art making *for me*. Making art for myself (instead of for my dissertation) would help me connect to myself as an artist, and I see this happening at The HEART with three components and practices: walking, photography, and textile arts.

As part of the application, I had to record a video and put together a portfolio of my creative work. I gathered some published poetry (Shopa, 2020a), an article about my history as a photographer (Shopa, 2020b), photographs of recent textile work and works in progress (e.g., Shopa, in progress; see Chapter 7). I revised my CV to look more like an artist's CV and sent off the application on July 1st, 2021.

Less than two weeks later, I received an email from The HEART:

July 16, 2021, 10:37

Subject: Creator Residency at The HEART - Fall 2021

Dearest Amanda Shopa,

It is with great joy and a full heart that we write to inform you that your application to be a resident researcher/creator at The HEART Center for Research & Creation has been selected for the Fall of 2021.

We have been moved by your authenticity, sincerity and vision to contribute to the visibility of what we hope will be a quickly-growing field of exploration: Love-Studies. We are delighted to invite you to contribute to our work and we look very forward to all of the discoveries, questions, and wisdom that will emerge through your practice.

We have reserved your room beginning October 4, for the duration of 8 weeks. [...]

I burst into tears.

I'd finally put together an artist portfolio. I'd been honest in my hang-ups over being "an artist." I'd been accepted into a residency, a part of the Art World. It would be in France!⁴⁹

But I had applied from the Land of No Cancer, and I'd since crossed over to the Land of Cancer.

I no longer had time to worry about calling myself an artist. As Dr. Steeple had said just a few weeks earlier, my cancer had to come first.

Endnotes

³³ This dissertation is about identity and how my identity shifted and changed (or didn't) after the shock of my cancer diagnosis. Although first-generation teacher identities are no longer central to this dissertation, being a first-generation student has been a salient part of my identity for years. That identity strengthened as I became more deeply entrenched in my doctoral work.

Although my dissertation's primary focus has shifted, the first-generation piece continues to show up in my life and in this dissertation. It's also what I kept thinking about when my cancer diagnosis made me reflect on the past in a new way. Thus, I want to discuss who first-generation students are and what is known about them.

³⁴ Research on first-generation college students has exploded in the past twenty years (London, 1989; Sharpe, 2017; Wildhagen 2015). A first-generation college student (first-gen student) is loosely defined as the first in their family to go to college—in other words, neither parent has a degree.

At first glance this definition may seem simple, but there is no single definition of who counts as a first-gen student. How the term is defined is dependent on who is using the term and for what purpose (Nguyen & Nguyen, 2019; Sharpe, 2017; Toutkoushian et al., 2018; Wildhagen, 2015). The term is primarily used in higher education, where identifying first-gen students is used in admissions, to provide financial aid, to create programs and supports for first-gen students, and in institutional and programmatic "diversity" statistics (Sharpe, 2017; Wildhagen, 2015).

In a review of the literature, Nguyen and Nguyen (2018) found eighteen different definitions of first-generation college student in use. The Department of Education even has multiple definitions for first-gen status: the legislative definition says no parent in the household has a bachelor's degree; one research definition allows for no degree after high school; another research definition allows for no education beyond high school (Sharpe, 2017). And colleges and educational groups often use their own definitions to determine who counts as a first-gen (Sharpe, 2017).

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The term first-generation college student masks the importance of race in the educational experiences of students (Nguyen & Nguyen, 2018). One could argue that the term was created to do just that. Sharpe (2017) argues the term “entered the legislative lexicon in 1980 as a better way to identify disadvantaged students without referring to race or ethnicity” (para. 4).

Nguyen and Nguyen argue that having an unclear definition of who counts as a first-generation college student “leads to a muddled understanding of the actualized inequality facing first-generation students” (2018, p. 147). They also note that research studies about first-gen students primarily rely on data from young white students, even though “it is collectively affirmed by scholars that first-gen students are more likely to be low-income, racial/ethnic minorities, female, and older” (2018, p. 154).

First-gen status is not a stand-alone social force, and studies often fail to acknowledge that first-gen status is “a circumstance born from other social forces” (Nguyen and Nguyen, 2018, p. 153). Nguyen and Nguyen say the term must be used intentionally to “uncover the precise social realities studies in this population face, unique from the inequalities defined by other social forces alone” (p. 156). Ultimately, they criticize studies for not addressing the intersection of race and generational status and argue that focusing on generational status obscures the importance of race and how race shapes a student’s experience on campus. Because the research about first-gen students uses an inconsistently defined population, the term first-generation college student itself “relies on a false binary” (Nguyen & Nguyen, 2018, p. 154).

I recognize this is an issue, but have no solution. This is a significant issue that needs to be clarified and addressed by future researchers.

³⁵ I grew up knowing I would attend college. It was a strong family expectation, especially from my mom. And I was an academically strong student, so I always thought college was a place where I belonged.

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Literature about first-gen students has, unsurprisingly, been focused on the college experience. Generally speaking, the literature about first-gen students can be divided into core categories of “getting there,” “being there,” and “getting through” (Terenzini et al., 1996; see also Jehangir, 2010a, table of contents). Although there is some overlap across the areas, literature about getting there explores getting FG students into college (Kantamneni et al., 2018; Saenz et al., 2007). Literature about being there focuses on academic and social issues that first-gen students face in college (Collier & Morgan, 2008; Jehangir, 2010a, 2010b; Jehangir & Deenanath; 2018; Longwell-Grice et al., 2016; Orbe, 2004; Saenz et al., 2007; Stephens et al., 2012), and how first-gen students relate to their families, experience changing family dynamics, or find support in their families (Jehangir, 2010a, 2010b; Jehangir & Deenanath; 2018; Jehangir et al., 2019; London, 1989; Longwell-Grice et al., 2016; Orbe, 2004; Saenz et al., 2007; Stephens et al., 2012). Literature about getting through examines how post-secondary institutions can retain first-gen students (Longwell-Grice et al., 2016; Saenz et al., 2007) and resilience and persistence of first-gen students (Banks-Santilli, 2014; Collier & Morgan, 2008; Stieha, 2010).

³⁶ Using a critical cultural wealth model framework, Garriott et al. (2021) examined students’ sense of belonging and connection at two- and four-year institutes of higher education. Compared to their peers, students of color and first-gen students reported lower levels of belongingness and connection at four-year institutions, but higher levels of belongingness and connectedness at two-year institutions.

This rings true for me. I definitely felt like I fit in better at my community college than my traditional college. At the community college, I took daytime classes (which skewed younger, although not necessarily “traditional aged”) and nighttime classes (which skewed older, with more working adults of “non-traditional age.”). No matter when I took classes, I didn’t feel out of place.

Garriott et al. (2021) also found that both first-gen and non-first-gen students reported that campus classism influenced how connected they felt to their school and what sort of

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psychosocial distress they felt. “Classism is perpetuated in higher education institutions and has been shown to compromise students’ psychosocial and academic outcomes. Specifically, institutional classism fuels an oppressive cycle where organizational structures exclude those with lower class privilege” (Garriott et al., 2021, p. 2). Unsurprisingly, navigating classism is also influenced by race (“socio-race”). As a white student, I didn’t experience racism on campus. My experiences were heavily influenced by my family’s socioeconomic status. But for students of color, race and class in higher education are tightly linked and experienced (Garriott et al., 2021).

³⁷ When considering why first-generation students feel a lower sense of belonging and connectedness on college campuses, Ma and Shea (2021) suggest non-school obligations such as work and family make for limited time to participate in social and campus activities. They say that “for FCGS who are commuters and juggling multiple responsibilities at work, school, and home, connecting with and seeking support from their faculty, peers, or family can be challenging” (p. 100).

This was absolutely the case for me when I transferred to the women’s college to complete my undergraduate degree. I was a day student on an almost entirely residential campus. When I started, both the library and the student center were undergoing renovations. This meant that day students—especially new ones—didn’t have anywhere to congregate. We also didn’t have access to resources like computer labs, which were inside the locked dorms that we didn’t have keys for.

I also was a first-year transfer student, which meant I wasn’t in any of the traditional first-year classes where I might get to widely meet other first-years. I found my pockets of people, but I was not heavily involved in campus because so many activities were in the evenings or on weekends and I was working throughout my studies. In fact, I applied for two on-campus positions (as a campus tour guide and as a writing center consultant) and was told I wasn’t considered for those positions specifically because I was a day student. More than a year into my

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studies, the library and student center were finally finished, giving day students a place to meet each other and hang out. (We did have to ask the college to put a keyed lock on the day student room, because residential students wanted to come in and use our computers!) I also became the Day Student Coordinator for the Orientation Committee, which gave me a way to meet incoming day students.

I am proud of the college I attended, and I am happy I went there; I am not trying to denigrate the institution. Yet when I consider the structural factors that made up the culture of my four-year college, I am able to better understand why I found it so difficult to ask for help in organic chemistry. I didn't know how to ask for help, but what help existed was also difficult to access because the resources were aimed at students who lived on campus and worked far fewer hours than I did off-campus.

³⁸ In Tate et al. (2015), first-gen students reported that they felt pressured to choose a “good career” by their parents, who thought that some fields and majors were more prestigious and stable than others. Work by other researchers (e.g. Manzoni & Streib, 2019; Trejo, 2016) had found that first-gen students choose majors that are associated with “good careers.”

In a quantitative study conducted using data from the National Longitudinal Study of Youth 1997 Cohort, Trejo (2016) found a statistically significant difference in the major choices of first-gen students and non-first-gen students. Trejo found a student's gender, cognitive abilities (as measured by the Armed Forces Qualification Test), family income, and race all have statistically significant effects on college majors. Even when controlling for those factors, however, Trejo found that first-gen students chose statistically different college majors than non-first-gen students. As occupational concentration and expected wages of a major group increased, so did the likelihood that first-gen students would choose that major compared to otherwise identical non-first-gen students; as unemployment rates of major groups increased, first-gen students were less likely to choose that major. first-gen students were more likely to

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major in computer science and math, health care, engineering, education, psychology and social work, and social sciences. In short, when compared to non-first-gen students, first-gen students tended to choose majors with “strong labor market rewards and a clear career path” (Trejo, 2016, n.p.).

Trejo (2016) suggests that “first-generation college students may lack family members accounts of the non-financial rewards to a college education, leading them to give the expected market rewards of a major more relative weight when selecting their field of study” (n.p.). He also says first-gen students may emphasize the rewards of the labor market when choosing a major, may have to answer the questions about why they chose to attend college more frequently than non-first-gen students, and may have certain pressures put on them that lead to their major choices.

More recent research (Manzoni & Streib, 2019) finds that continuing- and first-generation students have access to different cultural and social capital, and this influences their career and major choices. They found continuing-generation students (men and women) are more likely than first-generation students to major in the humanities and arts, and for men, social sciences and STEM. First-generation men and women are more likely to major in business, and first-generation men are more likely to major in vocational fields. Although the differences were not as great, Manzoni and Strieb (2019) also found that first-generation students were slightly more likely to major in education and health (2019).

³⁹ A teacher’s lived experiences influence their teacher identity development, how they teach, and how they interact with students (Aspinwall, 1986; Clark/Keefe, 2016; Dharamshi, 2019; Izadinia, 2012; Kissling, 2014; Olsen, 2011). As Aspinwall (1986) says, “study of teachers’ life histories is offering insight into the ways in which teachers’ life experiences influence their careers, their development and even their choice of subjects to teach” (p. 210).

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⁴⁰ Having a “better” or “easier” life than one’s family members is commonly mentioned by first-generation students and/or their parents as one of their motivations in attending college and choosing careers (e.g. Jehangir, 2019; Tate et al., 2015) In Jehangir et al. (2019), participants’ career choices were influenced by intrinsic and extrinsic factors. Intrinsic motivations, such as joy and a sense of meaning, were often shaped by a critical event in their lives, such as obtaining health care. Regarding external motivations, participants indicated they wanted to make their families and communities proud, they wanted to “raise the prestige of their parents and community” (2019, p. 8), and they wanted to provide and have financial stability. These participants sought a balance between financial security and upward mobility for themselves and their families with their own individual interests and passions (Jehangir et al., 2019).

Participants also reported wanting to be agents of change (Jehangir et al. 2019). These participants—who were people of color, immigrants and refugees, and/or from low socioeconomic households—felt they were described as having deficits. They wanted to challenge these perceptions and use their careers to break barriers and fight stereotypes. As Shelton (2013) said, “First generation students sought college degrees in order to realize careers that would lead to economic stability, or to change the social injustices they experienced as children” (p. 59).

⁴¹ Using theories from Communication Studies, Orbe (2004, 2008) researched whether or not first-gen students found their status to be a salient part of their identity and how students enact this status through interactions with others. Orbe’s participants came from six different campuses ranging from small commuter colleges to large universities, included undergraduate and graduate students, traditionally age and non-traditionally aged students, and more than half of the 79 participants were people of color.

For some students, first-gen status was a highly salient student identity (Orbe, 204). For these students, FG status was a central part of their student identity; for some, this served as a key motivator in pursuing college, while other participants said that this status added pressure to

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their college experiences. Orbe says that “several students of color were particularly adamant” in sharing how their FG status was important because it was a link to others in their families who could build on their success in college (2004, p. 137). Orbe also found that for some participants, FG status was a salient aspect of their identity because they felt they experienced hardships their non-FG peers did not experience; Orbe reports that “it seemed most relevant to students who were attending a selective university ‘where students had a lot of money’ ” (2004, p. 138).

For other students, the salience of their first-gen identity was variable (Orbe, 2004). For these students, the salience of their FG identity was contextual. One part-time doctoral student said that she was aware of her status when taking certain classes, when she felt like she “started on a different level than a lot of people. And [she] was always trying to catch up” (Orbe, 2004, p. 139).

Finally, some students’ FG status was a nonsalient part of their identity. These students said they had never considered themselves to be first-gen before being informed of the study. Interestingly, all of these students attended “less prestigious campuses.” Also, the only four-year university participants who found their FG status to be nonsalient were traditionally aged white males (Orbe, 2004, p. 140).

A first-gen student’s status was known at home, and oftentimes in their communities, but on campus, there was no overt marker of being a first-gen student (Orbe, 2004). Students had to decide how to enact their college student identity at home, in their home communities, and on campus. Speaking of campus interactions, only one student, a white woman, reported being proud to disclose her identity. Some students reported feeling a negative stigma attached to being a first-gen student, and students also assumed that their peers were non-first-gen, until someone disclosed otherwise (Orbe, 2004).

Orbe (2004, 2008) found that a saliency of a first-gen status was influenced by context (being at home vs. school) and type of college campus and that first-gen status appeared to be

Endnotes—continued

more salient when it intersected with other identities such as race, age, or gender. Orbe (2004) found that “students of color, students from a lower socioeconomic status, and nontraditional female students most often described a high saliency regarding their first-gen college] status” (p. 140). White students, students from a middle to high socioeconomic status, and traditional aged students were more likely to have variable salience in their identity. Finally, he found that first-gen students lack any sense of community when in groups of first-gen students; when first-gen students supported each other, it was in small groups of two or three and not in larger groups. Orbe said first-gen students do not have a collective “we” (Orbe, 2004).

Orbe’s work (2004, 2008) is nearly twenty years old, and I wonder how this salience may have changed over time as programs for and recognition of first-gen students proliferate in high schools and colleges.

Also, the fuzziness and complexity of “first-generation college student” that Nguyen and Nguyen critique (2018) may help explain why I connected with it when I first heard it. The term masks racial identities (Nguyen & Nguyen, 2018), but in my experience, my whiteness often masks the economic realities I grew up with. In my case, being able to use the term “first-generation college student” has quickly alerted people that assumptions they have made about me based on my race were incorrect.

⁴² When I was reviewing the literature about first-gen students and first-generation college graduates, I uncovered a genre used in telling their stories. I refer to it as the first-gen genre; it applies to both students and graduates. First, first-gen students are described as different from and deficient compared to “traditional” students. Next, their trials and difficulties are detailed. Finally, first-gen students are found to “overcome” their family histories and “better” themselves compared to their parents (for a clear example of this, see the title of Blackwell & Pinder, 2014; see also London, 1989; Longwell-Grice et al., 2016; Saenz et al., 2007; Tate et al., 2015; Terenzini et al., 1996).

Endnotes—continued

The first-gen identity, like other identities (Holland et al., 1998), is socially constructed (Orbe, 2004, 2008; Nguyen & Nguyen, 2018; Wildhagen, 2015). Stories—narratives—are also socially constructed (Frank, 2013), and it can be hard to break free from the norms of these stories (Segal, 2007).

As much as I want to, I'm not sure I've successfully resisted the norms of the first-gen genre in this piece of writing.

⁴³ First-gen students tend to link their major to specific occupations, while continuing-gen students tend to see the value of a major in the skills they learn (Shelton, 2013). Ultimately this results in a split where first-gen students seek out careers that are different from those of their parents, while continuing-generation students want careers similar to their parents. For continuing-generation students, post-secondary education reproduces social class, whereas for first-gen students, higher education acts as a means of social mobility (Shelton, 2013).

Furthermore, since people tend to be surrounded by others of similar socio-economic backgrounds (DeOrtentiis et al., 2022), first-gen students and continuing-gen students are exposed to different career or job possibilities, and have access to different social and career networks (Tate et al., 2015; see also DeOrtentiis et al., 2022, although their focus is on student's socioeconomic status rather than generational status). For example, continuing-generation students may have more access to internships through their parents (Tate et al., 2015). Because continuing-generation students have been exposed to more people with college degrees, they may also have a better idea of how flexible college majors can be when applying for jobs (Shelton, 2013; Tate, 2015).

If I'd attended the Arts High School, I almost certainly would have been exposed to more career possibilities for arts- and creative-field majors (Manzoni & Streib, 2019). But at the time, the idea that a major would have value beyond a job was beyond my grasp at the time. Honestly,

Endnotes—continued

I still feel the imprint of this thinking today. I wonder about the value, career-wise, of getting a PhD when I'm not pursuing tenure track professorships or school administrator roles.

⁴⁴ Bourdieu's theories of distinction and capital exchange apply to college students, according to Manzoni and Streib, 2019. These researchers find that students habitually distinguish themselves based on class structure.

Those from more privileged background, such as continuing-generation students, show their status in part by "*distancing themselves from necessity*"; less advantaged people, such as first-generation students, distance themselves from higher social positions by "*making a virtue of necessity*" (Manzoni & Streib, 2019, p. 582, emphasis in the original). Put simply, first-generation students make economic decisions about where to attend college, while continuing-generation students show "they are not bound by economic need" (Manzoni & Streib, 2019, p. 582).

Interestingly, this pattern of making virtue of necessity or distancing oneself from necessity also applies to college majors (Manzoni & Streib, 2019). First-generation students tend to choose majors associated with stable careers and high pay. Yet, continuing-generation students can distance themselves by choosing majors that are not associated with high pay. "In particular, Bourdieu argues that privileged individuals use the arts to show that they can focus on a field known for its intrinsic, rather than extrinsic, rewards" (Manzoni & Streib, 2019, p. 583).

Choosing to attend college full time as part of the PSEO program was absolutely making a virtuous choice in my family.

⁴⁵ I've focused a lot on how my status as a first-generation student influenced my decision to not even consider applying to the Arts High School. But focusing on my status as a first-generation student, and my family's expectations for what I should get out of college, risks putting the burden of belonging on me. As if it's an individual choice.

The art world itself isn't off the hook.

Endnotes—continued

The art world has not been particularly friendly toward people of color (e.g. Buren, 1973; Carroll, 2016; Estep, 2002; Houston, 2017; Juneja, 2011; Lee-Yang, 2018; Miranda, 2020; Ober, 2018), working- and middle-class people (Bahler, 2019; Stalp, 2015), or women (Bain, 2004 and 2005; Nochlin, 1971/1989; Stalp, 2015).

I've briefly discussed class above (also see Bahler, 2019 for a detailed breakdown of how much money matters in the pursuit of art), and as a white person, I don't face racism, so that wasn't an issue that kept me from the art world. But I'd like to talk about the last point—women and the art world.

Men's experiences in the art world are treated as standard, while women's experiences are gendered (Stalp, 2015). Women are frequently discouraged from pursuing art (Nochlin, 1971/1989; Stalp, 2015), and have to consider how family and children might fit into an artistic practice (Bain, 2004; Stalp, 2015). Women have to fight to make their art in a way that men don't (Bain, 2004; Nochlin, 1971; Stalp, 2015).

And then there's the issue of the art/craft divide.

Women who work in "fine arts" such as painting or sculpture are often seen as hobbyists, rather than artists (Bain, 2005; Nochlin, 1971/1989; Stalp, 2015). I am a textile artist, and women have been at the center of textile work since the beginning of human history (see Barber (1995) for an excellent history of textiles and women's work; see also, Postrel, 2020 and St. Clair, 2018). Creating, using, and embellishing textiles have long been seen as women's work, and as craft rather than art—and even that craft ranks low in the hierarchy of craft (Auther, 2008; Ługowska, 2014; Tyson, 2016).

Over 40 years ago, Miller and Swenson said, "Women artists must work in pieces—pieces of time, pieces of money, pieces of material. Women have always had the leftovers from society with which to work" (Miller & Swenson, 1981, as quoted in Bain, 2004, p. 183). That is still true today.

Endnotes—continued

⁴⁶ I was joking about getting a PhD in craft, of course. I had no idea that there was actually scholarship around craft. Today, the one academic journal I read most regularly is *Textile: The Journal of Cloth and Culture*.

⁴⁷ I find it telling that my mind immediately went to “doctorate = administrator.”

⁴⁸ First-generation graduate students face many of the same issues first-generation undergraduate students do (Gardner & Holley, 2011; Smolarek, 2019), and I can see how much I didn’t know about doctoral programs when I think back to my immediate, knee-jerk reactions to Felicia’s suggestion.

The night of our conversation, I went home and looked up local doctoral programs aimed at working teachers. I thought that was the only way I could possibly earn a PhD. Luckily, one of the people who wrote a letter of recommendation for me was also earning her PhD. When I told her what my GRE scores were, she encouraged me to look into a wider variety of programs. She explained to me that funding was available, and that I didn’t have to work as a teacher, full-time, while also earning my doctorate. I’m grateful for her guidance, because I wasn’t close to anyone else who had earned or was working on a PhD in education.

⁴⁹ If I’d been able to attend the residency, I would have flown into the airport in Brest, France.

Chapter 5: Active Treatment

After Visit: 8/26/2021

Surgical Oncology Provider Note (Progress, Follow Up)

Amanda Shopa is a 40-year-old female who returns for her 1st post-operative follow-up visit.

Cancer Staging

Malignant neoplasm of upper-outer quadrant of right breast in female.

Staging form: Breast, AJCC 8th Edition

- Clinical: cT1c, cN0, cM0, G2, ER+, PR+ - Unsigned

Treatment to date:

1. Genetic testing

- Hereditary Cancer - Gyn Expanded Panel: ATM, BARD1, BRCA1, BRCA2, BRIP1, CDH1, CHEK2, DICER1, EPCAM, MLH1, MRE11, MSH2, MSH6, MUTYH, NBN, NF1, PALB2, PMS2, PTEN, RAD50, RAD51C, RAD51D, SMARCA4, STK11, TP53
- Pathogenic/Likely Pathogenic Variant(s): None detected

- Variant(s) of Uncertain Significance: None detected

2. Right wire-localized segmental mastectomy and axillary sentinel lymph node biopsy (8/10/2021)

History of Present Illness:

Patient underwent a right wire-localized segmental mastectomy and sentinel lymph node biopsy on 8/10/2021. She is currently 2 weeks post-op. Final surgical pathology showed a pT1cN0 invasive ductal carcinoma with clear (uninvolved) margins. 0/2 lymph nodes were involved.

Patient has had some bruising in the dependent portion of the lateral right breast. Over the weekend, she went to the emergency department due to drainage and bleeding from a pinpoint spot in the incision. She was wrapped in an ACE. She denies any fever/chills.

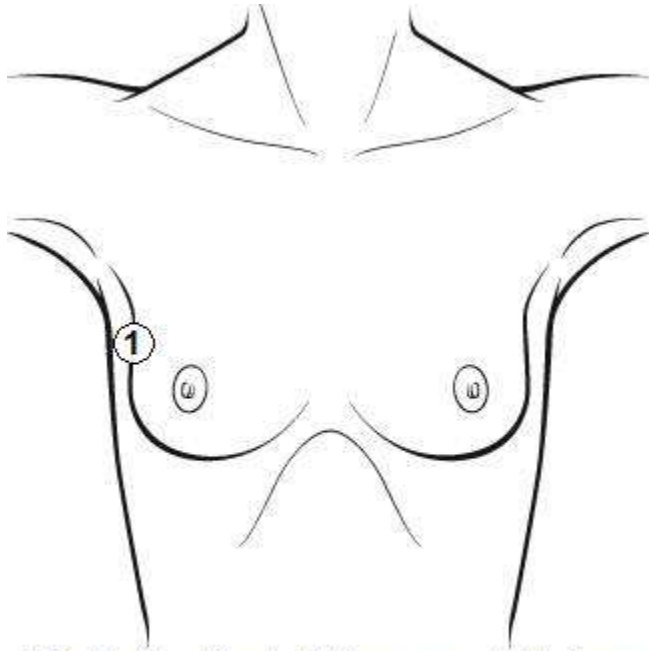
BP 115/80 | Pulse 81 | Temp 99.4 °F (37.4 °C) | Resp 16 | LMP 08/10/2021 | SpO2 98% | Height and Weight recorded

Physical Exam

Constitutional, Appearance: She is well-developed.

Pulmonary, Effort: No respiratory distress.

Chest:



1: Single incision with central dehiscence approximately 6 mm wide, draining dark clear fluid. No purulence or surrounding cellulitis.

Figure 3: Line drawing showing incision location.

This image courtesy my medical file.

Skin, General: Skin is warm and dry.

INVESTIGATIONS:

Surgical Pathology (8/10/2021):

Final Diagnosis

A. RIGHT AXILLARY SENTINEL LYMPH NODE #1, EXCISION:

– One lymph node, negative for malignancy (0/1).

B. RIGHT AXILLARY SENTINEL LYMPH NODE #2, EXCISION:

– One lymph node, negative for malignancy (0/1).

C. RIGHT BREAST, WIRE LOCALIZED LUMPECTOMY:

– INVASIVE BREAST CARCINOMA OF NO SPECIAL TYPE (DUCTAL), Nottingham grade 2, 1.1 cm in greatest dimension.

– Ductal carcinoma in-situ (DCIS), intermediate nuclear grade, solid type with focal central necrosis.

- Margins are negative for in-situ and invasive malignancy; invasive carcinoma is at 4 mm from posterior and inferior margins; DCIS is at 0.5 mm from anterior margin and 1 mm from inferior margin; all other margins are greater than 5 mm from tumor.
- Biopsy site changes.
- AJCC pathologic stage is pT1c N0(sn).

ASSESSMENT:

Amanda Shopa is a 40-year-old female with RIGHT breast cancer, s/p resection.

She had a hematoma that is now resorbing. Her incision has dehisced and is leaking out the old hematoma/seroma fluid. There is no sign of active bleeding or infection. The incision was packed with gauze today and wound care teaching was provided to Amanda and her mother. (Mother is an RN and will teach Amanda's spouse how to do wound care.) We discussed continuing to support the breast to prevent the incision from opening further. There is a large lumpectomy cavity that now will have to heal. I will see her in 2 weeks for a wound check.

We reviewed the pathology today and a copy of the report was provided. No further surgery is indicated. We reviewed the role of Oncotype DX in decision-making for adjuvant chemotherapy; this is pending. She will follow up with Medical Oncologist to further discuss. We reviewed that she will also need adjuvant radiation therapy to complete breast conservation therapy; a referral to Radiation Oncology will be made. I recommend surgical follow up with my PA-C in 3 months' time. I will see her on an as needed basis.

All of the above was discussed with the patient and all questions were answered.

PLAN:

1. Oncotype DX pending
2. Follow up with Medical Oncologist
3. Radiation oncology consultation
4. Follow up with me in 2 weeks
5. Wound packing with 1/4 inch NuGauze daily

Signed,
Surgical Oncologist, MD MSc FRCSC FACS
8/26/2021

Previous appointment:

8/21/2021 (Emergency Department)

Next three appointments:

8/30/2021 (Medical Oncologist)

9/9/2021 (Surgical Oncologist)

9/16/2021 (Radiation Oncologist)

After Visit: 10/14/2021

Progress Notes by Radiation Oncology Nurse

Patient: Amanda C. Shopa

Diagnosis: Breast cancer (IDC, stage PT1CN0, ER positive, PR positive/HER-2 negative)

Reason for Visit: Staging of radiation treatments, patient education.

Radiation Therapy Patient Education

Person involved with teaching: Patient and friend

Patient educational needs for self-management of treatment-related side effects assessment completed.

Education Materials Given

Skin care, simulation pamphlet, schedule given

Educational Topics Discussed

side effects expected
pain management
skin care
activity
nutrition and weight loss
when to call MD/RN

Response To Teaching

Verbalizes understanding

Referrals sent: None

Chemotherapy? No

Other

During staging appointment today, Amanda asked that we stop and remove the medical students from the room.

Patient expressed frustration that medical students were brought in the room mid-staging.

She explained that in her position (supine position, unclothed above the waist, arms raised flat above her head, head and chin twisted to the left side, partially inside the CT machine) her view of the providers and students was obscured. What she could see in her peripheral vision was one student who, in Amanda's words, "kept popping up and down like a nearsighted mole" next to her right axilla and breast.

Patient said that that specific student was much too close to her body, and especially her lumpectomy scar. Explained that the student was looking at her "like a diseased breast and not a human being."

Thanked patient for feedback and reminded her that she can refuse to have medical students present at any time. She said she usually doesn't mind having medical students present; she knows future physicians are only going to learn by examining patients. However, this time she felt vulnerable due to body position and inability to see. She also stated that other medical students were not a problem, just the one.

Radiation Oncologist apologized and said that she would remind all of the students that they are dealing with people and not body parts, and that she would talk to the medical student of concern individually.

Staging was completed without medical students present.

Amanda is ready to get radiation started.

Signed,
Radiation Oncology, R.N.
10/14/2021

Previous appointment:
10/11/2021 (Emergency Department)
10/11/2021 (Surgery)

Next three appointments:
10/20/2021 (Radiation)
10/21/2021 (Radiation)
10/22/2021 (Radiation)

Artistic Interruption: *Lopsided*



Figure 4: *Lopsided*, 2021, glass.

The most chaotic time period during my active cancer treatments, the time when I was absolutely using the chaos narrative (Frank, 2013) to describe my life, was the time between my surgery and the first few weeks of radiation.

My surgical incision was slow to heal, in large part because of the weight of my breast. The incision was partially open, and to help the tissue heal, it needed to be packed with medical gauze. Of course, I couldn't pack it myself, so my mother (a registered nurse) taught my husband how to pack it. Once or twice a day, I would camp out on the couch, my arm crammed behind my head, just like it had been when I'd gotten the ultrasound. Kisu would crouch down next to me, clad in gloves and a mask, and replace

the packing in my incision. I had to be on alert for any signs or symptoms of infection the entire time the wound was open. I had to be extra careful showering and washing myself, and I had to wear super compressive bras every moment I *wasn't* showering.

Because my incision wasn't healed, I couldn't start my radiation treatment. So on top of this hyper-awareness and worry I had about infection, I also worried that tiny cancer cells were growing back before we could blast them with high doses of radiation.

I saw my surgical oncologist every other week, and she kept saying she thought it would take "two more weeks." What should have been two to four weeks of recovery became closer to nine weeks of recovery.

And then, when I was *finally* approved and scheduled to start radiation, I woke up in the middle of the night with intense back pain. I had a kidney stone, and even though it was small enough that it should have passed on its own, I had to have it surgically removed.

I hadn't needed any surgeries for the first forty years of my life, and then I'd had two in less than nine weeks.

I had no control over my body, and I felt like I couldn't trust my body to work the way it should.⁵⁰

During this time, I also felt like my house was falling apart. My textile arts studio flooded and I had to call on friends and family to help me move everything out of the room, since I was still on lifting restrictions.⁵¹

Our fridge broke with no warning on a major family holiday (Chuseok, the Korean fall harvest festival). I had planned on cooking something special for dinner, but instead of spending the day preparing japchae and banchan I had to find a replacement

fridge. COVID had made it so I had only two options: a Samsung model with an ice maker, or the same model without.

Except COVID meant that the two weeks delivery date kept getting pushed back, two weeks at a time. (“Two more weeks.”) I borrowed some coolers and mini-fridges from friends at first. Eventually, my friend Abby and her husband picked me up in their truck. We managed to get the last apartment-sized fridge at the local Home Depot. It wasn’t a great fridge—condensation formed on the back wall of it—but at least we could keep eggs and meat for a few days.

Our garage door broke, the car needed some minor repairs, and the mailbox fell off its post.

“And my boob’s still not healed,” I’d say whenever something new fell apart.

I got to the point where I was afraid to go anywhere, because I worried I would fall and break a bone, or a tire would blow out on the car, or I might get abducted by aliens.

I felt stuck in chaos, in my body and in my house, and I was definitely emotionally battered by the nonstop string of bad luck. Finally, life came into a chaotic pause. My incision had healed, and I had to start radiation. (I still didn’t have a fridge.)

But starting radiation brought on complex, unexpected emotions.

When I finally got to my first radiation treatment session—one of twenty-one sessions in a row, every Monday through Friday for a month—I cried. I texted my friend Rae. “I’ve been waiting forever for this and I’m just relieved. But also, this is the beginning of the end of my active cancer treatments, and I don’t know how to do life without cancer.”⁵²

Rae admitted she didn't quite understand what I meant, but she didn't argue with me or tell me I was wrong. She was supportive, listening to my concerns and letting me voice my fears.

After we chatted for a bit, she said, "Want to make glass and move and talk about loss and grief?"

"'Make glass?' I don't know that slang," I texted back.

"Actually make a glass object." Rae explained that the dance company she belonged to had partnered up with a local glass making studio to create a two-part workshop using artistic creation, movement, and writing to work through grief.

I was still afraid to leave the house (in case of alien abduction, of course), but I decided playing with fire and molten glass was exactly what I needed to do to get over my fear of... leaving the house, being in the world, living.

At the glass studio, we used glass to burn images into heavyweight paper, and we made a paperweight. When the instructor told me how to center the color in the paperweight, I said, "I want it to be lopsided, it's about my breast cancer. It's made everything lopsided."⁵³



Figure 5: *Untitled* (detail), 2021, molten glass on paper.

After Visit: 11/18/2021

On Treatment Visit Note

Patient: Amanda C. Shopa

Diagnosis: Breast cancer (IDC, stage PT1CN0, ER positive, PR positive/HER-2 negative)

Reason for Visit: On Radiation Treatment Visit

Treatment Summary to Date:

Treatment Site: Rt Breast	Current Dose: 5245/5490 cGy	Fractions: 20/21
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Chemo concurrent with radx? No

- Oncotype DX Score: 15

ED Visit/Hospital Admission: None

Treatment Breaks: 10/29 and 11/1 due to machine malfunction.

Subjective: Amanda continues to do well with radiation treatment. She has irritation in the axilla, but denies pain.

Psychosocially, Amanda is in distress. She reports that a friend has died of cancer.

Friend was diagnosed with Ewing's Sarcoma three years ago and underwent successful treatment. Friend had a "clear scan" in August. In September, she was diagnosed with acute myeloid leukemia (AML) which was caused by the treatments for Ewing's Sarcoma.

She died yesterday.

Amanda is unsure if she wants to "ring the bell" when she completes treatment tomorrow. She says, "what's the point of all this if you can go from an all-clear scan to dead in less than 12 weeks?"

Discussed with patient that cancers are individual and cannot be compared. Discussed that her cancer is very treatable and is being treated with curative intent. Discussed

importance of completing treatments and following up with Medical Oncology re: tamoxifen and survivorship.

Expressed sympathy toward patient and her surviving friend.

Amanda says she will complete her treatments.

Nursing ROS:

Diet type: Patient's preference

Nutrition Note: Good appetite

Skin Reaction: 1-2 - Faint erythema or dry desquamation; minor wet desquamation

Skin Intervention: Mepilex given

Skin Note: Prescribed Silvadene cream for wet desquamation

Psychosocial Note: Very tired over the weekend;

(!) Patient in distress (acute - friend's death)

Pain Assessment (0-10): 0

Pain Management: Not required

Objective:

Gen: Appears well, in no acute distress

Skin: Mild diffuse erythema of the right breast with mild edema. Dusky appearance in the right axilla, minor wet desquamation.

Assessment:

Tolerating radiation therapy well. All questions and concerns addressed.

Toxicities:

Fatigue: Grade 1: Fatigue relieved by rest

Dermatitis: Grade 1-2: Faint erythema or dry desquamation; minor wet desquamation

Plan:

1. Continue current therapy.
2. Completes treatment tomorrow.
3. Mepilex dressing given to be used in the axilla.
4. Silvadene prescribed for wet desquamation.

Medication Review

Med Note: No changes per pt

Radiation Oncology

612-555-6700 clinic

Pager 612-555-8044

Please do not send letter to referring physician.

Signed,

Radiation Oncologist, MD

11/18/2021

Previous appointment:

11/17/2021 (Radiation)

Next three appointments:

11/22/2021 (Radiation Oncologist)

12/7/2021 (Therapy)

12/9/2021 (Lymphedema Therapy)

On Survivorship

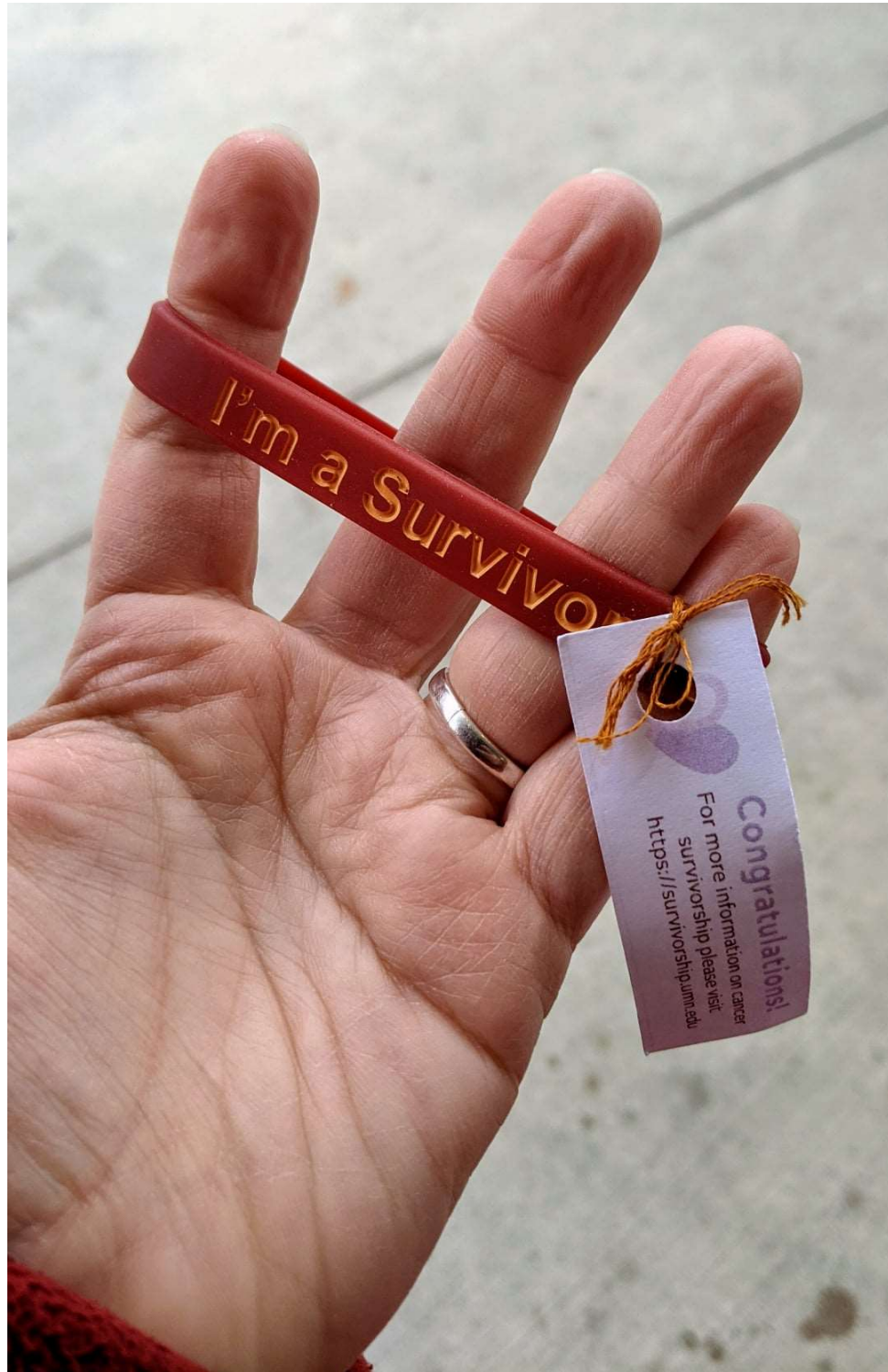


Figure 6: *Survivor*, November 19, 2021, digital photograph.

What follows is a Facebook post I wrote on November 20, 2021. It has been lightly edited for clarity and length.

I finished⁵⁴ my radiation yesterday.⁵⁵

I thought I'd be really excited, but I'm actually feeling a bit ambivalent about the whole thing.

Relieved and scared and sad and excited and tired.⁵⁶

My radiation center has a bell you can ring at the end of treatment. People clap, and you can get your photo taken if you want. I've seen people ring it a few times, in fact, a woman rang it yesterday while I was in the waiting room. She said, "I have been waiting to ring this since the very first day. I made it through."⁵⁷

I was really happy she got to ring the bell, but I chose not to.

My skin is a mess, and it's supposed to get worse for about two more weeks. I'm exhausted. I'm still at risk of developing lymphedema.

It's the end of my active treatment, yet nothing is really done.

But what really stopped me from "celebrating" is that I found out Thursday morning that I lost a friend to cancer.

Mariel, my friend Cynthia and I met online through our creative writing. We've been friends for five or six years. And we've all been diagnosed with cancer.

Mariel was diagnosed with Ewing's Sarcoma three years ago, and was in remission when Cynthia was diagnosed with breast cancer. When I was diagnosed, I sent the group chat a message that said something like, "Mariel, if I were you, I'm not sure I would believe what I'm about to say, but..."

She wrote back, "I knew as soon as I read it that you had cancer too."

Mariel got another all-clear scan in August and we all celebrated, but in October she was diagnosed with leukemia—caused by the treatments for her first cancer. And less than six weeks later, she's gone.

I know you can't compare cancers, but it's a real mindfuck to witness a friend go from an all-clear cancer scan to gone from a second cancer in twelve

weeks while you're being expected to celebrate your own cancer treatments. Ringing the bell—a celebration—just didn't feel right, and I knew I'd burst into tears if I did.⁵⁸ (And what was I going to do, explain to a waiting room full of people with cancer that I'm mourning a friend who just died of cancer?) I simply wanted to finish my treatment and get the hell out of there so I could cry in my car.⁵⁹

The receptionist gave me this bracelet to mark the end of my treatment. It's another thing I'm feeling mixed emotions over.

You're considered a "survivor" from the moment of diagnosis. But I don't feel like I'm a survivor.⁶⁰

Yet.⁶¹

Rest in peace, Mariel de Jesus. You are missed. ❤️

Artistic Interruption: *Natural Patterns*



Figure 7: *Natural Patterns*, 2022, quilt made of cyanotypes on cotton fabric.

At my follow-up mammogram, I asked the mammogram tech to show me my original mammogram and what they were looking at. She pointed at a foggy spot on the image.

“Oh,” I said, “it looks like a four-leaf clover.”

She gave me a funny look, but didn’t say anything.

Later, I’d know that it looked like a four-leaf clover because the tumor was “spiculated.” Spiky. And in breasts, the vast majority of spiculated masses are cancerous (Sturesdotter et al., 2020).

The cancer treatments were draining, physically and emotionally. But the

treatments had a finality to them, an end date. Eventually the incision healed, and I had received all of the radiation I was going to get. I have on-going issues with lymphedema in my breast, even though I did every single thing I was told to do to prevent it from developing.

What has been a harder thing to come to terms with is how I view myself and my body and my relationship to my body, what Frank (2013) calls body-relatedness.

At my follow up diagnostic mammogram and ultrasound, the medical team pressed the ultrasound wand so hard against my skin that I could feel it for days. There was no visible bruise, but I could feel where they had jammed that wand against my skin. At night, in bed, I thought I could feel the tumor growing.

Language used to describe cancer often relies on violent metaphors. A battle, a war, a fight. The tumor may be described as an invader. Invasion even built into the name for my type of cancer, *invasive ductal carcinoma*. The lymph nodes that were removed were *sentinel* lymph nodes—lymph nodes that stood guard over the cancerous tumor (Bell & Iqbal, 2021).⁶²

Other people with cancer find positive ways to describe their cancer. Journey metaphors are common. Cat Bordhi, a popular knitting designer who came up with new ways to knit socks using two circular needles and created a very popular cast on for moebius cowls, had breast cancer (twice) and endometrial cancer (once). She died of cancer in October 2020, and in her *New York Times* obituary, her daughter described her mother's relationship with cancer, saying: "She was really unique in how she approached cancer. [...] She chose to view the cancer on her body as a friend she was on a journey with" (Jenny Low, as quoted by Rosman, 2020, para. 26).

A few people, including musicians Sheryl Crow and Melissa Etheridge even describe cancer as “a gift” (Nash, 2014).

I did *not* view cancer as a gift. And I couldn’t view my cancer as a friend. But I didn’t like the journey metaphor, either.⁶³ And I hated all of the war talk.

The cancer cells weren’t out to get me. One cancer cell didn’t decide to reproduce and recruit its friends into a murderous rampage. The cancer cell was just doing what it was supposed to do: reproduce.

But my dislike for the war metaphors wasn’t about semantics. Metaphors are mapped on, and experienced by the body (Banks, 2003), and I didn’t want to be at battle with my own body. I already wondered if I had brought the cancer on myself, by being overweight for so long, by not exercising enough, by eating too much sugar and not enough cruciferous vegetables. (Broccoli was supposed to kill cancer cells, right?)

I wanted to protect my body, I wanted to take care of it. That meant, first and foremost, removing the tumor. It also meant swaddling myself in tight dressings and wearing a compressive sports bra twenty-three hours a day. It meant asking others for help and saying no. (And it meant eating more broccoli.)

Going to war with my body didn’t feel like protecting it.

How could I find a way to protect my body, without seeing it like a battlefield, without seeing the tumor like a friend?

* * *

The answer—at least the answer for now—came through artmaking.

I started experimenting with fabric cyanotypes in the early spring. Cyanotype printing is one of the oldest photographic processes, and cyanotypes are usually shades of

blue. Historically, cyanotypes frequently feature natural images such as feathers, ferns, or algae (James, 2015).



Figure 8: *Natural Patterns* (detail), 2022, cyanotype on fabric.

The spring was very snowy and cold. Even though the land seemed to be in a state of rest, it was easy enough to find leaves, brown flower stalks, stems and seeds. As the seasons changed, I continued to collect plants, creating prints of the plants I chose to place in my garden, the plants that arrived in my garden naturally but weren't a bother, and the invasive plants (primarily creeping bellflower). All of these plants, like my tumor, were natural. Even the bellflower, which threatened to choke out everything else.

As I made the cyanotypes, I saw that the malignant tumor was like the creeping bellflower. It was neither my friend nor my enemy. It was simply a clump of cells that

needed to be removed. It was invasive, but it wasn't unnatural.

In this cyanotype quilt, I wanted to show that the cancer tumor, as well as the physical side effects and reminders of cancer treatments, were natural, even when they were invasive. To do this, I created cyanotypes using mammogram images, photos, and natural materials.⁶⁴

Creating this piece—taking time out in nature, feeling sunshine on my skin, letting the seasons change—gave me time and space to think about how I viewed my tumor, my body, and my relationship with both.



Figure 9: *Natural Patterns* (detail), 2022, cyanotype on fabric.

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⁵⁰ Thinking of Frank's work (2013), I can see how I was dealing with at least two problems of embodiment during this time period. I felt like I had no control over my body or what was happening to my body, and I didn't know how to relate to my body. I felt like I couldn't trust my body to be healthy. Perhaps I had abused it too much. In any case, I didn't know how to be with my body anymore.

⁵¹ I want to linger on my textile arts studio flooding for a bit.

Spaces where students work and live impact students' well-being and academic work (Hopwood & Paulson, 2012), and studios are important sites for artists (Bain, 2004; Porter Lofaro, 2017). Studio spaces are an important part of an artist's creative practices and—for women especially—their professional identity (Bain, 2004; Porter Lofaro, 2017).

In my previous homes, my sewing/crafting/making place was part of the shared family space. I'd make at the kitchen table, or in the living room; I'd cut out fabric on my hands and knees on the floor, or on the dining room tables. I didn't have a private space.

Although you can make art under these conditions, it's much easier to have dedicated space for artistic practices (Porter Lofaro, 2017); women especially find value in having, as Virginia Woolf (1929) said, "a room of one's own" (Bain, 2004). Remember Miller and Swenson's argument that women artists work with pieces of time and materials? They also work with "pieces of space" (Bain, 2004).

When we moved into this house, we were able to create a craft room. As I started to call myself as an artist, as I started to see my work as craft and art, I began calling it my textile arts studio. Although I continued to knit in front of my computer (while watching Netflix) or on the couch (while chatting with friends or family members), my studio was a place where I could store all of my materials and work in (mostly uninterrupted) peace.

Then COVID hit, and I needed a private space to work. The textile studio was the easiest place for me to go, and as the pandemic dragged on, my paid work and doctoral work took over

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the space. I actually had to remove the sewing machine from the table because of how much space non-artistic work took up.

“Spaces are not a backdrop of activities but they become an integral part of what people do in everyday life” (Porter Lofaro, 2017, p. 112) and as the activities in my space changed, so did the space itself, and vice versa.

My studio space had gone from being an artist’s space—where I could problem solve, work out ideas, lose track of time in a state of creative flow, and leave an utter mess behind a closed door—to being an office space. In an effort to separate work-life from home-life during COVID (Liu, 2020), I avoided the room as much as possible.

(I am aware of how tone deaf this may sound, considering how many people had to attend work and school in much more limited spaces during COVID. I do recognize how fortunate I am to live in a house where my husband and I could have separate office spaces, and where I could have a room of my own. At the same time, losing that space was hard, and I think it’s worth acknowledging how that made things even more difficult.)

A year into COVID, when I found out I’d be on fellowship, I was thrilled. I was going to get my studio back!

Then I was diagnosed with cancer—*OK, so maybe I wouldn’t be able to use my studio much in the fall, but after treatments I could, and at least I could spend time in the space, dreaming about future projects, even if I was too tired to work on them right now*—and then the studio flooded, making it so every single thing in the room had to be removed. We’re talking multiple sewing machines, hundreds of yards of fabric, a half dozen large bins of yarn and embroidery floss and fiber, beads, a gravity-feed iron, dozens and dozens of books...

The only thing we could do was jam all of the materials into other areas of the basement. There couldn’t be organization; things simply had to go where they fit. If I wanted, I could take over the kitchen table as a working space, but I could barely find anything I needed. Even the

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darkroom became nearly impossible to use—the entry was almost blocked off, and it was difficult to set up the exhaust fan in the window when I needed it.

In her work with fine artists living in the Toronto area, Bain (2004) found that for women, “to lose the studio is to lose a substantial component of their professional selves” (p. 174). In the year or so before my cancer diagnosis, I had finally started to see myself as an artist, to claim the title—and having studio spaces (the textile arts studio and the darkroom) were a large part of that. Then I lost those spaces, first due to COVID, then due to the flood.

This compounded the lack of control I felt during my cancer treatments. I felt like medical providers had primary control over my body, and then I lost my control over my private creative space. It felt like I lost control over one of my coping mechanisms.

I must admit, though, there was a positive to the flood. When I was melting down over the whole thing, my husband said something like “behind every crisis is a good opportunity.” He suggested we redo the room entirely. We had the room redone down to the studs, including having an egress window installed. It took a year to get my space back, but the space is much improved.

⁵² The benefit of living in chaos, with a breast that was very slow to heal and a house that needed non-stop repairs, was that I didn’t have to go back to normal. I didn’t have to act or be normal. I didn’t have to face the future, because there was none.

When radiation started, I finally had an end date of my treatments, a date in the future. After that, I’d have to “get back to normal.” And I didn’t know what normal looked like after “had cancer.”

⁵³ What’s interesting to me is that now—not even a year after this all happened—I can barely remember everything that went wrong during this chaotic time in my cancer experience. I

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remembered the physical problems and the basement flooding, but time has provided narrative smoothing, and I forgot about the rest of it.

I had to look at my day planner, text messages, and my journal to remember everything else that went into creating a chaos narrative. As I sifted through those materials, I felt tension rising in my body, and emotions washed over me. I wondered if I should include this story at all, if I should go into this much detail. Is this story really important? Or does it just come off like whining? Why dwell on any of this, when everything is fine now?

Frank (2013) says that someone can only provide narrative structure to the chaos narrative when the chaos has subsided; he also says that chaos narratives make the listener very uncomfortable.

In this moment, as I write this, I'm both the teller and the listener. And I'm uncomfortable.

Perhaps that's reason enough to include this narrative.

⁵⁴ The term *cancer survivor*, which was coined approximately forty years ago by a doctor with cancer, is commonly used in the United States. It is meant to point out that people are not cancer "victims" as well as bring attention to the fact that cancer "patients" have on-going needs (both emotional and physical) after cancer treatments have "ended" (Kaiser, 2008; Khan et al., 2012). According to the National Cancer Institute at the National Institutes of Health (n.d.), "In cancer, a person is considered to be a survivor from the time of diagnosis until the end of life."

This seems like a direct, simple definition, but it's actually very open-ended and flexible; in fact, some organizations even consider any family members or caregivers as cancer survivors (Stephens, 2017) or co-survivors (Sulik, 2011). Much like the term "first-generation college student," the term "cancer survivor" is used in different ways, depending on who is using the term and for what purpose. As Khan et al. (2012) says: "The definitions of cancer survivorship remain widely interpreted depending on the purpose of the research, patient perspectives, or advocacy and policy motives of the different organizations applying the term" (Kahn et al., 2012, p. 34).

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Despite the ubiquity of the term “cancer survivor,” cancer survivors themselves often don’t find the term a good fit (e.g. Breen, 2021; Sheilds et al., 2015; Stephens, 2017).

Sometimes it’s a matter of word choice. “Previvor” is used by some people who have genetic markers related to cancer, such as BRCA1 or BRCA2, but have not yet been diagnosed with cancer (Stephens, 2017). Other survivors have used the term “aliver” to focus on living rather than surviving (Sulik, 2011).

The dominant breast cancer culture’s focus on early detection and treatment often excludes women with metastatic breast cancer from their narratives, and many women with metastatic breast cancer don’t identify as “survivors” (Jacobson, 2018).

“Thrifer” is often used in place of survivor (e.g. Breen, 2021), especially among women with metastatic breast cancer (e.g. Glenn, 2015; *Living Beyond Breast Cancer*, n.d.; Minneapolis Metsquerade, n.d.). People with stage IV metastatic breast cancer may also be called “metavivors” (Jacobson, 2018).

According to Sulik (2011) and Kaiser (2008), many people don’t consider themselves cancer “survivors” because they don’t think their suffering ranks highly enough to be called a survivor. For example, a woman whose cancer is caught “early,” and who doesn’t need chemo, might say she doesn’t consider herself a survivor. Women may also reject the term survivor because of fear of recurrence (Kaiser, 2008).

Kaiser (2008) found that some women rejected the term survivor specifically because they didn’t want to take on the social identity of a survivor. This rejection can happen for several reasons. For example, cancer may be chronic (such as metastatic breast cancer), or women may want to move on with their lives and not be reminded of cancer, or women may feel like the current breast cancer culture doesn’t focus on important things such as causes of cancer (Kaiser, 2008).

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Other women do accept and use the term, in whole or in part (Kaiser, 2008). Some women embrace the term wholeheartedly, as defined. Other women redefine the word to include uncertainty about the future, or draw on the multiple ways they are a survivor to help shape the term. Finally, some women reject the term outright (Kaiser, 2008).

Although I use the phrase “cancer survivor” throughout this dissertation, I still don’t really identify with it. I use it as a form of shorthand with medical professionals, because I know that’s a language they understand. And I use it in this dissertation because it’s much more succinct than “people who have been diagnosed with, are living with, going through treatment for, or have completed treatment for cancer.”

At the beginning of my cancer experience, when speaking with people in normal, day to day settings, I’d say “I have cancer” or “I’m a cancer patient.” After I was cleared from further treatment by my surgical and radiology oncologists, my friends encouraged me to switch to “I had cancer.” It felt unnatural to use such a definitive past tense, so for several months, I said “I was diagnosed with cancer” or “I just finished cancer treatments.” Both of those phrases felt accurate.

More importantly, they didn’t feel like tempting fate the way a confident past tense verb might. Saying I have or had cancer felt like I was calling up bad luck, encouraging cancer to stay (if it hadn’t ever left) or return (if it had left). I felt caught in a superstitious double bind.

⁵⁵ “By far, the most loaded word in the cancer dictionary is survivor” (Sulik, 2011, p. 318). Sulik says that the term survivor came from the movement to decrease social stigma related to cancer, but has become “an obligatory status” which prioritizes and ranks suffering and trauma, gives the impression that nobody with cancer is dying, and ignores quality of life issues.

Sulik (2011) says that the term survivor puts the emphasis on people who are living, ignoring those who are actively dying from cancer (Sulik, 2011). The emphasis on five-year survival rates makes survivorship look attainable to the majority of people with breast cancer, even though breast cancer can and does metastasize, even when “caught early.”

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(It should be noted that there is an opposite argument. Kahn et al. (2012) argue that the term implies a higher mortality rate from cancer than actually exists; they argue against using the term, because it “could fuel unnecessary fear about cancer among the general public,” which could in turn prevent people from seeking out medical care (p. 35).)

Sulik (2011) also argues that the term survivor says nothing about quality of life, instead focusing on number of years lived after a cancer diagnosis. Sulik points out that knowing how many years someone has lived after being diagnosed with breast cancer can be inspiring, especially to newly diagnosed patients. Yet “counting the years a person remains alive does not consider the state of her life during those years” (Sulik, 2011, p. 320). In short, surviving is not the same thing as living.

Finally, the term survivor has been criticized because breast cancer survivors are expected to be “cheerful” and hide emotions such as anger or grief, as well as the physical effects of cancer and cancer treatments (Kaiser, 2008). The survivorship language (and its association with war metaphors) also encourages a restitution narrative, even when a cancer diagnosis and treatment—even a “successful” one—leaves behind uncertainty (Kaiser, 2008). “While success stories may be inspiring, they may also be alienating” (Kaiser, 2008, p. 4).

Segal (2007) concurs, saying: “Is the opposite of a survivor a person who [...] has not had the important wake-up call that breast cancer provides? The opposite of a survivor is, in any case, by definition of person who has died, succumbed, lost the battle—a person who was not strong enough or, it seems, in some of the discourse of survivorship, positive enough, not loving enough to fix the image of [people who need her] in her mind and refuse to die” (p. 9).

⁵⁶ Cancer patients commonly feel anxiety or fear (or “terror,” as Frank, 2013, says) when treatments have ended. Often, this fear is described as fear of the cancer returning or spreading. Yet, Frank challenges that explanation, saying “that explanation, with its emphasis on cure, turns their stories into restitution narratives.” (Frank, 2013, p. 107).

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Instead, Frank (2013) suggests, the fear is about having to go out into “a world that could not, and would not understand” (p. 107) what the patient has gone through. Staying in treatment—even a treatment course that one hates, such as radiation or chemotherapy—gives the patient a place to be. It keeps the outside world at bay. “When liberation from the hospital comes,” Frank writes, “as welcome as it is, one’s real trouble begins: the trouble of remaking a sense of purpose as the world demands” (p. 107).

⁵⁷ Many radiation or chemotherapy centers have a ship’s bell mounted on the wall. At the end of treatment, patients ring the bell to indicate that the treatment is over (William et al., 2019). The practice has been critiqued because it ignores the fact that some people will never reach an end of treatment or have a positive outcome from treatment (Gale, 2019; Williams et al., 2019).

Interestingly, a study of patients who did and did not ring the bell at the same radiation treatment center found that those who rang the bell later remembered the experience of receiving radiation as more distressing than those who didn’t ring the bell (Williams et al., 2019). Williams et al. (2019) suggest that bell ringing may create a “snapshot memory” that heightens the emotions associated with the event of completing radiation.

⁵⁸ My radiation therapists knew that I was unsure about ringing the bell because of Mariel’s death, and they said that Mariel wouldn’t be mad at me for ringing the bell, and that it was worth celebrating if I wanted to.

Although they didn’t use the term, they were hinting at the issue of “survivor’s guilt.” Survivor’s guilt can indeed relate to surviving cancer when another cancer patient/survivor dies from cancer (Long, 2014). But survivor’s guilt is about more than surviving.

Cancer survivors can feel guilty for: being NED (no evidence of disease) when a fellow survivor deals with recurrence or metastasis; being diagnosed at an earlier stage than others and having an “easier” time than people diagnosed at a later stage; having an easier time with

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treatment or experiencing few side effects; having a genetic form of cancer and possibly passing those genes onto one's children; impacting the lives of other people, being unable to do the things one has normally done, or needing to ask for help; wanting to put cancer behind them rather than fundraising or wearing ribbons or being an advocate (Long, 2014).

Sulik (2011) found that breast cancer survivors also felt guilt for having cancer in the first place. One woman who had a genetic component to her breast cancer expressed guilt over not having a preventative double mastectomy, while other women with no family history wondered if they had brought their cancer onto themselves through health habits (such as weight) or life decisions (such as whether or not one had children and at what age).

⁵⁹ My issue wasn't that Mariel had died though. I didn't feel guilt over her death, only grief. My survivor's guilt came from elsewhere.

Long (2014) and Sulik (2011) find cancer survivors may feel guilty for not being positive enough or not handling their cancer diagnosis the way they think they "should"; they might also feel guilty for not having a life-changing, transformative, epiphany-inducing cancer experience. In other words, cancer survivors may feel guilt for not being a "good" cancer survivor (Long, 2014; Sulik, 2011).

These feelings of guilt relate to the cultural norms and expectations set around cancer. For women with breast cancer in America, these cultural norms and expectations are heavily influenced by pink ribbon culture (Sulik, 2011).

I believe that the feelings of guilt I had over not being a "good" cancer survivor related not only to the irrational-and-still-very-real fear that I might be inviting my breast cancer back by not "having a good attitude," but also to the fact that I was finding cancer so difficult even though my stage was early and treatable.

I had done some of the things I was "supposed" to do as a "good" breast cancer survivor. I had gotten my routine mammogram screening, and the cancer had been found early. I'd listened

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to the doctors and undergone the treatments they wanted me to do without argument. Because I was on fellowship, I was in the very privileged position of going through treatments without needing to work at the same time.

I had absolutely no reason to complain, according to breast cancer culture.

And yet, I couldn't exhibit the sunny optimism, strength, hope, and courage I saw in other breast cancer stories. I couldn't summon myself to that state of mind. I kept thinking I "should" have a better attitude, and then I felt guilty over having that bad attitude.

I was failing at being a good breast cancer survivor. I wasn't living out my socially-defined role.

Rejecting the bell ringing ritual was one way I could honor Mariel's death, but that rejection was also public refusal to pretend I was a good cancer survivor. It was a way to resist the label I never wanted.

⁶⁰ "By definition women who write narratives of their breast cancer experience are survivors; they narrate their stories only when they are emotionally and physically well enough to undertake a sustained project—typically, after successful treatment of the initial incidence of breast cancer" (Couser, 1997, p. 39).

⁶¹ I remember that the responses to this post were supportive. One friend, who was also a cancer survivor, said she didn't ring the bell because it didn't feel right to her either.

But a lot of the responses I got to this post were friends arguing that I was a survivor, that they could see the strength I couldn't see. Those are the responses that I remember, nearly a year later.

I wasn't surprised. I knew that by posting this, by stating I didn't feel like a survivor, I was going against the warrior survivor image that breast cancer survivors are expected to enact. Including the word "yet" at the very end of my post, after saying I didn't feel like a cancer survivor,

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was my attempt to soften the post with an implied promise of future “good behavior.” In the future, I would be good and claim “cancer survivor” as an identity.

But, as Bury (2001) reminds us, a storyteller doesn’t have complete control over how their story is received or responded to. The “yet” wasn’t strong enough to do what I wanted it to do.

⁶² Military metaphors in medicine came into wide use in the 1880s, with the recognition and identification of bacteria (Sontag, 1978), and cancer is often discussed with a war metaphor. It’s a battle, a fight, a war against an invading tumor. It’s also an “uncertain state of affairs,” says Sulik (2011), and “societies perceive uncertainty to be so dangerous that they develop complex classification systems to recast ambiguous situations into something clear-cut and manageable” (p. 75).

A war metaphor lends itself well to a cancer diagnosis—or to cancer as a whole, as in “the war on cancer”—because there’s a clear enemy (the cancer) and a clear desired outcome (banishing cancer from the body and surviving).

War metaphors can be empowering for patients (Marron et al., 2020; Semino et al., 2014), but the use of war or violence metaphors to discuss cancer has been critiqued for a number of reasons.

War metaphors often make patients feel disempowered, guilty, and fatalistic (Marron et al., 2020). War metaphors make it seem like patients have power over their medical outcomes and victimize those who can’t “win the war” (Marron et al., 2020). Medical providers who rely on war metaphors may view their patients as the enemy (Couser, 1997). The war trope also relies on the power of treatment instead of the power of prevention (Marron et al., 2020). Finally, the war trope may encourage the use of “heroic measures of questionable effectiveness that may cause unnecessary suffering” (Couser, 1997, p. 45.)

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And of course, there's this point: "If cancer is a war, it is one we might not win, no matter how we define victory" (Marron et al., 2020, p. 624).

⁶³ In addition to war metaphors, "journey" metaphors are frequently used to describe cancer (Semino et al., 2014). At first glance, journey metaphors may seem more positive than war metaphors. Yet, like war metaphors, journey metaphors can be empowering or disempowering.

Patients who use journey metaphors in empowering ways may view themselves as a traveler in charge of their journey, which can be a form of regaining control, or they may describe other cancer patients and survivors traveling companions, giving them a sense of community (Semino et al., 2014). Patients may also use the journey metaphor in disempowering ways, including describing the journey as difficult or feeling like they have no control over the journey. (Semino's team doesn't explain why they consider finding a cancer journey difficult as disempowering. I'm wondering why it can't simply be a neutral, description statement.)

I also noticed that researchers referred to a cancer experience as a journey. Some researchers did this without any explanation (e.g. Shields et al., 2015), but others explicitly used "cancer journey" as a framework for their research (e.g. Tighe et al., 2011).

Jacobson (2018) finds that women with metastatic breast cancer don't like the term "journey" because it implies the speaker is willingly taking part in the journey.

I don't find the journey metaphor a helpful one, and neither did my friends who had also dealt with cancer. We'd usually joke that a journey is a trip somewhere, and the only place I kept going to was the cancer center or the radiation department of the local hospital.

What I haven't seen discussed in the literature is that journey can also be used in a figurative way, to refer to a "pilgrimage" or "passage through life" and I believe this is the way that people are using journey when they refer to a cancer journey. This cultural subtext of a journey being a pilgrimage seems closely related to how women with breast cancer are supposed to see cancer as a transformative experience.

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Although Sulik (2011) focuses on the war metaphor, I believe this use of journey as a metaphor is another way that Pink Ribbon Culture specifically, and cancer culture in general, shows an expectation that someone who has cancer will turn the experience into something positive. A pilgrimage is usually undertaken to find new meaning, to learn about the greater world, or to connect with a holy or sacred place and one's own religious beliefs. One goes on a pilgrimage to benefit in some way, mentally and/or spiritually.

Similarly, a cancer survivor is expected to find some benefit from cancer. They're supposed to become better, kinder, and wiser. They're supposed to turn cancer into a positive, even though they were forced to go on this "journey" and never chose to become pilgrims.

⁶⁴ Deciding to include my mammogram images and my personal photographs was difficult. I wasn't sure anyone else would be able to "read" my mammogram images like I could. But the real issue was showing photos of my body in such a public manner.

According to Couser (1997), when breast cancer narratives include photos, they usually don't show images of the breast cancer experience. Instead, they show the breast cancer survivor in their healthy, normal lives.

Some women do show the effects of breast cancer treatments, of course. In 1993, the artist Matuschka was featured on the cover of *The New York Times Magazine* (Peterson, 2018). On the cover, one side of her body is bare, exposing her mastectomy scar. Matuschka's photo was one of the first to be shared with a wide audience (Couser, 1997; Sulik, 2011) and when I looked for images of what breast cancer treatments would look like, I found plenty of photos of healed breasts.

What I couldn't find easily however, were graphic images of breast cancer treatment.

Finally, I found Jenn Alter's blog post. In her post, Alter addresses breast cancer awareness campaigns and activities such as "save the tatas" or "go braless days." She, like

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others, argues that such activities sexualize breast cancer, and ignore the woman in favor of lavishing attention on the breast (Bahadur, 2015; Cleland, 2020; Cunha, 2015).

In her since-deleted Tumblr post, Alter shares a photo of her breast. A nipple is missing, and the skin around her breast and up to her neck and armpit are raspberry red. “Here's your fucking breast cancer awareness,” Alter writes (quoted in Cunha, 2015). “Does this make you uncomfortable? It should.”

I also found some artwork made by women who had or were living with breast cancer. While much of it was heavy on pink ribbon imagery, I was excited to find the Breast Cancer Art Project (n.d.), which features artwork from people around the world. The artwork here showed me how others had used artistic practices as part of their own healing.

In the end, I decided that I wanted to include images of my body throughout treatment; I wanted to see the images I couldn't easily find. The bruise on my breast that looked like a boot print, the deep purple marks on my nipple from where they injected radioactive tracer dye, the cloudy tumor I described as a four-leaf clover. I wanted to see these images, and I wanted to manipulate them, to make art that helped me make sense of what I'd gone through.

It didn't quite work out that way, though.

I made several transparencies of my mammogram images and well as photos I'd taken of my own body. The mammogram images printed fairly well, but the images of my body were more difficult to work with. When I tried to print them onto the treated fabric, I lost too much detail, and it wasn't clear that I was trying to show radiation burns and post-surgical rashes and bruising. Changing fabric color or exposure time didn't work. In the end, I was left with my mammogram images and one photo of my nipple showing the damage of radioactive tracer dye.

I'll need to find another way to use the photos I've taken.

Chapter 6: Rest

What follows is an excerpt from my research journal (7/21/2022); it has been lightly edited for clarity. I wrote this entry because I was struggling to find my way into this chapter.

I need to write about being at Pacem in Terris for my dissertation. It's necessary, because it's where I got to do my own private healing. Surgery, radiation, and medication were about physical healing; Pacem was about emotional healing. It was just as much a part of my cancer treatments as everything that happened in a hospital setting.

It's also where I truly dug into what I want to do. It's where I realized what I need to put *first* in my life. It helped me get clarity on my values.

And yet... I don't want to write about it. I don't want to put that experience—something that felt so personal and so sacred—up for public consumption and scrutiny.

It's not that I've kept this experience private. My friends and family know about it. But I trust them. And when I put this on paper, where strangers can read it... it

still feels a little tender, like I need to protect it, keep it to myself.

Abby has reminded me I can write whatever I need to and edit things out later. That's an idea.



Figure 10: *Pacem I*, 2021, silver gelatin print.

I sank into the wire patio chair at the end of the boardwalk. My long, rust-colored fleece jacket was zipped up to my chin, its hood slouched over my forehead. A thin layer of ice skirted around the edge of the lake. Even though it was almost December, we hadn't had any snow yet.

My phone was tucked away in the closet in my hermitage. For the first time in five months, I could turn my ringer—my phone!—off. I wouldn't need it here.

I stared at the lake. Dead grass and still-green moss lined the boardwalk, the pale brown reeds and cattails rattled dryly in the clear winter air.

I was finally alone. No appointments, no doctor's visits, nobody to answer to. I had no obligations except to rest and simply *be*.

I sat there for a long time. I thought about the skin that had started peeling in my armpit—"wet desquamation," my radiation oncologist had called it. I thought about Mariel. I thought about how bone tired I was. I thought of my dissertation and how I had no idea what to do with it, or how to get back to it. I thought about Mariel and her all-clear scan. I thought about Thanksgiving dinner we'd had at my friend Mark's house, and how happy I was that nobody in his family had suggested we go around the table and share what we were thankful for. I thought about Mariel and how I didn't get to say goodbye to her.

I wondered if I would be able to make it seven days without any books, without any doctor's appointments, without any schedule at all. I had brought my journal, photocopies of some journaling exercises, my camera, and some wool to practice nålbinding.

I heard a noise behind me, like a cackling laugh. I jumped, startled, then whirled around and searched the marshy ground. My whole body was tense.

Pacem in Terris means "peace on earth," but I didn't feel peaceful. In fact, I briefly wondered if someone was going to murder me. *Maybe I'm listening to too many true crime podcasts*, I thought.

After a long time, I relaxed enough to turn my body halfway back to the water. I could see the boardwalk on my left, the lake on my right, and a cattail in front of me. The

catkin still had some dense, fluffy seeds stuck to the stem. Maybe I could take a picture of that. Later.

Blurb.

The noise came from my right side. The lakeside. I slowly, quietly turned in the chair, searching the water. I saw nothing.

I tried closing my eyes for a bit, raising my face to the sun. I tried faking calmness.

Blurb.

This sound was higher pitched. A lighter sound.

I looked out to where the water was still open, wondering if a fish was coming up for air. I couldn't see anything.

I sat out there for a long time, this entire cycle repeating itself. I'd hear rustling and that mocking laughter and jump in my skin. Then I'd hear a single gurgle of water.

Frustrated that I couldn't place at least *one* of the odd noises, I got out of my chair. I sprawled out on the wooden boardwalk in a prone position, my chin resting on my hands. Leaves from the forest marred the surface of the ice, leaving indents where the sun's radiation had heated up the decaying leaves. Horsetail rush poked through the cloudy ice. I could see a few large pockets of air trapped under the ice.

The stiller and quieter I got, the more often I heard quiet popping noises. *But what is it?*

I softened my focus, loosened my gaze, and waited.

Then, I saw it.

A tiny bubble traveled along the underside of a reed. It reached the surface of the water, where the ice had not yet grown thick around the vegetation...

Pop!



Figure 11: *Pacem II*, 2021, silver gelatin print.

Pacem in Terris is a Catholic hermitage retreat center located about an hour north of Minneapolis-Saint Paul. At Pacem, each pilgrim—“one who travels a distance to a holy place to seek God” (Pacem in Terris, private communication)—stays in a simple cabin with no electricity or running water. Pacem provides simple “hermit food” (bread, cheese, and fruit) and water, and hermits are encouraged to turn off their phones and discouraged from bringing books. Since Pacem was founded by a devout Catholic woman, the emphasis is on time alone with God. Guests are encouraged to spend time with “God’s word” (the Bible) and “God’s creation” (nature). But first and foremost, Pacem reminds hermits of the importance of “holy rest.”

When I received my radiation schedule, I called Pacem to schedule a visit. Although most visitors stay two nights, giving them one full day spent in “desert time,” I asked to stay six nights. The woman I spoke to explained that anyone wanting to stay more than three nights on a first visit would need to talk to the director. “It’s a really long time to be alone and in silence,” she said.

I told her that was fine, I’d happily talk to the director. She asked why I wanted to come. I spoke through tears. “I have breast cancer, and my radiation will finally be over... I’ve wanted to come to Pacem for years, but haven’t been able to... I need some time to be alone, away from phones and doctors... I need time to process what’s happened to me... I need to start seeing myself as a cancer survivor, instead of a cancer patient... I need time to heal.”

“Oh,” she said. “I’m so sorry to hear that and I’m so glad you called.” She told me I didn’t need to talk to the director after all. She’d take care of it for me.

“Thank you,” I said. I tried clearing my tears away quietly, taking a deep breath.

We chatted for a bit longer and she gathered some information. “Religious affiliation?”

I knew that anyone could visit Pacem. Accepting visitors from all faiths, or none at all, was a core part of Pacem’s Franciscan tradition.

Still, I froze, unsure of what to say. “That’s complicated,” I finally said. “Just put ‘unaffiliated.’ ”

“ ‘ Unaffiliated...’ OK, I’ve got you down for seven days, six nights...”



Figure 12: *Pacem III*, 2021, silver gelatin print.

My week at Pacem was simple. Divorced from a schedule or any appointments, my days were ruled by what my body needed. I slept *a lot*. I napped each day, often more than once. I went to bed early, usually by 8 pm, and I had several very vivid dreams with

each sleep session. During the day, I ate when I was hungry, supplementing the simple food with some pistachios, peanut butter, and packets of tuna I'd brought from home.

I spent a lot of time outside, following Pacem's meandering paths through the woods and along the edge of a meadow. The small patch of Native Minnesota prairie was golden brown, the flowers having long gone to seed. Each day, I walked down to the lake. I spent a lot of time on one of their two boardwalks, and by the end of the week, it felt like home.

Every day, I shot at least one roll of film. It helped ground me, and it helped me slow down and notice the land around me. In retrospect, it also gave me a project and something to do with my hands. It gave me some sort of optional direction, something to focus on if I needed it.⁶⁵

Although I didn't know it when I reserved my space at Pacem, I needed that full week of holy rest. I spent that first day at Pacem settling into my skin and learning that I was physically safe. I spent the second day settling into my spirit and learning I was emotionally safe. During this time, while I walked the prairie, the word *trust* came to me suddenly. It was a word that I'd return to throughout the retreat.

For the next three days, journaling became part of my daily activities. I used prompts from *The Woman's Retreat Book* (Louden, 2005) to explore the emotional wreckage I felt mired in. I also tried to figure out, with broad brush strokes, what my next steps were. During this time, the word *fear* became an important touchstone word.

Throughout my time at Pacem, I would return to these two words: trust and fear.



Figure 13: *Pacem IV*, 2021, silver gelatin print.

At Pacem, I found a pile of the tiniest acorn caps I'd ever seen in my life. The vertical line on the left of the image is a section of photographic paper that was exposed to light; the paper wasn't perfectly centered in my "speedy easel" when I was printing it.

I also spent a lot of time in tears or near tears. My cancer treatments were over, but my body was still healing. At Pacem, the skin in my armpit continued to peel off in damp sheets. One day, overnight, the peeling subsided. I was left with bright pink, hairless, baby soft skin. It was a very strange sensation, almost slippery, like touching the flesh of a warm, dry fish.

More importantly, I was trying to heal emotionally. I knew a week at Pacem wasn't going to make me "get over" my cancer diagnosis. But I hoped having a week

completely to myself, where nothing was expected of me except that I simply be, would help me feel more like myself rather than a cancer patient.

And of course, I was grieving Mariel's death.

The thing about Mariel is that she did everything "right." Mariel was a "good" cancer patient. She went to all of her treatments, she did what her doctors said. She used traditional and complementary therapies. She took up tap dancing after her first cancer diagnosis, learning a new skill that made her happy. She went vegan and exercised more. She went to all of her appointments and all of her scans. She kept singing in her church's choir, and because she believed "laughter kills cancer cells," she made sure to laugh every day.

Above all, Mariel was optimistic. She managed to find the bright side of chemo (lots of time to watch Korean dramas and chat with her sisters) and of losing her hair (she took on difficult clients at work, because "nobody argues with a bald cancer patient," and her hair grew back curly). I rarely heard her complain, and any complaints were quickly followed by a more positive comment.⁶⁶

A message I received—from society, from cancer organizations, from some of my medical team, a few friends, and a cancer survivor several years out of treatment—was that I needed to be happier. This message was implicit and explicit. Just six days after my diagnosis—before we knew much at all about my cancer treatments, whether my cancer was genetic, or if I'd need chemo—someone I respected told me I should "choose to be fortunate" and quit being angry, because "it [would] have an impact on [my] recovery."⁶⁷

I heard similar comments over and over. I should be happy that the cancer was found early—look at the miracle of mammograms!⁶⁸ I should be patient with an incision

that wouldn't heal, being angry wouldn't make it heal any faster, but positive thinking probably would.⁶⁹ And sure, cancer's not ideal, but maybe it'd make me a better person⁷⁰ in some way or another. I'd learn something from it, at least.⁷¹ There was also an implicit message that cancer wouldn't return or spread,⁷² as long as I was a Good Cancer Patient.

I knew there was no research to back up any of these beliefs. But it was hard to shake cultural conditioning, especially when trotted out by people I loved and trusted, people who were uncomfortable⁷³ hearing about the difficulties I was having.⁷⁴

But cancer doesn't care how good of a person you are.

And Mariel was proof of that.

It felt patently unfair. And I selfishly worried about myself. Because I was *not* a Good Cancer Patient.

I was an emotional, tender, tearful, resentful one. I was not optimistic. I was scared.

And I was pissed.



Figure 14: *Pacem V*, 2021, silver gelatin print.

I sat in the rocking chair with my feet resting on the stool in front of me. The scent of peppermint tea wafted up from the mug in my hands. I stared out the window, wishing for a deer to cross in front of me. I had seen their tracks in the mud, but I hadn't seen a single one.

I didn't know what to do⁷⁵ with myself.⁷⁶

Before I was diagnosed with cancer, I was already unsure of what I wanted to do after completing my PhD. How did I want to spend the next twenty or thirty years of my life?

When I landed the financial awards, I was relieved. I would have time to work on my dissertation *and* figure out what I actually wanted to do with my life.⁷⁷

Then I got the cancer diagnosis.⁷⁸

And I was so wrapped up in getting through cancer that I couldn't focus on my dissertation or career discernment.⁷⁹

And now I was sitting in a tiny cabin, staring out in the woods, trying to figure out what to do next with my life, now that treatments were over. Now that I finally had some control over my life. Now my time belonged to me again. (Mostly? Maybe? Possibly? It seemed too dangerous to hope I might actually have some control over my time again.)

I'd been worried about the next twenty or thirty years of my working life. I'd always chosen the responsible, stable job—teaching. I'd always figured in retirement I could really dig into my hobbies, but what if I never got a retirement? But what if my cancer came back? Did I even *have* twenty or thirty years of life left?

I stared out of the window.

I didn't know how I could complete my dissertation. I didn't know how to get back to it. I wasn't even sure I *wanted* to get back to it.

I took a long, cold swig of my tea and grabbed my camera. Might as well go take a walk.⁸⁰



Figure 15: *Pacem VI*, 2021, silver gelatin print.

When I was going through treatment, I had to trust the doctors and believe that they knew best and that their treatments would work. I had to believe in the power of modern medicine.

Before I was diagnosed with cancer, I held the common belief that as long as cancer stays in remission for five years, it's highly unlikely to return.⁸¹ After my diagnosis, I learned that this is only true for some types of cancer; the type of cancer I was diagnosed with can hide out in the body for a long time before metastasizing and spreading to other parts of the body.⁸²

Still, I was able to push this knowledge aside during treatment and focus on just getting to the state of “no evidence of disease.” If I could get to that point, my anxiety

might subside and I could believe that the cancer wouldn't return or spread. Those beliefs were the only thing that kept me going through the exhaustion and pain treatment caused. I had to hope things would look better after treatment.

But then Mariel died, shattering the thin veneer hope provided.

Mariel's second cancer was caused by the chemotherapy she endured for her first cancer diagnosis. And she'd gotten an all-clear scan just weeks before the second cancer was found. How was I supposed to believe in the power of medicine when it had failed my friend?⁸³

Mariel was only a few years older than me, and her death made me reconsider time and how I wanted to experience it. I don't mean this is a "grateful for every day" or "living every day like it's my last" way. Those clichés feel too lighthearted, like the type of captions you'd see on Instagram under a stock photo of a woman driving down a lone stretch of highway in a convertible, one arm thrust skyward.

No, I didn't feel like that.

Instead, I felt this intense, deep longing to make sure I was living the life I *needed* to be living. Right now.

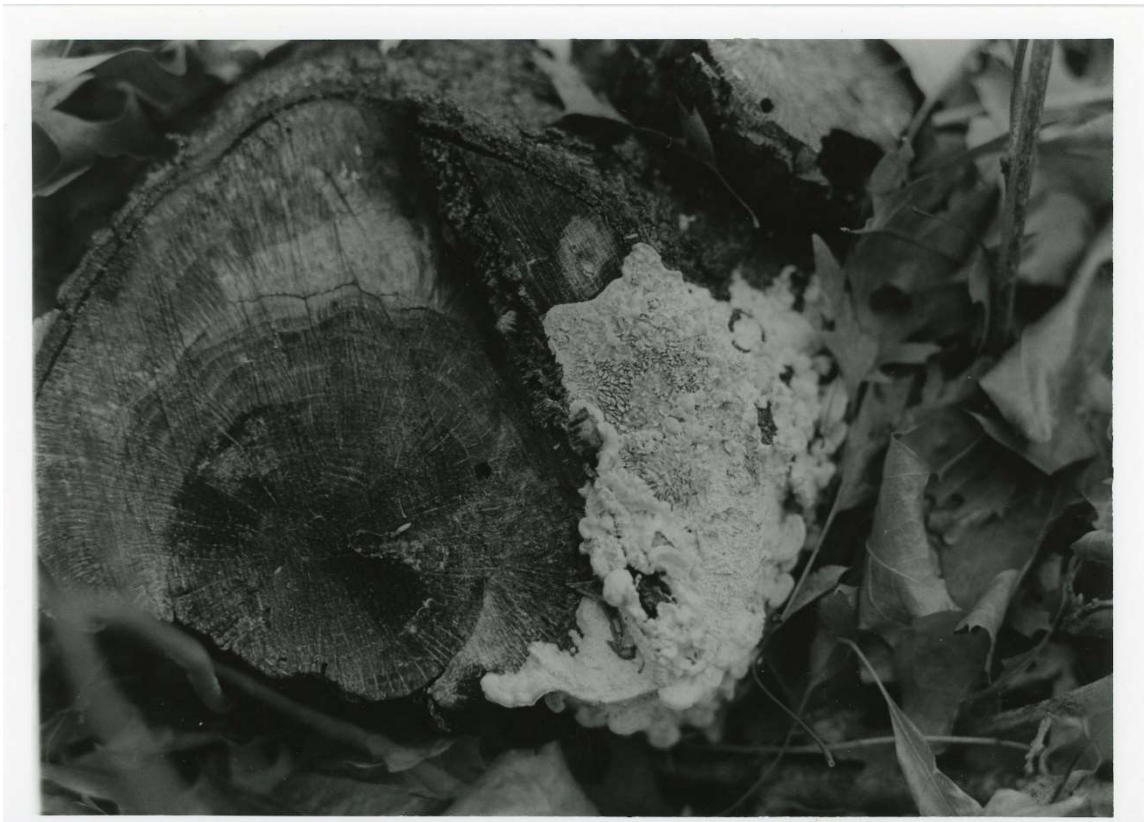


Figure 16: *Pacem VII*, 2021, silver gelatin print.

A few days into my Pacem visit, I started doing some journaling exercises from Jennifer Louden's Woman's Retreat Book (2005). I wrote what follows Thursday night, after a particularly powerful exercise. This journal entry has been lightly edited for clarity.

This morning, when I journaled, I was surprised to find this line popped out of me: "I fear dying before I've lived the life I want."

For months, hell, probably years, I have been saying I want to write more, sew more, read more, hike

more, knit more, make more art, be in the darkroom
more, etc.

But this cancer experience has made this "should
do more _____" feel like a life-or-death matter. If I
don't start living out the authentic, art-making parts
of me, I'm going to be alive in body and dead in
spirit—or at least *dull* in spirit. And if that's the
case, then what was the point of any of this??

This is not a should. It's a *must*.

Now the question is... Can I be brave enough to
make the changes I need to make? Can I be brave⁸⁴
enough to give up distractions? Can I be brave enough
to take risks and *make*? My friends keep calling me
brave.⁸⁵ Well...⁸⁶



Figure 17: *Pacem VIII*, 2021, silver gelatin print.

After writing the previous journal entry, I went to bed feeling energized and excited. I had to make art. I knew it down to my bones. But when I woke up on Friday, I wanted to erase everything I'd written. I wrote the following in my retreat journal.

Why am I so resistant? Yesterday I was so excited. I was seeing where and what was missing in my life (Creative time! A creative practice!) and I could see how my two words, *trust* and *fear*, fit together. I was excited, so excited!

And today has been a struggle. I want to do anything but return to that idea.

Because I read so much before I do anything, I read two books about going on a retreat. One book said this is the point where you can turn toward the thing that scares you or you can run from it and go back to comfort and no change.

That's the point I'm at. Turn toward the unknown or seek comfort in the familiar. All I want to do is the latter.

But *why*?

I *know* what happens if I keep going the way I have been. I make and create, I sew and knit, I get in the darkroom—in fits and spurts.

I play a lot of games on my phone, I feel guilty about it. I doomscroll. I open up tons of tabs that I never read. I watch TV and read other people's blogs

and I feel mostly happy in the very late-stage capitalism sort of way—when I'm sad, I buy shit.

But putting art-making, creating—first...

That's unknown. It feels scary and dangerous. Selfish, even. Because what if it doesn't make me happier? What if it changes *nothing*? Or rather, what if I change my habits and routines and practices to make more, but I'm not any happier? Hell, what if it gets *worse*? What if I'm filled with self-doubt? What if a pile of art is formed and nobody cares? What if a pile of art is formed and *I* don't care?

What if I make all of these changes and I'm still afraid of dying?

That's the crux of it. I'm hoping that living differently will make me less afraid of the cancer coming back, but there are no promises.

There's another feeling bubbling to the surface too.

I don't give a shit about my dissertation anymore, and I need to find some reason to care.⁸⁷

And I'm afraid not caring about my dissertation means this is all a waste of my time—and Kisu's time.

(And a waste of money, especially considering the pay cut I took to do this.) I have to find some reason to care, if only to carry me through the end.

OK... I just wrote a whole page of negative what-ifs. I wrote a whole page about fear. But... thinking of *trust*...

What if I gave the idea of putting creative time first for one year? Or even just six months? What if January through the end of June I put artmaking first each day, or if not first, I put it on the same level as dissertation work. And housework. And the internet.

What if I gave myself six months to get into a habit, to get into a practice?

Before I came on this retreat, back when I wept over that plate of sushi, I said I wanted to work halftime and make art with the remaining time. OK, well, why wait until I get a paying job? Why not do it now? I could see if it would make me happier.

(Note—"Happier" is a simplification. I'm trying to see if this would make me feel more like *me*. If it would make me feel more whole.)

This would require trust. I would have to trust I

won't run out of creative ideas. I would have to trust I wouldn't be missing out on some crucial news that magically appears on my phone. I would have to trust I might eventually find an outlet or audience for my work (if that's what I even want?).

Hell, I would have to *trust* that this might all actually make a difference and help me feel more like me.

Can I?



Figure 18: *Pacem IX*, 2021, silver gelatin print.

I threw open the drapes to greet Sunday.

A family of deer looked at me, startled. I looked at them, startled.

The deer started chewing on the young, tender stems of the saplings right behind my hermitage. Occasionally, one would glance at me.

The ground was covered in a thin layer of snow.

I lifted the lid of the tea pot, checking to see if I needed more water. I turned the gas burner on, and held the lighter near it. A blue flame leapt across the cast iron surface. While the water came to a boil, I made a mental plan for my day.

I needed to come out of desert time and bring the gifts of Pacem home with me.

I would eat breakfast, drink some tea, and clean the hermitage. I would pray for the next hermit, as Pacem requested. I'd finally turn on my phone and send my mom a message. I'd go down to the boardwalk and wait for Mom to pick me up.

I was going home, and that's where the real test would begin.

Artistic Interruption: Dendro-Oncology (9:30)



Figure 19: *Dendro-Oncology (9:30)*, 2022, handspun fibers, cotton thread, wooden hoop.

I hand spun the yarn (primarily wool) using a drop spindle.

During my first Pacem visit, I was trying to figure out the place of cancer in my life. I don't mean the importance of cancer, or the effects of cancer. I mean I was consciously trying to consider how cancer fit into my lifespan and my lifestory.⁸⁸

Before my cancer diagnosis, I had been reading a lot about how humans view time. In Western philosophy, we have the idea that time is linear, like a straight arrow moving through time. This idea is relatively new, and came along with the Cartesian revolution. Before then, time was seen as cyclical (Headlee, 2020; Shahjahan, 2015).

Inspired by Kimmerer's work (2015), I was also considering how my concepts of time impacted my relationships with other beings. I also realized that my own belief of time as linear, as something you can't get back, fed into a scarcity mindset that didn't serve me. And, of course, I was considering how I could use the gift of time that my easy year had given me (see Chapter 4).

In short, I was consciously challenging my concepts of time.

And then I was diagnosed with cancer, and time ceased to exist in any way I'd ever experienced it before.

* * *

Time already felt distorted by COVID, and then cancer took over my schedule.⁸⁹ I felt a complete lack of control over my own time. My days were scheduled and organized by doctor's appointments. I remember opening up MyChart and seeing an appointment three months in the future. I was never asked if I was available, it was simply assumed. (To be fair, since I wasn't working, I *did* have a very open schedule.)⁹⁰

The start of radiation offered temporal and narrative structure that I craved and needed. With radiation came a weekday ritual. For more than a month, I drove to the hospital on my university's campus for my 2:15 pm appointments. The appointments lasted only minutes, yet those few minutes a day gave me a strange sense of community. I recognized the valets who parked my car, the person who did my COVID screening, the security guard, the women who greeted me in the radiation department. "Hi, Amanda, I'll let them know you're here." Every day, I had two or three technicians and students pulling my body into place, putting a roll of foam in the crease of my breast to separate it from my armpit. They'd tell me to hold still, keep my head craned to the left so my chin

didn't get radiation. While they worked, we'd make small talk. "How's your knitting project going?"

Then they'd leave me alone in a lead-lined room so my breast and chest wall could be blasted with rays that would kill my cancer cells—and healthy tissue like skin and hair. I learned the pattern of the machine, how it would rotate around my body, and the sounds it would make. I knew the sound the thick, heavy doors would make as they swung open. A few seconds later, the radiation technicians would reappear in my line of sight.

The treatments seemed too short to make a difference. But my skin told the story. I had to choose clothing carefully, looking for the softest fabrics with the fewest seams. I had to apply lotion several times a day to help keep my skin from breaking down.

And I was exhausted. I was napping during the day, but completely unable to sleep at night. I was also having tamoxifen-induced hot flashes, which woke me up at night covered in a sheen of sweat and flushed red. But no matter how much I napped—and I napped *a lot*—any sleep I got wasn't enough. My appetite was all over the place.

I had temporal structure, but nothing else was normal.

And then Mariel died, and my questions about time shifted and changed.

* * *

My time still didn't feel like my own when I went to Pacem, but I was rolling over ideas about time, and cancer, and its position in the span of my own lifetime—however long that might be. I wanted to view the "active treatments" as finite. They had a set duration. Yet, I also recognized that cancer *wasn't* in the past. It was something that I would be reminded of, especially at annual mammograms and "cancerversaries," but also

daily, when I took my tamoxifen pill to help prevent any cancer cells from making a home in my body again.

Walking along the native prairie at Pacem, I noticed a cut tree stump. *Maybe rings like a tree...* What did I know about trees? I knew one ring meant one year of growth, and you could sometimes see evidence of disease or injury to the tree if you knew how to read the rings. And I knew the inside of a tree, the heartwood, was strong and stable, but not the lifeblood of a tree. That was in the cambium, the layer beneath the bark.

That sounded perfect. I could see my breast cancer as a ring, evidence of disease, and something that would always be a part of me, but in time, it could become part of my core, and no longer such an important part of my active, pumping lifeblood.⁹¹

How could I represent this?

* * *

In one of my undergraduate philosophy classes, we discussed viewing life experiences like a rope. Ropes are created by twisting fibers together. One wisp of fiber will break when you put tension on it, but if you twist a few strands together, the fibers become stronger. Twisting fibers together also allows you to make a longer rope, longer than the longest fiber length you can find naturally in either bast (plant) or animal fiber.

In this life rope, one strand (an experience) might be short (perhaps a fight you had in third grade), while another strand might be long (for example, how you experience social class). When these strands are twisted together, all of the fibers touch each other in some way, from beginning to end.

This example is linear, at least the way we were discussing it in class. There's the beginning of a life rope, and an end, and the chronological experiences in between.

But I bring it up because this is the same way you make thread or yarn. You twist fibers together, making a stronger length that can remain under tension.

I developed an intimate understanding of this process as I created this circular tree ring weaving. Woven materials include *warp* and *weft* threads. Warp threads are vertical supports that are held under tight tension; weft threads are woven under, over, and around the warp.

In this work, I used a strong, commercially made cotton crochet thread for the warp. The weft, fiber that is woven over and under warp, is all homespun yarn. I used a drop spindle, one of the world's oldest inventions (Barber, 1996), to spin the weft used in this weaving.⁹²

As I worked on this piece of art, I was reminded of the opening line in Lorde's book *The Cancer Journals*: "Each woman responds to the crisis that breast cancer brings to her life out of a whole pattern, which is the design of who she is and how her life has been lived" (1980/2020, p. 1).



Figure 20: *Dendro-Oncology (9:30)* (detail), 2022, handspun fibers.

Endnotes

⁶⁵ I brought my camera rather than books or knitting because its material nature made it a limited activity. I had a dozen rolls of film and no way to process them. Once I'd taken the photos, I was done. Books or knitting had no end. There would always be one more page or one more row. I needed something that wouldn't consume my time, something I could turn to when journaling and working through grief and being alone and being in silence—when being in desert time—got hard.

I also brought nålbinding, a form of single-needle knitting that was used by the Vikings. I was just learning nålbinding and I knew exactly two stitches. It's a very slow, time-consuming form of textile work. I wasn't worried about it consuming my time at Pacem though. It's incredibly boring and monotonous work, and I could only stand to work on it for short spurts of time.

⁶⁶ In *Pink Ribbon Blues*, Sulik (2011) explores, in depth, what makes a “good” breast cancer survivor in American society. Although Mariel didn't have breast cancer and wasn't American, in many ways Mariel lived out the ideal American breast cancer survivor.

⁶⁷ The worst part about being told I should quit being angry was that this woman had lived through her own breast cancer diagnosis. There was definitely a paternalistic tone to her unsolicited advice (especially when considering our personal history, which included an unequal power dynamic). Her comments, and how angry they made me, have ensured I won't ever respond to someone sharing a cancer diagnosis in a similar manner.

Even though her statement made me angry (it still makes me angry, truthfully), I can see that she was living out the “optimism at all times” attitude she was supposed to have as a breast cancer survivor.

She can choose to be fortunate. I choose to honor my emotions, even the “bad” ones like anger, as they come.

⁶⁸ Although it's well beyond the scope of this dissertation, there is mixed evidence on how much “early detection” of breast cancer really matters. Sulik (2011) and Ehrenreich (2018) both explore

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this more in depth, and I'm hesitant to explore scientific debates over breast cancer too deeply because I don't want to misrepresent matters.

But in short, early detection has led to an increase in the number of Stage 0 "pre-cancer" breast cancer cases being found and removed. In stage 0, clusters of abnormal cells are seen, but these cells have not yet spread. Stage 0 can be seen as a precursor or risk factor in later developing invasive cancer, and there is debate over whether or not "pre-cancerous" cells should be considered cancer (Sulik, 2011). However, one clear outcome of finding more Stage 0 cancers through mammograms, and counting them in breast cancer statistics, is that the number of breast cancer cases is increasing, but in a lopsided way that favors a stage with a near 100% survival rate (Sulik, 2011).

Breast cancer can metastasize from any stage, including stage 0 (Jacobson, 2018), and some estimate 20-30% of all early-stage breast cancer cases will metastasize (Metastatic Breast Cancer Network, n.d.).

There is also a debate about how useful mammograms are in finding cancer, and whether or not mammograms actually increase cancer risk through increased exposure to radiation (Ehrenreich, 2018; Sulik, 2011).

But the party line is that early detection (via mammogram) saves lives. There is very little space to deviate from that belief when writing about breast cancer.

The difficult thing about writing this, that mammograms aren't the life savers people claim they are, is that I absolutely feel grateful for getting my first mammogram screening at 40. Screening recommendations say that women with no family history can start screenings at 45, but my tumor was small (undetectable by hand) and right up on my chest wall. I believe if I had been screened at a later time, the tumor would have spread into the chest wall, putting me at a much later cancer stage, and necessitating more aggressive treatments.

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⁶⁹ “Social support and a positive mental attitude can contribute to positive health outcomes, but they do not predict survival” (Sulik, 2011, p. 243). In fact, the cultural expectation for a positive attitude that “makes optimism compulsory and omits the full range of emotional responses to cancer,” can act as a negative stressor on cancer survivors, which in turn can contribute to negative health (Sulik, 2011, p. 243). Second, this call for optimism puts the burden of getting and being sick on the cancer survivor, and ignores social factors that influence health and access to healthcare (Sulik, 2011).

The belief that the mind can control the body, or that positive thinking will cure or prevent cancer, is a false one (Coyne & Tennen, 2010; Frank, 2013).

Because this is such an important point, and such an obnoxious and common belief, I'm going to say it again: “Studies have shown that keeping a positive attitude does not change the course of a person's cancer. Trying to keep a positive attitude does not lead to a longer life and can cause some people to feel guilty when they can't 'stay positive.' This only adds to their burden” (American Cancer Society, 2020, para. 6).

Although I knew positive thinking wouldn't heal my incision faster, I did get a kick out of imagining little gnomes inside my breast, knitting together tissue and vessels, repairing the damage left behind. It was such a ridiculous image, it made me laugh when I was most frustrated with my slow rate of healing.

⁷⁰ In *The Cancer Journals*, Lorde writes: “Coming home from the hospital, it was hard not to feel like a pariah. There were people who avoided me out of their own pain or fear, and others who seemed to expect me to suddenly become someone other than who I have always been, myself, rather than saint or buddha [sic]” (1980/2020, p. 41).

⁷¹ “Going through illness was not empowering for all, and even for those who found positives out of illness, coming to those outcomes was fraught. Participants resented the recasting of their

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realities by others as inspirational and resisted the suggestion that they ought to seek out positives from the illness experience” (Cheung, 2019, p. 141).

⁷² Sontag (1978) says that in England during the sixteenth and seventeenth centuries, it was widely believed that happy people wouldn’t get the plague. This belief in optimism and mind over matter goes centuries back. She writes, “The fantasy that a happy state of mind would fend off disease probably flourished for all infectious diseases, before the nature of infection was understood” (Sontag, 1978, p. 55).

Of course, now we have a much better understanding of how infection—and even cancer—works. Yet, we’re still using the Cartesian mind-body split to convince ourselves we have control over our own body (Frank, 2013).

⁷³ When friends and family encouraged me to be upbeat, they were acting via the cultural and social conditioning they’d learned about illness in general (Frank, 2013) and breast cancer in particular (Sulik, 2011).

The difficulty for me was that this was neither comforting nor helpful. I didn’t want to behave as expected. I didn’t want to be good.

I tried finding polite ways to resist what they were saying, but since I wanted to protect social relationships, it was often easier to simply brush it off and move on. Of course, maintaining relationships and pushing the self’s needs away in favor of making other people feel comfortable is one of the ways women are socialized to deal with breast cancer (Sulik, 2011), so in the end, I was doing something right, I suppose.

⁷⁴ I often wondered if I should’ve kept my diagnosis private. At least then I wouldn’t hear about how optimistic I should be.

⁷⁵ “Cancer is as much an existential crisis as a physical one” (Couser, 1997, p. 63).

Endnotes—continued

⁷⁶ After cancer treatments, “there seem to be existential difficulties in finding a firm footing in the sense of self, with individuals questioning their self-understanding considering who they were before the cancer and who they really are now” (Ueland, Dysvik, Rørtveit et al., 2021, p. 702).

In their article “Cancer Survivorship: Existential Suffering”—which, I must say, was quite possibly the most depressing title I could have come across while going through my own existential crisis—Ueland, Dysvik, Hemberg et al. (2021) found cancer survivors: experienced limitations in their everyday life, including physical and fatigue and brain fog; felt an inner struggle of what sort of life to live moving forward, and how to achieve that life, and; felt they bore the burden of cancer alone.

Drawing on the work of phenomenologist Anthony Steinbock, Ueland, Dysvik, Rørtveit et al. (2021) describe this existential stress using a “homeworld/alienworld” framework. Everyone has a homeworld, which they take for granted, where they feel comfortable and knowledgeable about how the world works. But we also belong to an abnormal and unfamiliar alienworld. Both worlds exist simultaneously in our bodies and experiences, but people generally live in their familiar home world, until a “light” or “heavy” break (a minor or major disruption) forces them spend some time in the alienworld (Ueland, Dysvik, Rørtveit et al., 2021).

A heavy break—such as a cancer diagnosis—“upsets an individual’s entire communal homeworld” (Ueland, Dysvik, Rørtveit et al., 2021, p. 707). A cancer survivor must navigate and negotiate in an alienworld while also remaking their homeworld with their new perspective; in interweaving the homeworld and alienworld, the homeworld is refreshed and renewed (Ueland, Dysvik, Rørtveit et al., 2021).

This process of remaking is made more difficult by the medical field (Ueland, Dysvik, Rørtveit et al., 2021). “The biomedical discourse is so dominant in the history of cancer survivors that it is challenging to find one’s own deeper understanding of a changed self” (Ueland, Dysvik, Rørtveit et al., 2021, p. 707).

Endnotes—continued

⁷⁷ In her research with students who had been diagnosed with serious illnesses during their doctoral work, Cheung (2019) found two major narrative patterns emerge. In one pattern, students said they were diagnosed at a time in their program when they felt the most optimistic and confident about their work and their place in the academy (Cheung, 2019). Illness was viewed as something that knocked these students off balance, and illness was seen as “unfair,” because it “dismantled that security so swiftly and effectively” (Cheung, 2019, p. 80).

In the second narrative pattern, participants indicated illness was a “continuation of existential and experiential insecurity vis a vis their doctoral study” (Cheung, 2019, p. 80). For these students, the diagnosis of illness seemed like an extension of the stress and uncertainty they already felt.

I feel like I had both narratives going on at the same time. I was very optimistic about having a year to focus on my dissertation, and I felt more confident in my scholarship and in myself as a scholar. But I still wasn't sure what I wanted to do with my life after I completed the PhD program, and that gave me a strong sense of insecurity.

As discussed in Chapter 4, one of the reasons I was feeling optimistic is that I thought landing the fellowship would give me time to work on my dissertation *and* time to figure out my existential crisis. With my breast cancer diagnosis, I saw that time and optimism dissolve right in front of my eyes—along with my sense of self.

⁷⁸ Since my diagnosis came right on the heels of landing those financial awards, for a brief moment, I wondered if I had brought my cancer on by being too excited about “my easy year.” I wondered if I'd exhibited hubris and cancer was my punishment for it.

⁷⁹ Students who are diagnosed with serious physical illnesses during their doctoral work face challenges other students do not face (Cheung, 2019). Students needed to reconcile their illnesses with their sense of self, manage frequent doctor's appointments and doctoral work,

Endnotes—continued

figure out whether or not they still fit within the confines of the academy, and navigate the social side of illness such as feeling isolated and different from their peers. Cheung found that as students managed their diagnoses, their feelings of uncertainty that inherently come with doctoral work increased and intensified. Although her participants *did* finish their doctoral degrees, Cheung (2019) found that their diagnoses made them feel uncertain about the future and their post-doctoral lives; they also felt unsure about whether or not they wanted to continue their doctoral work or if they had a place within the academy at all (Cheung, 2019).

⁸⁰ Yang et al. (2010) describe cancer patients as losing their “anchorage” in the world, and say “we feel it may be justified to call this loss of anchorage a sign of an existential crisis” (p. 54). Yang et al.’s research focused on cancer survivors who had existential crises and cancer survivors who didn’t have existential crises. Of the survivors who had an existential crisis, Yang’s team found they experienced: an awareness of their own mortality; a dissolving of the future and their sense of how much future they had left; loss of meaning and unsureness of what to do with the time one had left to live; fear, anxiety, despair, and panic; a sense of loneliness; a sense of powerlessness; an identity crisis, which could be exacerbated by on-going side effects of cancer and cancer treatments. Interestingly, the existential crisis could occur at any point, including immediately after diagnosis, during or as a result of treatment, or when getting news—including good news, such as there no longer being a threat to one’s life (Yang et al., 2010).

Although cancer survivors worked through their existential crises in different ways, Yang’s team (2010) found three dimensions that occurred in most stories to varying degrees. They called this a psycho-spiritual process.

Survivors had to mourn, and “those patients who allowed the brutal reality to penetrate into their consciousness and live through the accompanying emotions, surrendered to their mourning process and were, in this way, sincerely and adequately dealing with their existential crisis” (Yang et al., 2010, p. 60).

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They had to heal. In part, this healing happened through mourning. But it also came from connecting with the self and finding some new sense of personal meaning. Finally, there was a spiritual aspect to the survivors' existential crises. They found and made new life meanings, re-examined who they wanted to be, and worked to reconstruct their new self with their new life meanings. Interestingly, "it often also seems to be important to seek a quiet situation, a walk through the woods or meditation, wherein such an experience of meaning may be received" (Yang et al., 2010, p. 61).

Yang et al. (2010) warn the reader that "we should nevertheless be careful not to romanticize this process in patients. It is often a very intense and oscillating process [...] in which patients swing to and fro between two extremes: Hope and anxiety, resistance and surrender, desperately clinging and letting go" (p. 62).

⁸¹ The language used to discuss the absence of cancer after diagnosis and treatment is not universal. My medical team doesn't use the term "remission," but instead says that their monitoring, screenings, exams, and tests show "no evidence of disease" (NED). Some doctors may use the term "cancer-free," while others might even declare a patient "cured" (DeMarco, 2021).

Yet, breast cancer can return locally (called recurrence) or throughout the body (called metastasis). Women who experience metastatic breast cancer, which can be treated but not "cured," often express anger over their diagnosis, saying that they had been declared free or cured of cancer (Jacobson, 2018).

⁸² According to a recent study which drew on the Danish Breast Cancer Group registry of patients (Pedersen et al., 2022), "late breast cancer recurrence" can happen ten or more years after diagnosis. Late recurrence cancers were more common with initial cancer diagnoses involving larger tumors, lymph-node involvement (cancer has spread to local lymph nodes), and estrogen-

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receptor positive breast cancers. In one case they found, a patient's cancer spread 32 years after diagnosis (Pedersen et al., 2022).

⁸³ Mariel and I had different cancers and very different treatments, which my medical team reminded me of when I talked with them about her death. Like the chemo Mariel had, the radiation I had can cause secondary cancer. In my case, the benefits of radiation outweighed the risks, and my medical team highly recommended I go through with it. I'm sure Mariel's team thought the benefits of chemo outweighed the risk for her, too.

⁸⁴ I didn't realize how big my local circle had become in Minnesota until I was diagnosed. I have very supportive friends and family members, and I'm grateful, because I know that made things so much easier.

But.

I hated, hated, hated it when one of them would call me brave. "You're so brave."

I hated hearing this for a few reasons. First, nothing I was doing felt brave. Doctors took control of my schedule and told me when to show up and what to do at appointments and how much radiation to receive and what medications to stop and what medications to take and what side effects to look for and how to contact them if I had any concerns.

I did what my doctors told me to do.

Nothing about that felt particularly brave.

Plus, the framing of a cancer diagnosis as a fight makes it seem like only the brave survive and only the weak die of cancer. That's absolutely incorrect. Eventually, we all die. We can't fight off mortality. And one person surviving one cancer while another dies of the same cancer doesn't mean one is stronger than the other. So much of this is a total crapshoot.

But my frustration at being called "brave" ran deeper than the fact that nothing I was doing was actually brave.

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In Chapter 5, I briefly discussed and critiqued the war metaphor used to discuss cancer.

One concept I haven't yet explored is this: The war metaphor comes with a simple value system which uses binary terms such as good/evil, brave/coward, strong/weak, and winner/loser (Sulik, 2011). In each of these pairs, one term is more valued by society than the other. Clearly, if you want to win the war against cancer, you must be good, brave, strong, and victorious (Sulik, 2011).

These binary categories extend past the war metaphor. Societies generally value health over illness, or "normal" over "abnormal" bodies, for example. And many societies—including ours—value masculinity over femininity (Sulik, 2011). Sulik explains that as part of this value system, men and boys are equated with the socially valued traits of toughness, rationality, and dominance. "Not only are women defined to be the weaker sex, the feminine characteristics of emotionality and nurturance falter beneath the masculine pursuit of rationality and power" (Sulik, 2011, p. 76).

As discussed earlier, pink ribbon culture allows women breast cancer survivors one way to be a survivor: Breast cancer survivors need to be aggressive (masculine) warriors (good, brave, strong) who kick cancer's ass (victors) with style (feminine physical attractiveness), lightheartedness (feminine frivolity), and humor (an acceptable, inoffensive emotion granted to women). They listen to doctors (follow rules) and approach their illness with a rational (masculine) belief in science. And above all, they're optimistic and sunny (protect other's emotions).

Because of the entangled social narratives around (breast) cancer, "bravery" does not travel alone. In this context, "rationality," "humor," and "lightheartedness" accompany it.

But I didn't feel strong. I felt tired. I felt tender, physically and emotionally. I felt vulnerable. And even though I knew (in my head, rationally) my cancer was at an early stage, and it was being treated with "curative intent," that didn't stop my emotions. I still felt scared (a female-

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coded, unvalued emotion) and angry (a masculine-coded emotion women aren't allotted in pink ribbon culture).

I didn't feel like the single-breasted Amazonian warriors Audre Lorde (1980/2020) looks up to. I was exhausted and I didn't want to fight.

I just wanted my cancer to go away.

I wanted it to never have existed.

And being told that I was strong and such a warrior felt like pressure to live and act in a way that didn't feel authentic. Put on a mask, smile, pretend I wasn't napping for several hours a day, and yet wide awake and unable to sleep at night. Pretend my skin didn't ache and I wasn't tired of binding my breasts as flat as I could. Pretend the sight of my radiation tattoos didn't bother me. Pretend I wasn't scared. Pretend I wasn't angry.

Pretend, pretend, pretend.

⁸⁵ When my friends called me brave, I'd say something like, "I'm not brave, I'm just going to the doctor when they tell me to." It would only cause them to double down on how brave I was, and I stopped arguing.

I learned I couldn't discuss this unease—anger, actually; I was angry about it—at being called a brave, strong warrior with my friends. They were trying to be supportive. And that support came through using the motifs of pink ribbon culture (Sulik, 2011).

⁸⁶ Having said all that, there's one more way I want to consider the concept of bravery.

In *The Wounded Storyteller's* afterward, Frank (2013) addresses hope and courage. He says oftentimes, the idea of "hope" is connected to medicine and how science can treat an illness. Frank reminds the reader that a serious illness changes a person's worldview, then uses Jonathan Lear's concept of "radical hope" to consider what hope might look like after someone's

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worldview has been radically altered. According to Frank (2013) “radical hope enables a person to continue to live after losing what organized his or her life and gave meaning to living” (p. 210).

Radical hope is believing that a new way of living is possible. And courage—to live life with and from a new worldview, to share knowledge gained with others, to take risks—feeds that radical hope (Frank, 2013).

I still don’t like being called brave or strong. But Frank’s work gives me a new way to think about those terms. Do I believe a new way of living is possible? And am I acting in ways to bring about that new way of living? Am I enacting courage? If so, then maybe I am brave.

⁸⁷ I seriously considered taking out, or at least heavily editing, this sentence. Saying “I don’t give a shit about my dissertation” in my dissertation feels risky.

Ultimately, I decided to keep it in. There’s a matter of ethics, of course. If an anonymous participant said this in an interview, I wouldn’t be afraid of including it in my dissertation. The fact that I said it, and that I’m not anonymous, shouldn’t matter. But the reason I kept it in goes beyond ethics.

This is one of the most important sentences in this entire dissertation.

First, it relates to two of the problems of embodiment that an ill body can face (Frank, 2013). “I don’t give a shit about my dissertation” is a clear statement relating to desire. What do I want and how do I show that with my body? How do I regain desire? How do I invite and enjoy new desires (a heavier emphasis on artmaking) and also give closure to old ones (finish the dissertation)?

The sentence also speaks to the issue of other-relatedness. How do I interact with others who have had the same illness or who will have the same illness? I changed my dissertation topic in large part because I couldn’t find stories of people who didn’t find shelter in their work. I couldn’t find stories from people who said, “Cancer changed my priorities, and I had to find a way to finish my dissertation even though it was no longer important to me.”

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In the academy, having a set research agenda, and being able to focus on one topic for an extended period of time is valued and seen as a sign that one is a serious researcher (Cheung, 2019). What happens to the grad student who wants to stay in their program but whose priorities have drastically changed? How can they make the academy work for them, for their body, for a body that the academy was never built to accommodate? Where are those counterstories (Delgado, 1989)? Certainly, telling that counterstory must include being truthful about the lack of desire, even if that risks making one look like a less serious scholar.

Finally, the problem of body-relatedness is not only about being in relationship with ill or potentially ill bodies. It's also about being in relationship with healthy bodies and healthy people. To address that, I'm going to tell a story.

A few months after I finished treatment, before I had changed my topic and admitted I couldn't continue my old work, I went in for one of my quarterly appointments with my oncologist. After the nurse took my vitals, a medical student came into the room to talk about any concerns, how I was doing, whether I was taking my tamoxifen, and so on.

The student asked about work, and I told her I was a doctoral candidate. She had finished her PhD program in the previous year and was now working on her MD.

I said, "The problem is I don't give a shit about my dissertation anymore."

"Everyone feels that way at this stage," she said.

"I know, everyone reaches a frustrated point. But... this isn't the normal 'I'm nearly done and hate this' feeling. This is 'I had cancer and it changed all of my priorities and I don't know how to do this anymore.' "

She nodded at me and said, "Yeah, everyone feels like that. Just gotta finish, same as everyone else." She gave me a big smile, as if she were being helpful.

Now I was annoyed. Doctors need to listen to what's being said and what isn't being said. She wasn't listening.

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“Did you get diagnosed with cancer while you were a doctoral candidate?” I spoke flatly.

“Ah... no.”

“Then it’s not the same.”

⁸⁸ The *Natural Patterns* art piece in Chapter 5 was about how I could relate to my own body, and my tumor’s place in my body. This piece of art was about how I could relate cancer to my lifestory as a whole.

Despite Sontag’s call to ditch metaphor when it comes to cancer (1978), we make meaning through metaphors (Couser, 1997; Marron et al., 2020; Segal, 2007; Springgay & Irwin, 2005) and that’s how I’m making sense of cancer.

⁸⁹ Writing about the COVID pandemic, Takayama (2020) says that “[t]he lack of future certainty has generated considerable anxiety among us, but often forgotten is the opportunity that it has created for us to imagine differently” (Takayama, 2020, p. 1344).

⁹⁰ “The perception of lacking time, or experiencing only scheduled time, leads to feeling rushed and unsettled.” (Bosanquest et al., 2020, p. 741).

⁹¹ A brief dive into the dendrochronology (the study of tree rings) literature showed me how simplistic my understanding of tree rings was.

Tree rings hold a wealth of information. Trees show information about climate change (Linares et al., 2017; Pearl et al., 2020) and past events such as a massive earthquake in the Pacific Northwest (Schulz, 2015). They also hold onto carbon from nuclear weapon testing (Linares et al., 2017). Trace elements show activity from human pollution, but those trace elements can also travel from one ring to another (Trouet, 2020).

And tree rings don’t grow every year. In subtropical and tropical regions, where the wet and dry season affect tree growth, trees may show two growth rings—or none at all—in a year

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(Linares et al., 2017; Wils et al., 2010). In temperate regions, some trees show rings based on wet and dry patterns, whereas others are affected by having a hot and cold season (Living on Earth, 2020). Some types of trees (pines, oaks, and Douglas Firs) dominate the research, while other species and types of trees (including trees in tropical and subtropical regions, or at high latitudes, or trees with fewer than fifty rings) have been understudied (Linares et al., 2017; Pearl et al., 2020). This makes for limited understanding about tree ring behavior and climate change (Linares et al., 2017; Pearl et al., 2020).

Even trees growing in “ideal” situations can lose their rings for a variety of reasons, including droughts, insect activity, or fire (Carroll et al., 2018; Trouet, 2020). Or, as dendrochronologist Claudia Hartl’s team (2019) found in pine trees in northern Norway, due to chlorosulfuric acid used by Nazis to hide their battleship *The Tirpitz*. This artificial smoke likely damaged the needles on the trees, so they weren’t able to photosynthesize for several years. One tree showed no growth for nine years, then recovered; but it took thirty years to get back to normal growth (Hartl et al., 2019).

Learning more about the complexity of tree rings made me think this was an entirely appropriate metaphor for breast cancer.

⁹² Like people, trees do not all respond the same way to the same trauma. As Wils et al. (2010) found while studying juniper trees in Ethiopia, drought seemed to cause irreversible damage to one tree; it made another develop deeper roots.

Chapter 7: Recovery

After Visit: 8/15/2022

Medical Oncology

Provider Note (Progress, Follow Up)

Amanda Shopa is a 41-year-old female who is following up on right breast cancer on active surveillance.

History of Present Illness:

Patient underwent a routine screening mammogram in June 2021, which was her first baseline mammogram. Further evaluation with right breast diagnostic mammogram and ultrasound showed a spiculated mass, 1.5 cm, at 9:30 o'clock, 12 cm from the nipple. Patient returned in July 2021. Contrast enhanced mammogram of both breasts showed no additional lesions. An US guided biopsy was taken from the right breast at 9:30, 12 cm from nipple, and pathology demonstrated invasive ductal carcinoma, Nottingham grade 2, ER+ 95% / PR+ 99% / HER2- by FISH, with DCIS nuclear grade 2. Genetic testing was negative for BRCA1/BRCA2, and the expanded panel demonstrated no pathogenic variants or variants of unknown significance.

Patient underwent a right-localized lumpectomy and right axillary sentinel lymph node biopsy with Surgical Oncologist in August 2021. Pathology demonstrated invasive ductal carcinoma, Nottingham grade 2, 1.1 cm, no LVSI.

Oncotype DX score was 15. She is on tamoxifen.

Adjuvant radiotherapy to significantly reduce the risk of recurrence was recommended. Given the patient's young age and close anterior and inferior margins, radiation boost to the lumpectomy cavity was also recommended. She met with Radiation Oncology in September 2021, started rad in October 2021 and finished rad mid-November 2021.

Interval History:

Patient is doing well with her lymphedema specialist and is building muscle through strength training.

She also continues to take walks every day for the past 800+ days.

She experiences occasional hot flashes, every few weeks at night. Joint pain associated with tamoxifen has subsided.

BP 116/81 | Pulse 91 | Temp 98.9 °F (37.2 °C) | Resp 16 | SpO2 99% | Height and Weight recorded

Physical Exam

Constitutional, General: in no acute distress

Heme/Lymph: neg

Neck: Supple

Lungs: Clear

Abd: Normal

Extremities: No extremity edema

Breast exam: Right breast has edema in inferior portion. There is some skin discoloration and skin changes in the area as well. No nodules or masses.

Neurologic: Aware and oriented to space, time, and people. Speech normal.

General: Skin is warm and dry.

ASSESSMENT AND PLAN:

Coping: Well supported, doing well currently. Amanda reports that appointments make her extra emotional, says, “When I come here, it’s like I feel the emotions from every appointment I’ve had since last June, all at one time.” Reports that in regular daily life she feels less anxious.

She is still walking daily.

Doing well with lymphedema therapy; extended her referral for one year. She is working on her dissertation and making art, reports she expects to graduate in the next 6 months.

Discussed future appointments, every 3 months, and annual mammogram screening.

Bone health - discuss calcium and vitamin D. Pt is still premenopausal.

Renewed tamoxifen prescription.

Signed,
Medical Oncologist, MD
8/15/2022

Previous appointment:
6/9/2022 (Lymphedema Therapy)

Next three appointments:

11/17/2022 (Medical Oncologist PA)

2/13/2023 (Medical Oncologist)

[n/a] [n/a]

Sculpting a Metaphor

Hey friends.

As you know, I'm applying to a writing residency at a sculpture garden. Their theme for the next year is public health. Seems in line with my research work, huh? It's a writing residency, but I actually want to use the sculptures on site. The application will be scored on artistic merit, a demonstrated connection to the site, and a thoughtful connection to the theme. Since it's a writing residency, I'm applying as an academic writer, and I'll be using that JACE photography article as my solo-authored work sample.

I'm open to any feedback—I'm especially trying to avoid using too much academic jargon.

Thanks for your help!

—Amanda

25 Word Summary

I will use the artwork, grounds, and extended time at Sculpture Gardenⁿ to create illness metaphors based on artwork, resisting stereotypical war and journey metaphors.

Artist Statement

I am an artist, teacher, and researcher. I believe that interacting with art, whether through making art or experiencing artwork, is a form of thinking and sensemaking. In my

ⁿ A pseudonym.

research, I use artistic practices such as fiber and textile arts, film photography, and storytelling to explore identity development.

I use fiber and textile arts (including spinning, weaving, knitting, sewing, and surface design) specifically because these have historically been women's work, unworthy of being called art. Their tactile nature begs to be touched, held, and used. Physical sensation is also why I work in a traditional black-and-white darkroom; working with paper, chemistry, and film to create an image by hand is pure pleasure. Finally, because storytelling is a core part of being human, I incorporate stories into my academic research.

I am currently using these practices to examine, make sense of, and emotionally work through the existential crisis I experienced due to an unexpected breast cancer diagnosis.

I am especially interested in how cultural expectations shape the illness stories we tell others and how artistic practices can help us resist or sidestep those expectations. For example, how can women battling "pink ribbon culture" use artistic methods and experiences to tell the truth about breast cancer's physical and emotional effects? How can art add texture and nuance to the typical "miracle of mammograms" illness narrative? How can art be used to express emotions "good" breast cancer patients are supposed to suppress?

Work Plan

In my most recent research, I use artistic practices to make sense of the existential crisis that cancer brought on. Even though I was diagnosed with breast cancer over a year ago,

and I've completed my treatments, I still don't have a good way to describe the entire experience. The treatments, the emotional turmoil, the sense of isolation. The most common metaphors used to describe going through cancer are "journey" and "battle," but neither of those terms are a good fit for me. Cancer isn't a personal development course, and I don't want to view my own body—my life, my spirit, my self—as a battleground. Unfortunately, the phrase "cancer experience" isn't very descriptive.

At Sculpture Garden, I'd like to start a new line of inquiry. Rather than using artmaking as the primary form of sensemaking, I'd like to focus on experiencing art. I'll use the sculptures on Sculpture Garden's grounds to re-envision, rewrite, and extend metaphors used to describe the breast cancer experience.

I will use the time at Sculpture Garden to walk the grounds, spending extended time studying one or two sculptures daily. I expect I'll also be inspired by the cross-pollination that will take place with other writers, especially ones who write from different fields and in different genres. Finally, using the fertile grounds and extended time a Sculpture Garden Writing Residency allows for, I'll create illness metaphors that don't fall into the journey-battle cliché that's too common in cancer narratives.

Artist Bio

I am an artist, researcher, and teacher living in Saint Paul, Minnesota. I taught elementary school for 13 years in Georgia, Virginia, and South Korea before pursuing a PhD in Arts in Education. In my academic research, I draw on these three sides of myself, where I use artistic practices to make sense of identity development. Recently, I've worked with

textile and fiber arts, film photography, and storytelling to make sense of becoming a “cancer survivor.”

I am a Kennedy Center Changing Education Through the Arts (CETA) certified teacher, and making and experiencing art were vital components in my classroom. A creative writing project I taught to my students garnered our classroom media coverage in the Local Living section of *The Washington Post*. Recently, I was awarded the University of Minnesota’s Doctoral Dissertation Fellowship (2021-2022) and the Philanthropic Educational Organization’s Scholar Award (2021-2022) in support of my dissertation research.

Artistic Interruption: *Daily Dissertation Diary*



Figure 21: *Daily Dissertation Diary*, 2020–2023, wool yarn.

I was thrilled when I passed my oral exams in January 2020, but I was unsure of what it really meant. I didn't know what the day-to-day work would look like. It seemed like newly minted doc candidates simply disappeared, only to resurface a few years later to defend. I had no idea what I was supposed to *do* as a doctoral candidate.

Books presented the process of creating a dissertation as straightforward and linear, even the ones that warned writing a dissertation wouldn't actually *be* straightforward and linear. Doctoral student groups online were full of memes detailing misery. I tried asking a couple of friends a few years ahead of me how their research or writing was going, only to receive short grunts of "it'll get done" and "let's talk about something else."

The daily work, the processes, the management of time—it all felt very opaque. It's no surprise that I didn't know what doctoral candidates do. Ten years ago, Hopwood et al. (2011) said, "Existing literature suggests that everyday experiences [of doctoral students] are significant, variable, but rarely investigated, documented, or acknowledged" (p. 214). In the decade since, work has been done about time in the academy: how time is treated in the academy (e.g., Shahjahan, 2015), how doctoral candidates and early career academics experience and sense time (e.g., Bosanquet et al., 2020), how COVID changed sense of time in the academy (e.g., Takayama, 2020), and the planning time to complete a PhD (e.g., Lantsoght, 2018). Additionally, some researchers have shared personal stories of being a doctoral student (e.g., Portman, 2021; Ridgway, 2022; Stanley, 2015). Still, little has been written about the daily work of being a doctoral candidate. Truly, "many aspects of graduate education lack transparency and facilitation. It's especially apparent

during what can often feel like an abyss following coursework and general exams” (Partman, 2021, para. 16).

While I wasn’t sure exactly what doctoral candidates did, there was also an aspect of arts-based research that confused me. I understood how art could be used as data and as a way to represent research data. But I didn’t understand how artistic practices could be used to make sense or generate knowledge.

Every session in the darkroom, every knitting project, and every sewing pattern I drafted was a learning experience. But in those cases, I was learning more about a skill, craft, or specific material. I couldn’t see how I was generating non-craft specific knowledge.

When I’m confused, I turn to books, to journal articles, to other people’s ideas. But in this case, that wouldn’t work. I had to get my hands busy and start making.

Luckily, shortly before my comprehensive exams, I learned about Joan Sheldon’s “Globally Warm Scarf.” Sheldon, a marine scientist at University of Georgia used Tunisian crochet to create a scarf showing yearly average global surface temperatures since 1600 (Sheldon, 2017). Other textile artists and crafters have used this idea to knit, crochet, weave, quilt, or embroider items that show their region’s temperature or weather over a period of time (Onion, 2020; Schwab, 2019).

I decided to knit a scarf that would also include a hidden message showing what I did, day by day, from reaching candidacy to dissertation defense. As Partman (2021) says: “The messiness, the ups and downs, and the deeply personal and lived experience of creating something from scratch are components of academic work that we need to attend

to, reflect on, learn from and share” (para. 3). I hoped this scarf would show the messiness of it all.

I also hoped the process of working on one piece of art for an extended period of time would give me a practice, time, and space to learn—through my own work—how artmaking could be a form of knowledge generation.

* * *

Before I could start, I had to make some decisions about material and setup. I was sure of one thing: I didn’t want to work on this *after* I defended. I wanted the scarf to be an ongoing project, a living artifact.

I needed a yarn with a really wide range of colors, and I wanted to use a lightweight wool yarn. If I wanted to wear it, wool would be great for Minnesota’s winters. And if I didn’t want to wear it, I could felt the wool and turn it into a dense fabric. I also decided to use a very simple stitch pattern. The garter stitch makes clean looking stripes on one side of the knitting, and the stitch is simple enough to knit without needing to pay much attention to it.

To come up with a color scheme, I brainstormed a list of things I knew I’d be doing as part of my research. Because I had conducted a pilot study and completed my proposal, I had some idea of the “big things” I’d be doing, and I asked friends for input about events or activities that surprised them in their work. After brainstorming, I created activity clusters, and assigned each a color. Each task was then assigned a specific shade.

For example, green was for photographic work, blue represented narrative inquiry activities, red was for artmaking, and purple—my favorite color—was used for writing. Yellow isn’t my favorite color, so I chose that for “administrative tasks.” (If I’d realized

how many administrative tasks would be involved in this work, I would've picked another color.) Orange was for peer reviewing, preparing for conferences, and other research-adjacent tasks. Shades of brown represented reading activities. Finally, I also made sure to have a color to indicate rest: white.

I wanted the scarf to grow as I worked on my dissertation. I also knew that I'd probably want to knit several days' worth of rows at once, so I kept a spreadsheet that briefly noted what I did each day. Although I did more than one activity most dissertation work days, I chose the color that felt most important each day.

Over time, I added more granularity to the chart, being careful to not affect or change any of the shades I'd already used. I added a shade for [fellowship, job, scholarship, residency, grant] applications. I included a shade for peer reviewing other's work, and another for showing my artwork in public exhibitions.

When I started this project in late January 2020, I expected the scarf to show a gentle progression of colors. Data collection would come first, then transcription, writing, then artmaking, more writing, more artmaking. I thought it would be five days of color and two days of white, over and over. I thought it would be much calmer and cleaner looking, more like a bookshelf pictured on Apartment Therapy, and less like a chaotic riot of color. I also expected the finished scarf would reach just past my hip.

The scarf reached my knees when I was diagnosed with cancer.

* * *

I wasn't sure what to do.

Cancer wasn't part of my doctoral work. Yet "academic study is itself a bodily practice, but one that is predicated on there being a healthy body able to perform it"

(Hopwood & Paulson, 2012, p. 674). I had a diseased body that needed to be taken care of, and it couldn't wait for me to complete my academic work. I had to acknowledge that.

No, cancer treatments weren't part of my dissertation "work," but I'd never seen cancer (or disability, or any other chronic, long-term illness) acknowledged with depth in any "how to write a dissertation" book, article, or podcast.

And wasn't this part of the messiness? The ups and downs?°

I added two more shades, to represent school specific issues that the cancer diagnosis caused, and to indicate appointments and treatments for or related to cancer. The colors were sort of dusky, or pearly. They weren't quite brown or grey or pink, but all of those shades. When my topic changed, I added a third shade, a darker shade with brown undertones. It represented "reading/researching, about cancer."

I wanted to show how much time those treatments took up, how many days they interrupted. I wanted to show that you could complete a dissertation, even after such a diagnosis.

And I wanted to show that it could be done on my own terms: with plenty of rest.

° "The body is inevitably present whether we acknowledge it or not. [...] It is an important source of knowing that has been ignored, delegitimized, or marginalized" (Shahjahan, 2015, p. 489).



Figure 22: *Daily Dissertation Diary* (work in progress photo), 2020–2023, wool.

This photo was taken in May 2021. This is about as long as I expected the finished scarf would be. The first photo in this section (Figure 21) shows the scarf on a dress form that is adjusted to my height. As you can see, the actual finished scarf pools on the ground.



Figure 23: *Daily Dissertation Diary* (detail), 2020–2023, wool.



Figure 24: *Daily Dissertation Diary* (detail), 2020-2023, wool.

This photograph shows the Dissertation Writing Retreat I attended (far left, lilac purple color). It also shows my cancer diagnosis. In the center of this image, moving left to right, you'll see three white rows, one yellow row, and then two rows of a pearly grey color. Those pearly grey stripes are the days I got my "you have cancer" phone call and had my first appointment with my surgical oncologist. Those pearly grey stripes extend toward the left side of this photo and indicate continuing appointments, including surgery. You can also see how "rest" increased dramatically, by how much more white there is on the right side of the scarf.

Part III: ~~Closure~~ Composure

And yes, I am completely self-referenced right now because it is the only translation I can trust, and I do believe not until every woman traces her weave back strand by bloody self-referenced stand, will we begin to alter the whole pattern

—Audre Lorde, *The Cancer Journals* (1980/2020, p. 3)

But then again it feels like some sort of inspiration

To let the next life off the hook

She'll say "look what I had to overcome from my last life

I think I'll write a book"

—Indigo Girls, "Galileo"

Chapter 8: There Is No Conclusion

I changed my dissertation topic because I had to. Deciding what sort of research I wanted to do, and what sort dissertation I wanted to write, after such a disruptive diagnosis was, as Arthur Frank (2013) says, a moral dilemma. I could return to my original topic, or I could pivot entirely, writing about what felt the most pressing and needed.

I kept up my journaling habit throughout my treatment. But I was mired in the chaos of my greater environment, and so focused on my immediate physical needs, that I didn't have the space to process or even acknowledge most of my emotions. As such, my journal entries are focused on bodily matters, and forced optimism about the end of surgery and radiation. But then the end of treatment came, and as Arthur Frank says, that's when my troubles really began.

I wanted—no, I *needed*—to use the research process—reading, thinking, writing, knitting, questioning, walking, wondering, taking photos, talking, sitting in silence, pondering, gathering materials, learning from and through the land, learning from and through the body, learning from and through artistic practices, resting, and reckoning—to make sense of the world that had shifted, slid, gone off-kilter beneath me.

I wondered: How can I use artistic practices to make sense of the narrative wreckage that my breast cancer diagnosis brought with it? How can the process of creating a dissertation be used as a tool of emotional processing? In short: How do I get through *this* after going through *that*? And how can I use *this* to help get me through *that*?

I

The master plot then, of the breast cancer narrative, like that of autobiography generally, is a comic one; it ends “happily,” with some significant recovery; the narrators are healed, if not cured. Without exception, then, the narrators are, or claim to be, better off at the end than at the beginning.

For obvious reasons the resolution provided by these narratives appeals to writers, editors, and readers; few people want to read (and no one wants to write) an autopathography with a tragic plot. One powerful motive in going to the considerable effort of composing a book-length narrative of one’s illness must be precisely to “achieve closure,” emotional as well as narrative. (Couser, 1997, pp. 39–40)

II

I wasn’t sure creating a dissertation would answer any of my questions or help me. Saying I wanted to use the dissertation to help me heal felt risky. What if it didn’t work? What if mixing my dissertation and my cancer diagnosis just made them both... worse? What if I got caught up in an unending cycle of reading? What if I couldn’t put the art first? Would using the dissertation to help me process my cancer diagnosis put too much pressure on me to “move on” and “get over it?” Wouldn’t it just be easier to stick with my original topic? I already had so much work done... I wasn’t sure this was possible.

I’m not over my cancer diagnosis. I still think about it every single day.

But through the process of creating this dissertation, I've:

- Deeply considered my onto-epistemological beliefs and research orientation. As part of this work, I've made very conscious decisions to reject some of the norms and expectations expected from a doctoral dissertation. I've centered important beliefs about the world—non-human beings have agency and are in relation with us; stories are important; artmaking is a form of sensemaking, and should be treated as such—rather than centering the norms of academia. I recognize how important it is for me to honor the ethics that come with storytelling, artmaking, and being in relationship with non-human beings.

I recognize that my choices will make this work seem less academic or less worthy to some researchers. I accept that risk.

Ultimately, focusing my research skills and my artistic practices on my cancer experience gave me space to help make sense of myself and my own experience in a way that makes the most sense to me. I had to do this work.

- Reexamined the schooling and teaching stories I've been telling myself for the past twenty years. I've considered why I chose teaching as a career and how my schooling, and my first-gen identity and experiences influenced me as a teacher. That was always going to be a part of my dissertation, so that wasn't really a surprise.

What *was* a surprise was that I also made some personal sense out of why I *didn't* choose an art related career. I have a better understanding of the cultural narratives I was being exposed to, and why I didn't think it was possible for art to have that much importance in my life.

- Learned about American breast cancer culture and which illness narratives our society wants to hear from breast cancer survivors. Reading scholarship from medical sociology has given me a better understanding of where I do, or don't, fit within American breast cancer culture. It's helped me understand why I've felt interpersonal tensions with friends, family members, and strangers when they've wanted to hear a story I don't want to tell, or when I've told a story they don't want to hear.

As part of this learning, I've explored how to craft my own illness narratives, so I can shape restitution, chaos, or quest stories. I've experimented with hermit crab essays and I suspect these will become common in my work. I've learned how harmful quest narratives can be, especially when that's the only story option you're given. More importantly, by tuning in my ear to my own illness narrative(s), I've learned how to listen more closely to other people's illness narratives.

- Examined the internal tension I feel over not being a "good" breast cancer survivor. Creating this dissertation has given me the ability to see that the guilt I've felt over developing and surviving cancer is normal.

- Figured out why I hated being called "brave." I was able to situate myself in a larger social context, and use that larger social context to make sense out of something that bothered me. This was an unexpected outcome of this research, and I'm thrilled that I can put words to the difficulty I have with the term. I also considered how I can recast "bravery" into "courage."

- Started to rewrite the stories I've told about my life, in the past, present, and future. This rewriting, like any storytelling, will be a shifting, on-going process, for my lifespan.

- Put art first.
- Written the story I couldn't find at the beginning of my diagnosis, the one I needed to read.
- Used artistic processes to make sense of the conflicting emotions I was feeling. I gave myself over to my art. I took risks, I learned new skills, I asked myself, "What is this [photo, fabric, walk, yarn, etc.] trying to tell me?" And then I shut up and listened.
- Read, rested, written, taken long walks, had longer conversations with friends. I've made art. This dissertation is both process and product. And I've finally processed enough to be done with this product.

There's more work to do, but that work can and will be done outside the confines of this dissertation.

III

A [dissertation's] concluding chapter is often expected to bring a "sense of closure" and highlight key findings and contributions to knowledge. (Ingram, 2021, p. 254)

IV

Breast cancer isn't women draped in gauzy pink cotton with their arms slung around one another in a public service announcement with bold copy making declarations about sisterhood and courage. It's not pink froth and never-ending optimism and expensive fundraising walks for ultra-rich nonprofits. And the cure isn't going to be found in purchasing a pink spatula or rose-colored yarn or a bubblegum-bright bra.

Those are easy to swallow lies.

I'm afraid perhaps the stories I've told here are still too clean. Too palatable.

I'm not sure I've included enough about the physical trauma of breast cancer treatments.

I haven't talked about the pain of having radioactive tracer dye injected through the areola (four times), or the buzzing sensation that came with the chest block wearing off, or the terrible, horrific bruises that took forever to heal. I haven't written about the rashes I developed in the heat of summer. I haven't included how my nipple peeled during radiation—which is truly disarming—or how radiation made my nipple semi-erect, constantly, and how much it hurt to get dressed and undressed, which I had to do multiple times a day so I could slather expensive radiation cream all over my reddened skin.

I haven't written about the lymphedema I was told was very unlikely to develop. How my breast sometimes aches when I wake up in the morning, right near the scar. How I have to cradle it on the way to the bathroom, for just a few extra seconds, until my body gets used to being upright again. How I lose an hour of time every night when I use my lymphatic pump, how it immobilizes my entire right arm and makes it difficult to regulate my body temperature.

I haven't written about the hot flashes my medication causes and how they disrupt my sleep (and my partner's).

I haven't written about the aesthetic issues I'm still coming to terms with. None of my shirts fit me right. My breasts are uneven, and I'm self-conscious about it. None of that would matter if I could wear underwire bras, but I'm stuck in ugly, elastic medical bras because I need the compression. (Never did I think I'd long to wear an underwire bra.) They only come in black, beige, and pink, and they use "simple sizing" without any

consideration of cup sizes, which means they're too small in some areas and too large in the others, and they provide no separation of the breasts. They have extremely wide straps and zippers up the center front. They show under everything I wear. (At least the compression sleeve I need to wear every day comes in more colors. I flew straight past the "discreet" ones in "natural" colors and went for teal, fuchsia, and navy blue.)

I haven't written about the funny things that happened. The boob clock connection with other women. The drag show number that was all about how "you've gotta have boobs." The nurse who implied I didn't have cancer... at my follow-up appointment with my surgeon.

I haven't written about the anxiety I have every time I feel a twitch or twinge in my body. I haven't included weird risks I have to consider for the rest of my life, like the fact that my right rib cage has been permanently weakened. I haven't written enough about the fear of recurrence or metastasis. I haven't written enough about how guilty I feel for being so upset over this diagnosis when it was caught early, and when I was in a financially privileged position. I know other women have it so much worse than I do. Is it fair for me to complain? I haven't written about how angry the whole month of October made me, and then how angry I got at myself for being angry instead of thankful.

There's art I didn't have time to make and couldn't include.

There's so much more I could say. (There is always going to be more. Because this experience will be with me until I'm dead.)

I haven't written about how I still occasionally wonder if all of this was somehow my fault.

V

Such tidy, or “wrapped up,” narratives may form the basis for cultural imperatives or social prescriptions for living with illness, creating an assumption that once treatments have ended, narratives have also concluded and illness is no longer worthy of discussion. Yet, those who survive breast cancer show that the meaning of illness lasts far beyond the conclusion of treatments. The tendency toward the tidy or conclusive narrative may then become manifest in academic writing as well. (Thomas-MacLean, 2004, p. 1649)

VI

One thing I’m still pondering is the “so what?” for the reader. I know why creating this dissertation, making art, and writing my own breast cancer narrative matters to me. What I’m less sure of is what I want the reader to get out of this.

The problem is that I have no universal truths I want the reader to leave with.

If I were telling a restitution narrative (Frank, 2013), the universal truth would be about the miracle of modern medicine. But breast cancer and its treatments have left my body permanently changed, and there is no “cure,” only treatment with “curative intent.” This isn’t a restitution narrative.

If I were telling a chaos narrative (Frank, 2013), I would be speaking entirely through my body. I wouldn’t be able to organize my thoughts enough to create a dissertation. This is no chaos narrative.

If I were telling a quest narrative (Frank, 2013), I would have universal truths about the world or society or the self to share with the reader. But I have no universal truths to share. I haven’t gone on a quest and I haven’t come back a better, wiser person.

Besides, if I provide the reader with what I want them to “get out” of this narrative, I ignore the reader’s own ability to connect with my stories and with the theories and academic literature I’ve brought to the table. If I don’t allow the reader the space to connect with the work, I’m going against my own onto-epistemological beliefs about what stories can do, and how readers and stories are in relationship with one another.

I want my reader to come to their own conclusions. With one major exception.

I’m worried that a reader could decide, in the back of their mind and despite my protests, that the cancer was a good thing. Because we *want* good stories. And when it comes to breast cancer, we think a quest narrative is a good story. Turning breast cancer into a quest for wisdom and betterment makes breast cancer a woman’s rite of passage. Quest narratives make breast cancer—something that should be viewed as a public health crisis—a woman’s self-improvement plan. A good girl will turn breast cancer into a good story. She might even call it a gift.

And depending on how you read the Pacem chapter, it would be easy to say, “But look, Amanda, you’re fine. Your cancer was caught early, you got good treatment. And honestly, your cancer diagnosis brought you back to your art. It helped you find out what’s most important in your life right now. Isn’t that a good thing? Couldn’t *that* be the positive you find in this experience?”

No. Cancer didn’t bring me back to my art.

I had my brother build a darkroom in my house years before I found out I had cancer. I was already sharing my creative writing in online communities, and I’d long since become comfortable with calling myself a writer.

I'd already found arts-based research, and I'd ventured into the university's Arts department to take an art theory class, even though I was more than done with my coursework. The week after passing my oral exams and research proposal, I transferred into the Arts in Education program track. Even though this was largely symbolic, it felt like home.

I'd written an article about how my identity as a photographer had changed over time, and had gotten it published in the *Journal of Artistic & Creative Education*. Chapters I'd submitted about walking as an artistic practice had been accepted to a book project put out by an international organization for the arts. I'd submitted my work to an art show, I'd joined associations for artists and arts-based researchers. I was attending art shows and art talks and art openings.

I was already buying (and reading) books about incorporating creativity and artmaking into my life. I was already taking classes at The Textile Center and Loft Literary Center. I was teaching myself alternative darkroom processes. I was learning to spin yarn.

I was practicing saying the hard part—"I'm not sure I want to be a teacher anymore, I want to focus on art"—out loud. First it happened in my journals. I wrote about how I wanted to spend more time making art, and how scary that felt to say. This showed up, over and over again, throughout my journals. Then I started sharing this in conversations with friends. I allowed myself to feel the swirling that admission brought to the pit of my stomach.

I'd started calling myself "an artist," even when it felt uncomfortable. I claimed the space. I claimed the label.

Five months before my first routine mammogram, I applied for an arts grant. (I didn't get it.) Days before my biopsy, I applied for a slot in an artist's residency. (I got it.)

I was *already* moving toward art. I was already reconnecting with that side of me. I was already figuring out how to find more time and space to make art in my life. Cancer had nothing to do with it.

What cancer did—via the death of my friend—was intensify the *urgency* I felt in moving toward art.

But I'll never be grateful for that, because Mariel should be here.

VII

No, this is not my sisterhood. For me at least, breast cancer will never be a source of identity or pride. (Ehrenreich, 2001, p. 53)

VIII

There is a “seductive allure of telling a cohesive and linear narrative” (Ingram, 2021, p. 254), but I've failed to give you, Reader, a tidy narrative. I ~~fail~~ refuse to give breast cancer a tidy narrative.

Ultimately, my only wish is that you walk away as a witness.

IX

In narrative ethics, if the point of a story is not clear, don't explain, tell another story. (Frank, 2013, p. 183)

X

“What's your dissertation about?” The woman across from me sipped her sparkling water. We'd already shared which pieces of art we'd submitted for the Textile Center's annual member's show, and now we were making small talk.

“Ah, well... I’m in Arts in Education, and my topic changed earlier this year.” I took a sip of my own sparkling water, wondering how much to say. “I went through breast cancer treatments last year, and even though it was caught early, it was really... hard. I’m using artistic practices to make sense of my life after I got breast cancer, how to make sense of the ‘narrative wreckage’—the existential crisis—breast cancer left behind.”

“Oh, wow. How are you doing that?” she asked.

“I use textile arts, photography, and storytelling...” I went on, telling the woman about the cyanotype project I was working on. Six months earlier, I would have only been able to talk about my personal experiences, but now I was able to speak about broader breast cancer culture and societal expectations. When I interjected a bit of my story, I didn’t dwell in a chaos narrative, rely on a crisp restitution narrative, or celebrate with a quest narrative. I kept it honest and simple, without being simplistic.

And I didn’t cry. I didn’t choke up.

I thought, *Oh, maybe I’m getting to the point where I’m ‘done’ with my dissertation. Because I’m pulling in theory, and my story, and... Because I’m not crying right now...*

“I’m really interested in this,” the woman said. Her clear blue eyes met mine. “I was just diagnosed with breast cancer last Thursday.”

XI

A subtle but significant difference lies between claiming definitive closure, which implies that the story of illness (as well as the written narrative) is over, and

achieving composure, which implies readiness for whatever is in store. (Couser, 1997, p. 41)

XII

This is not the dissertation I wanted to write.

This is the dissertation I needed to write.

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