

Surviving Oncology: Living with Cancer in the Wake of Integrative Care

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ABSTRACT

This dissertation analyzes the emerging medical field of integrative oncology, attending to how this approach to cancer treatment unsettles and reconfigures existing biomedical ideas about bodies and cancer. Informed by twelve months of multi-sited ethnographic study conducted in the state of California, it examines the attempts made by integrative practitioners to provide “whole patient care” by incorporating complementary medicines such as Ayurveda and Chinese medicine into conventional oncology. I suggest that this approach enacts a kind of *sensitivity* for how cancer is lived as a disease conditioned by emotional, psychological, social, and environmental factors, requiring treatments attentive to these dimensions.

Throughout this study I grapple with the intentions of integrative oncologists and the realities of the political economy of medicine and insurance in the United States that leaves integrative care out of the reach of most people, producing a situation where many are strained to imagine different ways of surviving oncology. At the core of this project is a concern for what it means and what it takes to live well with cancer in biomedicine.

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PREFACE

I've been researching cancer for five years.

This work started with a phone call from my mum on a balmy September afternoon. It then grew slowly, eluding recognition.

It took me several years of obsessing with the modelling of cellular life in the health sciences before realizing that cancer was integral to what I cared about—a necessary companion. But on that balmy afternoon in 2009, the only research terms I had were diagnostic. Mantle cell lymphoma. A rare form of B-cell non-Hodgkin lymphoma, predominantly diagnosed in men—the identification of which followed all too closely on the heels of the treatment my father had just finished for a carcinoma on his adrenal gland. Over the course of my first semester as a doctoral student, the pungent smell of disinfectants and unwashed hair, the ghostly traces of medical tape on arms and clavicles, the rhythmic clicks of infusion pumps, and the groans of vinyl infusion chairs refusing to recline were transferred from one parent to the other.

I spent hours at her bed, and hours in Chrysler mini vans driven by retired auto-repair mechanics who volunteered as couriers for the Canadian Cancer Society. With each trip between the county and the city, her treatment intensified. She underwent two rounds of chemotherapy in two different hospitals. When these treatments proved to be

unsuccessful in quelling the growth of her tumor, she was asked to participate in a clinical trial testing an experimental combination of chemotherapy and autologous stem cell transplantation for lymphoma patients. As I read about clinical trials for my first comprehensive exam, I learned that she was the perfect experimental candidate—naive to pharmaceuticals, relatively young, and in good health prior to diagnosis (Petryna 2009; Dumit 2012). My reading lists became a kind of syllabus for supporting my mother through treatment—a way of understanding the daily negotiations with her oncologists, the trial coordinator, and the hospital pharmacists. These texts provided me with language and critical insight, enacted in moments where I pressed for clarity on how her tissues were going to be used were she to consent to donation, when I urged her to ask about the side effects of the treatment, and as I pushed to find subsidies or loopholes in her medical coverage when she received prescriptions for \$6,000 pharmaceuticals.

Throughout the nineteen months of aggressive interventions required for a disease found in its fourth stage, I made fieldnotes. I wrote when I realized radiation was being used as a last ditch, but altogether cosmetic application. I inscribed my frustrations after finding, without notice, that she had been moved into isolation, having contracted pathogenic *Staphylococcus aureus* from her extensive hospital stay. I jotted down what it felt like to watch her as she pressed her tear soaked face into a swatch of fabric she was embellishing after her containers of seed beads collided with the speckled tile of the oncology ward, her hands too sore from the transplant therapy to twist their lids shut—the unwarranted reaction of the nursing staff that made it seem as though those little

spheres were the most disruptive presence in the room. I made note of when she insisted that I be concerned about my classes, rather than her condition, and I filled pages after the immobilizing scrimmage which ensued when a resident read remission on a CT scan where it actually, acutely, decried unabated multiplication—etching to paper the way the atmosphere of her oncologist’s consultation room thinned completely in the moment of correction. The gasps for air she and I each uttered. The apology she never received.

What I haven't written about were the days before her diagnosis. The summer prior to her becoming an oncology patient, she didn't smile. There were days she didn't feel like painting, even when we had packed our oils and easels and driven to the highest point in the county—a spot which revealed the anatomy of the escarpment as a body of limestone bones, white cedar musculature, and radiant azure skin, gently curved, and often cloudless. She didn't ride her bike, or walk to the library. She spent many of those days wearing the arms of her chair with worry, hand rested on her abdomen—a comportment I'd never seen. Sometimes I would catch her wincing, and if asked, she would disregard the pain as something to do with dinner.

I can only now write about her belief that feeling something amiss in her body was an insubstantial complaint to bring to a physician—the insensitivity she expected to receive. I now have space to detail that she felt her cancer might respond to unconventional treatments, despite her oncologist’s insistence on staying the conventional course. I am able to describe and sit with the story she told me just days before Christmas when we

were seated in the basement level waiting room of the radiation clinician at the Princess Margaret Hospital in Toronto. She recounted a vision which revealed the cancer nested deep in her belly as a bright ball of heat. Having seen this, she felt that the ionizing rays of this treatment were making it grow. She took from the dream that the treatments weren't going to work—that each, all along, had been the wrong temperature. She felt that if she could only freeze the cancer, she might be free of it. Eventually ice was used therapeutically. I fed it to her, piece by piece, in an attempt to abate the thirst she felt as her organs began to fail.

...

The experience of shouldering my mother throughout the many interventions she endured left me with a series of questions concerning how the treatment of her cancer could have been different. It also left me with a container for this research—a story that holds together many of the tensions, struggles, and embodied experiences that were later told to me by those I became close to throughout my fieldwork—a story that began to unfold for me at the end of her life, in the company of her ghostly white skin, her eyes without lashes, her body whittled down by half, and the wonder for how it was that something different wasn't done.

But there were attempts. My siblings and I insisted that she seek care from practitioners who could help her through chemotherapy and eventually radiation. We would send emails to one another with links to journal articles and websites outlining complementary,

and alternative medicines that were described as being beneficial for people undergoing conventional oncology treatments. We marvelled that there could be relief for her nausea and pain, and at the possibility that she might get her appetite back if she pursued these practices.

I tracked down acupuncturists and yoga studios in and around the small city where she lived. I bought her blue green algae, probiotics, and protein supplements in an attempt to gently fortify her immune and digestive systems after each chemotherapeutic infusion indiscriminately destroyed all rapidly dividing cells her body—cancerous cells, hair cells, the cells the digestive tract. I hoped that these remedies would have a positive effect, convincing her to pursue other supportive treatments.

I remember finding those supplement containers lodged at the back of the refrigerator like forgotten tubs of takeout—her telling me, repeatedly, she'd call the acupuncturist tomorrow or that she needed to run the idea by her oncologist, again.

All of this sat uneasily with me having grown up in a household where everyone's ailments were treated with a trip to the chiropractor, a homeopathic remedy, or with an individually assigned package of dried herbs that were put to boil in clay pots bigger than my head, procured biannually from a Chinese herbalist. We very rarely consulted biomedical practitioners. It took deep cuts or high fevers to make those kinds of appointments.

Sometime after the second round of chemotherapy, but just before she became a clinical trial participant, I pressed for clarification, clumsily, on why she wouldn't pursue other additional forms of medical treatment. She revealed that she had met with a social worker when she was first diagnosed—a consultation mandated by the hospital where she first received treatment. She described how beneficial those sessions were—of how speaking with a social worker helped her work through the shame she felt for the inception of the malignant B-cells in her body—the feeling that she had these these cellular mutations were a kind of retribution for bad decisions or inaction. But she only had a handful of sessions, limited by the fact that there was only one oncology social worker available at a hospital serving a community with high rates of cancer.

Unfolding her resistance further, she confided to me that this all came down to a matter of cost. She couldn't afford to pay out of pocket for counselling, or acupuncture. She felt too much guilt to take a family friend up on her offer for free massage. A life lived against a canvas, with little time spent outside her studio, left her without health insurance benefits, or a liveable pension. Too, the tenor of the household had changed. After my father's brush with cancer he relinquished all his investments in Chinese medicine. The bathroom cabinet filled up with clear plastic tubes of pharmaceuticals and the packages of herbs he once celebrated with such intensity were left to desiccate further in the pantry.

Amplifying that abandonment, her oncologists dismissed her questions about supplements or supplementary medical modalities, citing a poor evidence base and his

unfamiliarity with the suggested practices. Without resource or recourse, she carried on with the standard of biomedical cancer care offered by the public health care system in Canada.

I do not want to suggest that my mother would have lived if her treatment course had included more than chemotherapy, stem cell transplantation, and radiotherapy. The prognosis for her diagnosis shifted quite early from positive to poor. I do want, however, want to leave open the possibility that how she lived, and how her experience of cancer treatment might have been different if she had been able to access complementary and alternative treatments.

Then and now, I find myself troubled to understand how bodies might be known by biomedicine in order that they be able to live and die well with cancer. This is a question once charged by the ache of watching someone die, but it also a question I came to after having spent a year researching the developing field of integrative oncology which attempts to tackle this problem by incorporating evidence-based complementary healing techniques into conventional cancer treatment regimens with the intent of making cancer therapies, and cancer, more livable.

In this dissertation I track the practices of integrative oncology, and the perspectives of its practitioners and patients using a multi-sited ethnographic research methodology. I explore how this field has taken shape, and its relations to biomedicine, and

complementary and alternative medicine. With this study I ask: What novel ideas about cancer treatment are propagating in integrative oncology, and how are these conceptions reconfiguring how bodies are known and experienced in the context of cancer care? What implications do these changes in approaching cancer and treatment in integrative oncology have for how people live and die with cancer? What differences are being imagined, how are they being mobilized, and what are the impediments to this practice?

INTRODUCTION: SURVIVING

It's the first of June, and I am on route to the UC Davis Health Center in Sacramento. In a month from now I will celebrate the Fourth of July, chasing after a little grey dog on streets illuminated by a sky of coruscating fireworks in my bathing suit and bare feet. I will run past front lawns ornamented with groups of people drinking from plastic cups, their gaze fixed on the bursts above. They will mistake my attempt to ask a question about the pup for a carousing comment about America, offering me a sparkler rather than a glimmer of insight into the direction she might have darted. But today, I sit on public transit, distracted by conversations within earshot concerning the price of hospital stay, on my commute to an event for National Cancer Survivors Day.

The temperature is cusp on the high nineties by the time I arrive on the edge of the campus. My shirt clings to my body as I make my way to the Cancer Center. Cutting through the parking lots, I can see the white peaks of event tents, and the round edges of yellow and blue balloons. Signs for the Survivors' Picnic stand alongside posters for the weekly farmers market held in a nearby parking lot. I question the scheduling of this event at midday knowing that light sensitivity is a common side effect of chemotherapeutic drugs such as cytarabine, fluorouracil, and tretinoin, and a persistent problem for patients who have received stem cell transplantation therapy.

Having arrived before the 11:00am start time, I take refuge from the heat in one of the waiting rooms that overlooks the courtyard between the Cancer Center and its recently completed addition where the picnic is being set-up. I watch as UC staff arrange the registration booth, packaging lanyards and notepads into canvas bags emblazoned with the University's logo. Across from these tables, local advocacy groups and various cancer specific organizations stack pamphlets and fill glasses with free pens. Sitting under an air conditioning vent I watch as they attempt to secure their signs from the wild, hot desert wind that occasionally whips up and through this corridor. At one table a woman is dressed in tie-dye. She picks stones from the garden and repurposes them as paper weights for her pamphlets on massage therapy for cancer patients. She seems suspicious of the two men standing beside her table dressed as popular superheroes. I later learn that Ironman and Captain Jack Sparrow belong to the West Coast Avengers Group—an organization of volunteers who entertain paediatric cancer patients in hospital.

I notice that Berdine—a programming coordinator at the Cancer Center who organized this picnic—has returned to the registration table, and I make my way to greet her. She welcomes me with a warm hug, and thanks me for coming. Echoing the email she sent me last month about the picnic, she mentions wanting to introduce me to Anna—a trial attorney who instructs the yoga class for cancer patients and survivors that Berdine implemented as part of the outreach programming for the Cancer Center. She tells me that Anna is the guest speaker for today's events, and that she will be talking about her experience of breast cancer and the effect yoga had on her survivorship. Noting the time,

Berdine implores me to grab some lunch and to take a look at the artwork on display inside the foyer of the new building.

As I move through the crowd I notice that people have accumulated a series of buttons on their chests. Some bear the logos of Relay for Life, others the UC Davis logo, but the most prevalent button is royal blue. On it, the words *I survived* give way to a blank box where various forms of cancer have been written in marker. The summer heat, combined with the placement of the buttons in the precise spot where the condensation collected on cooled cans of pop drip when drunk has caused these labels to smear and smudge. I pass several women whose chests read *breas...ncer*. Stopping to survey these buttons, I accidentally trip into a bed of lavender, caught off guard by the presence of young children with crowns of fine stubble and hotdogs in hand. Their shirts are studded with similarly smudged buttons

Leu...mi ... liver can..

Fragrant floral notes waft up at me as I find my footing after encountering these elisions — disappearances that remind me of all the people missing from this celebration of survivorship.

Walking into the recently completed wing of the Cancer Center, I am hit with the sharp perfume of new carpet and freshly applied sealants. I think of Lochlann Jain's poignant

point that conduits for cancer awareness are often also conduits of carcinogens (2007; 2013). In this moment I am also reminded of California's Proposition 65—a law which requires the posting of warnings to indicate if a product or place “might contain a chemical known to the state of California to cause cancer, or birth defects or other reproductive harm.” I first encountered one of these signs in a Starbucks at the Sacramento airport. It was hung low, adjacent to a counter covered in milk carafes, sugar packets, stir sticks, and coffee lids. I look for similar signage in this building, but the only mounted declarations I find are the steel-cut names of the funders underwriting the expansion.

Continuing into the space, I come upon the artwork Berdine had mentioned. A series of aluminum easels display reproductions of juried paintings submitted to the *Lilly Oncology On Canvas* competition (Figure 1). Each of these printed foamcore boards details the title of the work and description of its subject matter. In the absence of artist's names, the boards are indexed by a numerical code and labeled as *Painting and Mixed Media by Healthcare Professional*, *Painting by a Person Diagnosed with Cancer*, or *Painting and Mixed Media by Family Member, Friend or Caregiver*.

Oncology put to canvas portrays life with cancer as triumphant and defeated. These works make present a series of experiences and intensities often undisclosed in clinics and cancer centres.



Figure 1: Installation of works, *Lilly Oncology On Canvas Art Competition*, California, 2014. Photograph by the author.

Stories of when the drugs work and when they fail are folded equally into this catalogue. Stories of children apologizing for becoming distant after a parent’s diagnosis, unable to cope with the incapacitating possibility of death. Stories of people learning to push pigment to canvas as a way of coping with the stress of cancer treatment.

These images pull at me, cling to me, press into me for a reading which does not dismiss them as instruments in a clever pharmaceutical campaign. Curated for a competition organized by the pharmaceutical company Eli Lilly, and positioned as creating a platform for the expression of “cancer journeys,” in an effort to “[connect] people with cancer, as well as those who care for them,” these images create a field of resonance, palpable as people trickle into the space, quietly standing, mulling, with hands braced to their chests.¹

But, there is clearly a softening of Eli Lilly’s image as a pharmaceutical company that cares at work in this show—an exhibition that can be booked and installed anywhere in the United States. The website informs me that *Oncology on Canvas* is often presented in schools, cafes, and other public spaces—framed as a kind of educational and celebratory experience.² Indeed, the show has been curated to suit these spaces. These aren’t paintings of mastectomy scars or bodies disfigured by radiation and chemotherapy. These

¹ See <http://www.lillyoncology.com/lilly-oncology-on-canvas/>

² See <http://www.lillyoncology.com/lilly-oncology-on-canvas/index.aspx>

canvases do not depict oncology wards or patients dying in hospice—they do not render the tangling of tubes, flesh, and laundry soiled by sweat, vomit, and excrement ever present in the space of oncological practice. As seen in Figure 1, the grotesque dimensions of this disease and its treatment have been selected out, giving way to palpable images of flowers, animals, joyful movement, and abstract fields of colour.

As I sit among these works, I watch partners exchange nods and pull close to one another. Others join me on the couches in the center of the room. In knee length khaki shorts and pastel t-shirts— their fanny packs filled to the brim, bucket hats resting on their knees—they sip water and watch others who press on, reading each of the boards that encircles the space.

The website for the show also indicates that the winners of each competition are rewarded with a charity donation in their name. A paltry prize for paintings potentially depicting the experience of being treated for cancer with one of Lily’s three chemotherapeutic drugs, Erbitux, Altima, or Gemzar—a kind of compensation which does not consider that these artists, these survivors, might have paid out of pocket for these or other treatments so they could arrive at a place where they could paint about their “journey.”

I stand up from the couch thinking that it might be nearing the time of Anna’s talk when I overhear two people discussing yoga. I look around the corner to see two women: one

dressed in a form fitting floral dress and cream coloured heels and the other, wearing track pants and a long sleeve t-shirt, head wrapped in a floral scarf. I hear one woman say *come try the class sometime* and they part ways. Noticing the sheets of typed notes in her hand, I presume the woman in the dress is Anna. I introduce myself, and she laughs, reminded of the connecting email that Berdine sent several weeks ago. We speak briefly about the content of her speech, and the concern that people wont understand why she wants to talk about the discomfort she feels with the term *survivor*. As I begin to ask a clarifying question she interrupts asking for the time. Realizing her talk is in five minutes she invites me to walk with her to the courtyard.

Exiting the building, Berdine and several of her staff encircle Anna. I walk over to the edge of the courtyard, facing the stage constructed for the event. Two men tinker in the sound booth beside me, eventually lowering the volume on the music they've been playing since the start of the picnic. The microphone chirps in Berdine's hands as she takes to the stage. She comments on the celebratory nature of the picnic, inviting those present to revel in their survivorship. After outlining the remaining events of the day, Berdine introduces Anna as "someone who is very special" to the Cancer Center.

Explaining that Anna has been practicing law for six years, and yoga for one, Berdine suggests that this talk will offer insight on the "importance of yoga for staying healthy and physically active in helping alleviating the side effects of cancer." In bridging yoga and cancer care, Berdine reaffirms the Center's position on "addressing the *whole patient* with a variety of services and resources."

Anna takes the microphone and unfolds the pieces of paper clutched in her hand. Over twenty minutes, she speaks from and off her script, sometimes holding her pages above her head, shielding her already sunglasses eyes from the bright beams of the high noon sun. In an almost apologetic tone, she describes how “uncomfortable” she is with the word survivor. Leading us through a chronology of her diagnosis, Anna discloses that she was reluctant to participate in support groups because she did not want to draw attention to herself as someone with cancer, let alone someone who survived treatment for cancer.

I cannot shake Anna’s discomfort with the word *survivor*. I hear her critique not as an affront to those who willingly take on this moniker, but as a way of calling attention to the commonly held idea that conventional cancer treatment is something to be *survived*. In a conventional context, people don’t survive cancer, they survive oncology.

Survivorship as a state of celebration, as a reward of sorts, legitimizes this continued narrow and solitary escape from the toxic claws of chemicals and radioactive materials taken to be the most effective way to treat cancer.

The poignancy of Anna’s comments deepen for me as she describes how instrumental her yoga practice was in balancing the debilitating and disembodied effects of chemotherapy. That even when she was motionless on her mat, her body too sore and tired to broach a pose, the idea that something other than chemotherapy could help her heal made her feel stronger. What I hear from Anna is an attempt to sensitize this crowd to other possibilities—to ways of *enduring* cancer with the support of different practices

—that the integrative approach she took to her cancer treatment helped her do something more than survive cancer—it helped her live with cancer.

As the picnic begins to unwind, I find Anna and we walk to her car. As we discuss her speech, vehicles pull up beside her and drivers extend their hands to thank her.

Passengers lean out windows to tell her that they too “never really liked the word survivor,” acknowledging the bravery of that admission. Before driving off, each asks for details about the yoga class. Anna responds with flyers and an earnest invitation to attend the next class.

After leaving Anna, I walk back to the light rail stop by the health center. I try to write fieldnotes, try to get as much down about the picnic as possible, but I keep returning to the photographs I took of the *Oncology on Canvas* show.

I can't shake the hold of one piece in particular, “Transition” (Figure 1.2). The dramatic wash of pooling pigments—the portrayal of cancer as an inky black mass, ever encroaching on the spirited terrain of bright, furling fleshy pigments. The way the areas of white in this piece hold space against these obsidian claws—marking out headway in a battle with cancer—a kind of “conquering”—a “light emerging from darkness.”

I tuck my phone back into my bag, and begin to curl and bend my ticket with the fret that follows this rumination.

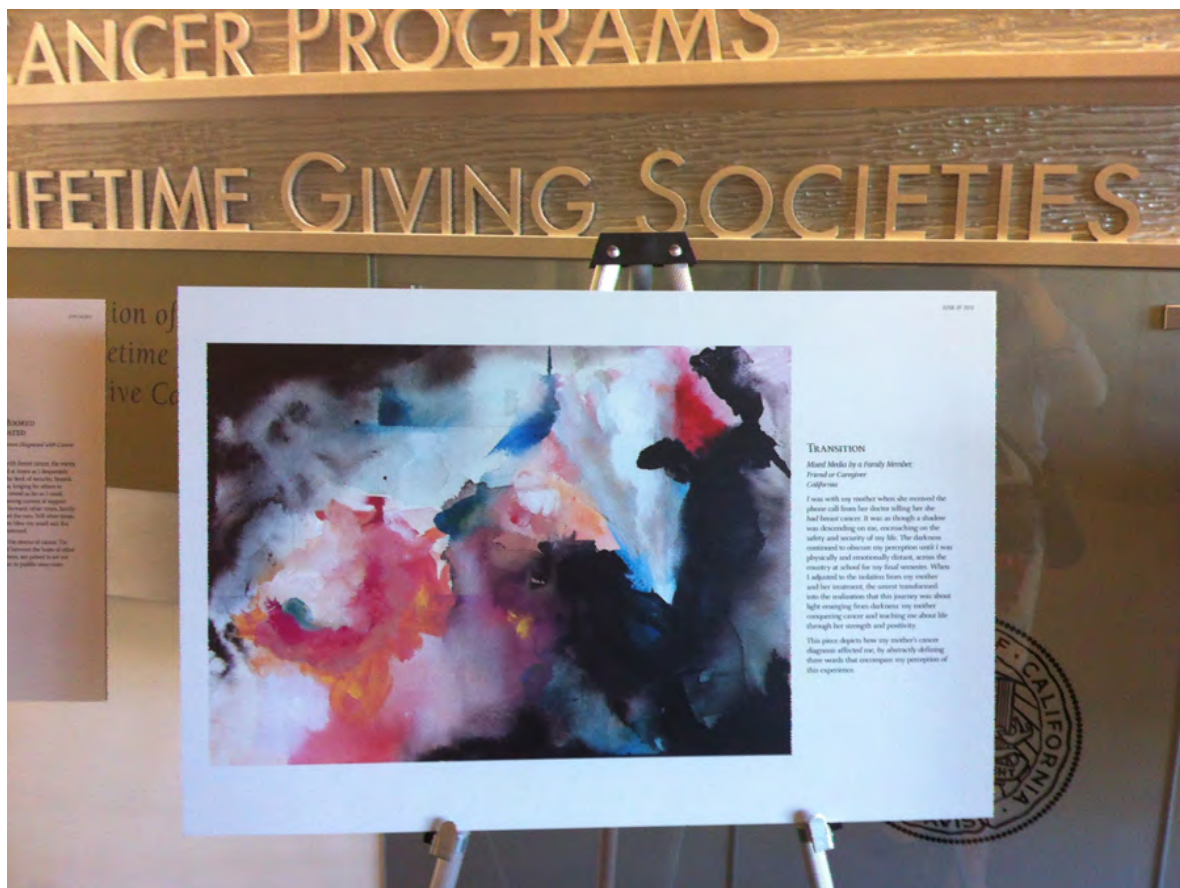


Figure 1.2: “Transition”, Mixed Media by a Family Member, Friend or Caregiver, Lilly Oncology On Canvas Art Competition, California, 2014. Photograph by the author. The caption reads:

I was with my mother when she receive the phone call from the doctor telling her she had breast cancer. It was as though a shadow was descending on me, encroaching on the safety and security of my life. The darkness continued to obscure my perception until I was physically and emotionally distant, across the country at school for my final semester. When I adjusted to the isolation from my mother and her treatment, the unrest transformed into the realization that this journey was about light emerging from darkness: my mother conquering cancer and teaching me about life through her strength and positivity.

This piece depicts how my mother's cancer diagnosis affect me, by abstractly depicting three words that encompass my perception of this experience.

What happens when the light doesn't emerge? When the murkiness of opiates administered to interrupt the debilitating ache of growing tumors, somewhere, anywhere, everywhere in the body becomes an obsidian hued encapsulation? Or when the view from the hospital bed is the same for weeks on end: a horizon of concrete buttressed by concrete, neutral walls too beige to call out the affront of such a unvaried, melancholy making view.

What lessons arise from living with, or alongside, a cancer diagnoses that does not end in survivorship? What picnics are held for people who don't survive? What about those for whom survivorship isn't an option—their bodies too reactive to administer treatment, their cancers too terminal for treatment to work. Who sits in the blistering heat, eating prepackaged hamburgers and Halloween sized bags of potato chips in their honour? What would their buttons look like, and where would we pin them?

I didn't survive.... I tried to survive... I didn't want to survive... this...

...

I begin with the story of the survivor's picnic because it refracts conventional oncology as I have experienced it in my capacity as a caregiver, and as a researcher interested in

understanding how integrative approaches to oncology pose possibilities for different forms of cancer treatment in biomedicine.

Indeed, this event is evocative of so many of the concerns about cancer treatment that I have carried with me in my investigation of integrative oncology, not least of which is the cruelty and contradictions of conventional cancer care which prioritizes treating forms of this disease at the expense of the patient. These tensions are perceptible in the conditions of the picnic—an event held in a shadeless atrium, an enclosure of mirrored walls that intensified an already sweltering mid-day sun, requiring that those in attendance recovering from or still receiving treatment for cancer spend the day repositioning their visibly sore bodies into what little shade was produced by the tents of the sponsors, reapplying sunscreen and trying to find a spot to sit and eat the processed foods provided for this celebration. The only things guaranteed protection at the picnic were the photographic prints of the Eli Lilly *Oncology on Canvas* installation—a show sponsored and curated by a pharmaceutical company that produces widely used chemotherapy and immunotherapy drugs for cancer treatment and who also happens to have been instrumental in the establishing of DowElanco, the agricultural division of The Dow Chemical Company whose herbicides have been identified as carcinogenic.³ This connection was not addressed, nor were any of the people missing from this picnic—all the patients who once walked or were wheeled around these buildings for treatment.

³See <http://www.dowagro.com/about/> and <http://www.bloomberg.com/news/articles/2015-06-22/dow-chemical-weedkiller-may-cause-cancer-who-agency-says>

Missing too from this event were the oncologists, physicians, and nurses who had a hand in treating those both present and absent. These nonattendances only ever hinted at in the announcements of extra burgers and hot dogs, and the invitation for attendees to have another plate.

Further, I begin with this story because it provides insight into how integrative interventions in the treatment of cancer are being positioned in conventional oncology. Anna's speech concerning the importance of yoga for how she lived through her cancer treatment is quite telling of this. As are the remarks provided by Berdine who is actively working to build outreach programming at the UC Davis Comprehensive Cancer Center that provides support for patients undergoing conventional therapies. Anna resists being identifying as a survivor precisely because to do so would mean conceding to a standard of care that she feels does not treat the effects of cancer on the mind or spirit—a standard of care in which surviving cancer requires the work of surviving oncology and its radioactive therapies, cauterizing instruments, and toxic cocktails of chemicals.

In this way Anna's agitations remind me of anthropologist Lochlann Jain's analysis of the ruse of survivorship (2013; 2007). Jain contends that the term survivorship was created to "distinguish the medical needs of people who had undergone cancer treatment" from those being actively treated (2013: 30). Noting that this term has "absorbed new social meanings," Jain points to the current "framing of survivorship as a personal accomplishment" (2013: 185-186; see also Sontag 1989). For Jain, the stories that get

told about survivorship as heroic work of strength, bravery, and courage produce narratives about personal struggle, “rather than a communal effort and responsibility” (Jain 2013: 199). Further, these narratives obfuscate the uncertainty tied to the reality that, “virtually all Americans are now born with body burdens of known toxic chemicals” (2013: 190). She suggests that in discourses of survivorship, “cancer becomes a passively occurring hurdle to be surmounted by resolve rather than the direct effect of a violent environment” (ibid). This violence is not only the way in which these stories distract us from recognizing the political and economic conditions that have given rise to toxic relations between bodies and environments that produce cancers (Petryna 2002, Masco 2004, Murphy 2008, Choy 2011, Fortun 2012); but as well, that talk of survivorship prevents us from making causal connections between chemicals encountered and malignancies grown.

Writing from her own experience with breast cancer, Jain argues that survivorship “[does] not leave room to recognize the structures of cultural and economic survival in which physical survival dwells. These underwrite a uniquely American insecurity and the fact that, every day, people lose medical insurance by losing a job or partner, and that many Americans can and will lose everything with a single diagnosis and not because they didn’t work hard enough” (2013: 59). The problem with survivorship is that it implicates the individual as the lone suffer, “represented outside of the very culture that produces [cancer]” (Jain 2013: 85). This positioning makes it difficult to recognize the broader

landscapes of this lived disease—that cancer is shaped by the politics and economics of exposure and consumption.

In the moments where Anna pushes back at the idea of survival, she is pointing to how the biomedical treatment of cancer, and the possibilities of living with and dying of cancer in oncology, might be otherwise with integrative approaches—a mode of treatment being positioned as providing support for the *whole patient* and not just the part of their body that is diseased.

Biomedical conventions

Survivorship is felt as such a constricting condition precisely because it is a narrative constructed of mechanical and reductionist ideas about bodies and disease that populate oncology as a subfield of biomedicine. As anthropological literature on bodies, embodiment, and medicine has revealed, “the singular premise guiding western science and clinical medicine...is its commitment to a fundamental opposition between spirit and matter, mind and body” (Scheper-Hughes and Lock 1987: 8). These dichotomies have been pivotal to the development of biomedicine, and have created epistemological and ontological conditions in which bodies are apprehended through reductionist logics that privilege the “material (rather than spiritual or intangible) forces” in accounting for health and disease (Samson 1999: 180). This insistence on the physicality of all ailments has led anthropologists to suggest that biomedicine produces a mechanistic view of the body

insofar as the materialist approach fragments “the unity of the person” and presumes that “the body can be fixed by mechanical manipulations” (Martin 1987: 20;). This view of the body also produced a model of disease as that which is “materially generated by specific etiological agents such as bacteria, parasites physiological and genetic malformations and internal chemical imbalances” (ibid: 183). Diseases became identifiable and treatable precisely because they were conceived of as having material, detectable presences in the body (Foucault 1975, Martin 1994).

It is this conception of bodies and disease that makes it so difficult for biomedicine and its practitioners to conceive of how illness and disease are embodied (Csordas 1990, Mascia-Lees 2011)—that cancer is biological but it is also lived, and it is experienced culturally, socially, physically, psychically, and emotionally.

This approach to medicine is particularly evident in conventional oncology and in the conception of cancer as the “result of defects in the genetic machinery within the cells that make up our bodies” (Price et al., 2008: 25). Oncology thus materializes an approach to cancer treatment that is designed to intercede in the mechanics of mutation. As cancerous cells generally proliferate at a higher rate than normal cells, standard forms of care such as surgery work to remove the site of cancerous growth, and chemotherapy and radiation are used to abate cellular growth. In the case of chemotherapy, cytotoxic drugs (drugs toxic to living cells) are administered in maximal doses that have been previously determined by clinical trials to be effective enough at affecting the growth of cancer cells

without eradicating a lethal amount of healthy cells. Chemotherapy drugs may also be given to target the specific growth phases in the life cycle of a cancer cell— the timing of which is determined by mathematical models (ibid: 76).

In the context of conventional oncology, what matters for the treatment of cancer is ensuring the that the execution of a materially-focused therapy is executed properly— that the right dimension of flesh is removed in extracting a tumor, the right intensity of radiation beams are administered, or the right dosage of a cytotoxic agent is delivered intravenously. Less pressing is the fallout of these procedures—the emotional scaring, the disfigurement, or living with the half- life of chemotherapy drugs that renders bodies and anything that leaks out of them toxic for anywhere between thirty minutes to nine hours. Here again conventional oncology is expressive of the broader biomedical view that mind and spirt have no bearing on disease—a mode of thinking that teaches doctors “to regard experience—at least the experience of the sick person— as fugitive, fungible, and therefore invalid” (Kleinman 1995: 32). As sociologist Colin Samson argues, “the realization that bodies are people complicates the tasks of medicine, for people have emotions, character and unpredictability” (1999: 179). In the context of cancer treatment, viewing bodies as machines allows oncologists to focus in on the physical body of the patient without having to handle the social and emotional contexts lived by those patients.

If, as medical anthropologist Arthur Kleinman suggests, “biomedicine constructs the object of therapeutic work without legitimating suffering” (1995: 32), integrative

approaches to oncology attempt to intervene in and relieve the dynamics and denials of this approach to cancer treatment. These interventions provide insight for thinking and doing bodies otherwise in biomedicine (Mol and Law 2004, Haraway 2010b).

Integrative oncology

Integrative oncology, at its simplest, is the adaptation of the principles of integrative medicine in the context of oncology practice. Integrative medicine is described as “a healing-oriented medicine that takes account of the whole person (body, mind, spirit), as well as all aspects of lifestyle” (Abrams and Weil 2009: vii). The principles which underlie integrative approaches to medical care have to do with the idea that human bodies possess the “innate” capacity to heal themselves; that the whole person, their mental, emotional, and spiritual lives, must be given attention in the context of any therapeutic practice; that lifestyle deeply influences disease development and progression; and that doctor-patient relationships be built on collaboration and trust (ibid: vii-viii).

As of 2015, there are fifteen integrative oncology programs, and hospital-based clinics across the United States, with the highest concentration in the state of California. Some of the most prominent medical institutes in the United States have integrative oncology services, including the MD Anderson Cancer Centers in Houston, Texas, the Memorial Sloan-Kettering Cancer Center in New York City, Johns Hopkins Medicine in Baltimore,

Maryland, and the Mayo Clinics in Arizona, Florida, and Minnesota. The Society for Integrative Oncology (SIO) lists 5143 members composed of physicians, hospitals, medical centers, and practitioners of complementary and alternative therapies.⁴

Integrative oncology is often conflated with complementary and alternative medicine (CAM); however, integrative oncologists resist and resent this fusing, emphasizing that unlike alternative medicine, their practice does not dismiss conventional biomedical therapies. Oncologists who adopt an integrative approach do so with the use of treatments that *complement* their conventional practice. In this sense, complementarity identifies healing practices that have been evaluated using clinical research, and determined to be compatible with biomedicine such that these modalities can be used alongside conventional treatment regimens. Unlike alternative therapies, which are not recognized by biomedical practitioners as being evidenced-based, the use of complementary medicines thus provides a means to expand the range and quality of therapies integrative oncologists can offer their patients. Integrative oncologists drawing on evidence-based healing techniques from Ayurveda, Chinese Medicine, and manual therapies to recommend techniques such as massage therapy, lymphatic draining, acupuncture, tai chi, hypnosis, self-hypnosis, guided imagery, mindfulness based stress reduction (MBSR), music and

⁴ These figures are taken from a survey of the SIO membership registry, which I have access to as member of the organization (since 2013), as well as the NCI's list of comprehensive cancer clinics (<http://www.cancer.gov/researchandfunding/extramural/cancercenters/find-a-cancer-center>), and Seely, Weeks, and Young's "Systematic review of integrative oncology programs" (2015).

art therapy, yoga, gentle forms of exercise, and breathing techniques. Integrative oncologists also make nutritional suggestions, promoting plant-based diets, and encouraging their patients to consume certain foods such as omega-3 fats, soy, cruciferous vegetables, berries, mushrooms, ginger, and turmeric. Oncologists who pursue training in integrative medicine do so because they feel that their ability to treat their patients is limited by the focus placed on the biological factors of health and illness in conventional biomedicine—an emphasis which limits considerations of the social, environmental, and emotional dimensions of disease.

The oncologists and professionals allied with this field that I met throughout the course of my research described their integrative practice as a way of treating “the body, the mind, and the spirit of a patient... not just their cancer.” In an effort to perform what they describe as “whole patient care,” an integrative oncologist will spend one to two hours in an intake appointment with a patient. The duration of this session allows the integrative oncologist to take a full medical history, inviting an account of the patient’s diagnosis, their current symptoms and complaints, and their diet. In order to meet the needs of their patients, integrative oncologists will solicit more personal information about their patients, asking questions about their fears, how they cope with stress, what their family dynamics are like, what social supports they have, as well as their views on religion and spirituality. These questions help to flesh out a more complex portrait of the patient and how they relate to their disease. The intake session is a critical exercise for understanding

what integrative modalities best suit the patient. For some physicians who are also trained in Ayurveda or Chinese Medicine, this extended intake also allows them to conduct a second diagnostic assessment fitting of those practices.

Throughout the course of treating a patient, an integrative oncologist might recommend acupuncture to relieve chemotherapy induced nausea and vomiting, prescribe a strain of medical cannabis to increase appetite and provide pain relief, recommend practicing yoga to improve sleep, advise on guided-imagery or mediation to decrease anxiety and distress brought on by diagnosis, massage therapy to treat lymphedema associated with the surgical removal of a tumor, or advise a change in nutrition to support immune function and improve quality of life (Cassileth and Keefe 2010; Deng et al., 2009).

What makes the uptake of integrative methods in oncology so significant is that many of the methods used and recommended in this field are predicated on views of bodies and disease which diverge from the prevailing biomedical model of bodies-as-machines (cf Scheper-Hughes and Lock 1987). These are practices in which bodies are animated by winds, vital forces, energies, temperaments, and disease is described as the result of imbalance and overabundance rather than mutation or mechanical breakdown (e.g. Kuriyama 1999; Barnes 2005). Brought to bear on oncology, the complementary medicines taken up in an integrative approach push back on the notion that cancer can be sufficiently comprehended as a condition that “hijacks” bodies (Keating and Cambrosio 2012: 308)—that all is required to treat cancer is to calculate the correct dosage of

chemotherapy, radiation, or immune-endocrine medication based on the tumor stage and grade, and the age, height, weight, and gender of the diseased patient.

Where these different ideas collect, mingle, and multiply in the therapeutic work of integrate oncology, this field puts forth the notion that it takes many different ideas about bodies and disease to begin to treat a patient as “whole.” The idea of treating the “whole patient,” an characteristic of this field in this sense might be better conceived as an attempt to treat the mind, spirit, and body of the patient using a whole host of therapeutic ideas and concerns, rather than a therapeutic focus on the malignancy itself. I track how this idea of the “whole” is constructed and enacted in practice.

Drawing on medical anthropology, integrative oncology might be conceived of as an example of medical pluralism—the idea that no medical system exists in isolation.

Charles Leslie (1976, 1980) put forth this influential argument in the 1980s after conducting ethnographic research on Asian medicines. He found that Chinese, Ayurvedic, and Unani medicine are not only replete with their own complex histories of sophisticated medical practice, experimentation, and innovation, but that these medicines are engaged in “competitive and complimentary relationships” with each other and other forms of medical practice including biomedicine (Leslie 1980: 1919). Leslie developed the concept of medical pluralism to examine medical systems as, “pluralistic structures of different kinds of practitioners and institutional norms” (in Baer 2011: 406). As a concept, it challenged the distinctions made between “‘traditional’ and ‘modern’

medicine” in order to insist that, “all bodies of medical knowledge are dynamic and change as the result of political and social factors as well as the diffusion of knowledge and technological innovations” (Johannessen and Lazar 2006: 2).

Medical pluralism has been taken up in medical anthropology to examine the “pluralistic” approaches taken by people to meet their health care needs (Lock and Nguyen 2010: 62). It has provided a framework for anthropologists to be attentive to and examine the many kinds of interests and modes of consumption that motivate people to seek medical care in and beyond biomedicine in the cultures where it dominates. Recent scholarship in anthropology has encouraged Leslie’s conception of medical pluralism to be broadened in order to account for the pluralisms operating “not only *between* medical systems but also *within* those systems” (Zhang 2007: 82). To this point, anthropologist Everette Zhang contends that medical pluralism needs to be positioned not “as something that occurs naturally and harmoniously,” but rather, as “a site of contestation and struggle, involving, among other things, the relationship between patients and doctors” (2007: 83). In response to this and the need to address the political economic dimensions of pluralism, particularly given that many medical practices “are *forced* to be fully open to the influence of biomedicine” (82), anthropologists have begun to suggest that instead of “trying to reveal ‘medical systems’ we should focus on studying practice (what people actually do when they are ill or suffer misfortune)” (Pool and Geissler 2005 in Singer and Baer 2007: 172). As Thomas Csordas indicates, the “distinctions that we may indeed find useful in mapping out situations of medical pluralism, can breakdown entirely” (2006: x).

Indeed, integrative oncology might be read as an example of this complication. Csordas also reminds his readers that, “the core topic of medical anthropology is neither politics, economics nor political economy; neither biology, chemistry nor biochemistry, but the misery of these who are ill, the pity of these who become healers for those who are in misery, and the unwillingness by either to tolerate such pitiful misery” (ibid).

With direction from literature on medical pluralism, I have learned to pay attention to how patients seek complementary and alternative medical modalities to treat “the experience of illness, not the biological reality of the disease” (Leslie 1980: 193). These literatures have also taught me to follow how complementary medical practices are pulled into oncology to treat cancer, and the importance of understanding how political, economic, and social forces contour what practices are permissible and impermissible as integrative options. These points influence and underwrite my conception of sensitivity, and the questions I have learned to ask about the possibilities for living with cancer different in biomedicine.

Methodology

This dissertation utilizes ethnographic research methods to examine how ideas about bodies and cancer are shifting with the emergence of integrative oncology and what this means for how people live with cancer and with liveable ideas of dying with cancer. This study is informed by twelve months of multi-sited ethnographic research, and involved

the participation of people who are in active treatment, have reached remission, and those who have healed their cancer as well as oncologists, psychologists, psychiatrists, clinical researchers, nurses, hospital administrators, patient advocates, and volunteers.

Throughout the researching of this dissertation I encountered several constraining issues of access. I wrote in the preface that I started researching cancer when my mother was diagnosed. This work began there, but my decision to develop a dissertation project concerning cancer was spurred by a phone call from an administrative assistant informing me that my invitation to conduct fieldwork at one of the leading institutes for psychoneuroimmunology research, located in California, had been rescinded. I had planned to investigate what cellular life was becoming in the hands of experimentalists in this field as they study the affective mechanisms of stress and emotion in the human body. The research ethics clearance I received reflected this, providing me access to laboratories, classrooms, and clinical buildings.

With my apartment subleased, my possessions packed, and my visa paperwork in process, I tried to recoup my project in a way that would make use of all the work and money that had gotten my fieldwork in California moving. Returning to major publications in psychoneuroimmunology, I noticed that this emerging science, in its efforts to demonstrate the biological connections between mind and body, was promoting the relevancy of its discoveries for the treatment of cancer. I started with this provocation,

following citations concerning mind-body medicine and cancer, and asking for recommendations, eventually coming into contact with integrative oncology.

Because this research departed significantly from the proposal I defended, the ethics clearance I took with me into the field was conditional to research and teaching facilities in institutional contexts. I did not have ethics clearance to conduct research in clinical settings for integrative oncology, and the integrative oncologists with whom I worked with were constrained by the ethics policies of their institutions.⁵ These institutional restrictions, though fair in protecting patient privacy and safety, were an impediment to the kind of research I wanted to conduct. The process of revising and resubmitting my ethics protocol to reflect clinical research, both with York University, and subsequently with the Research Ethics Boards of the University of California based hospitals I wanted to conduct ethnographic research in, would have extended my research timelines and exhausted my research funding in untenable and unmanageable ways.

Because of these limitations, offices, charting rooms, and lecture halls became a critical sites for my research. Anna's yoga class for cancer patients and survivors became particularly instrumental as it allowed me to learn about patient experience and cancer treatment without having access to oncology clinics. It was there that I met and practiced

⁵ In Chapter Four, "Treatment", I do follow Peter, a conventional oncologist specializing in hematology, on his rounds. I was able to observe Peter interact with his patients because each was involved in clinical trial research that he was running through his laboratory at Stanford where I had been conducting fieldwork. I was invited to follow him on rounds for an afternoon. Peter obtained consent from each patient to have me in the room. He then identified me and provided information on my institutional affiliations. No treatments were administered during these rounds. I did not speak to the patients, or attempt to solicit any information from them.

regularly with people recovering from and in active treatment for cancer. In practicing yoga with Anna, Nissa, Holle, and Keana and in listening to their stories in the time we spent outside that space, I was able to understand how integrative approaches make a livable difference in cancer treatment. Through yogic movement I was folded into their everyday lives— into their homes and routines, their fears and excitements. I provided support and company, and in moving with them as we ran errands, drove to classes, and shared meals, I learned a tremendous amount about the promises and constraints of integrative oncology.

When I wasn't practicing yoga, or speaking with integrative professionals in their offices, I was cultivating a regard for modes of description, metaphors, images, and jokes deployed in discussions about disease, and human bodies in biomedicine. I did this by conducting participant-observation in undergraduate and graduate courses in health psychology, cell biology, and immunology at UC Davis. The graduate course on immunology that I attended was particularly insightful insofar it provided a space to observe how scientists and clinicians are made in and through sustained engagement and critique of evidence-based research, as the course was heavily structured on evaluating emerging evidence on the microbiome and its importance for immunology. Indeed, these contexts provided me with the experiences required to understand more deeply the ideas about bodies and treatment that integrative oncology resists or attempts to rebuild.

Further, to foster a better sense of changes in conventional oncology treatment, I spent time in a laboratory for hematological research at Stanford University. In that setting I became familiar with the experimental problems and procedures involved in the production of knowledge about graft versus host disease—a serious risk in the application of autologous and allogeneic stem cell transplantation for the treatment of blood-based cancers—a form of conventional treatment this lab was also engaged in investigating. I also carried out research in Vancouver British Columbia in at tenth meeting of the Society for Integrative Oncology (SIO), and online in my enrolment in two training courses on integrative oncology offered by the Arizona Center for Integrative Medicine (ACIM) at the University of Arizona.

Nevertheless, because of these issues of access, my attention to integrative interventions throughout this dissertation is primarily concern the question of living and liveable ideas of dying precisely because the clinical spaces that deal with death, like those of palliative and hospice care, were also not accessible to me. I do provoke the question of the difference integrative oncology makes for how patients both live and die with cancer, by my research can only speak to one side of this question directly. The other side might be best read as a lament, or a hope for different conditions.

Approaching this research as a multi-sited project (Marcus 1998) has allowed me to pursue discussions with a variety of individuals connected to and critical of the development of integrative oncology. In this sense I take on both medical and mundane

spaces as research sites for this project, moving into homes, yoga classes, conferences, and contents of journals and textbooks. Further, my multi-sited ethnographic approach aligns conceptually with the work of integrative oncology as both bring together many different ideas and forms in order to materialize a practice, sensitizing me to the labour required to hold together multiple bodies, from multiple sources, in their harmony and discord.

In consideration of the meaningful, and at times intensely personal exchanges I have had with people living with and recovering from cancer, each has been renamed. However, I leave the names of several prominent physicians within biomedicine and integrative oncology unchanged in order to draw on their important published materials.

Frontiers of practice

More than an accidental alignment, and an attempt to recuperate a collapsed project, California is a critical context for the study of integrative oncology precisely because this state is a frontier space for health movements pertaining to complementary and alternative medicine. I use the term frontier here with direct reference and influence from feminist historian of technoscience,

Bretton Fosbrook, and his work on the technological frontiers of Silicon Valley in California. For Fosbrook, technologists at work in this area conjure the image of the

American frontier to tell stories about progress in the development and fortification of entrepreneurial capital (2012). Advancing a performative account, he offers a way to conceive of the frontier in its “mythical and material” effects in order to account for the social, political, and economic precipitates of the endeavour to make “better” technologies (2012: 13)—of the kinds of violence and dispossession that gets overlooked in the pursuit of progress. The displacements that Fosbrook writes of are all too evident in and around the Bay Area, particularly in the East Bay—cities like Oakland and Emeryville which have seen the displacement of working class people from their homes, and from their purchasing power, in order to accommodate the housing needs of the ever-growing Silicon Valley. These are spaces where bars are built beside wrecking lots, and where startup executives and Google employees wearing t-shirts and polar fleece jackets drink \$40 glasses of whiskey down from streets lined with rundown single storey houses with cars from the 1990s parked out front. These are neighbourhoods where massage therapy schools pop up offering free care to the community, but have their doors secured by pin codes that get emailed to clients in order to prevent people experience homeless nearby from requesting care.

For anthropologist, Anna Tsing (2005), the frontier is a space of capitalist expansion—a space configured as wild and as needing intervention, for the purpose of extracting resources. In his research on integrative medicine in America, medical anthropologist Hans Baer has described California as a kind of frontier landscape for the counter culture movements of holistic health

and new ageism that began in the 1970s. Both of these movements, “[focus] on a balance in the interaction of mind, body, and spirit in its attempts to achieve experiential health and well-being. New ageism also incorporates many theoretic techniques and practices, including medication, guided visualization, channeling, rebirth, psychic healing, and neoshamanism” (2004: xii). There were a bevy holistic health institutes that opened in San Francisco at this time, including the first acupuncture school in North America, The Holistic Life University (Baer 2004: 14, 47).

Baer also explains that by the late 1970s, biomedical physicians were losing their wealthiest clients to holistic health practitioners. Physicians responded by taking up these modalities into their own practices, some even becoming directors at holistic health centers (2004: xiii). The shift in language from holistic health to complementary and alternative medicine is a product of the historical and social conditions of this moment—of how this frontier of practice was “tamed” and “[evolved] into a professionalized entity” (Baer 2004: iv) as a means to make more expansive and lucrative markets.

Despite the historical significance of San Francisco for providing a port for so many “fringe” practices to find space to commingle, what Tsing and Fosbrook offer is a framing of this frontier that draws my attention to its political economic significance. As Tsing reminds me, frontiers, in their “material and imaginative” forms, are deregulated in order to allow for all kinds of exchanges, whether equal or not (2005: 27). Considering these arguments in relation to integrative medicine and integrative oncology, it seems that

both are deeply connected to the notion of the frontier—to this idea of the selection, extraction, and refinement of resources to meet consumer demands resonates with how certain medical modalities or therapeutic techniques are developed as complementary to biomedicine. Having conducted research in the frontiers of integrative oncology not only complicates how I analyze this practice, but it also emphasizes the importance of this state and my research sites for understanding how this field and the ideas it is generating about bodies are shaped by a set of social, political, and economic conditions specific to this landscape.

In addition to the frontier landscape of California, consideration must be given to how integrative oncology is affected by the social, political, and economic conditions of the frontier of personalized medicine. Indeed, the interest in applying complementary and alternative health care practices to the treatment of cancer began to emerge in the 1990s, around the same time that the broader field of oncology was shifting its focus toward the “promise” that personalized medicine posed for improving oncology (Sunder Rajan 2005: 19). Where treating the “whole person” in integrative oncology means providing therapeutic support for the physical, experiential, and spiritual effects of cancer and treatment, the personalized approach to treatment in conventional oncology means utilizing genetic profiling to produce molecular therapies specific to a patient’s cancer (Mansour and Scwarz 2009). Personalized oncology, the idea that chemotherapy drugs could be tailored to the individual patient and their cancer, is touted by medical professionals as a pioneering possibility insofar as it would lend personal specificity to

the treatment of cancer—something that is sorely missing in the mixtures of pharmaceuticals, radiation, cellular therapies, and surgery currently used in conventional oncology. The idea that pharmaceuticals could be designed to target and treat a patient’s individual cancer using information about their genome, is exciting in that it poses the possibility of shifting the biomedical response to cancer from generalized protocols based on clinical trial results to designing therapies based on the particularities of the patient’s condition, minimizing the toxicities that patients experience (Verma 2012).

It is here, with the recognition that oncology needs to be more personal that the problems with the biomedical view of bodies becomes apparent. The conventional response to cancer has been reactive because of the prevailing materialist perspective in biomedicine which promotes the assumption that fixing bodies matters more than the effects of their mending. Because of this model, the searing sensation, that feeling of flesh burning from the inside out, produced by a the drip of a chemotherapy infusion or the high-intensity beams of radiotherapy, the labour of expelling poisonous vomit for days after treatment, of losing clumps of hair to the touch of a brush and entire days to the fog of exhaustion, of the painful reality burrowed into marrow that secondary cancers will arise years later as a consequence of these therapies, are acceptable side effects if the treatment works, if it cures cancer.

Moreover, the move toward realizing personalized oncology intensifies the already “molecularized” view of bodies in biomedicine—the attempt to “understand diseases at

the (sub)molecular levels of proteins, individual genes, and genomes... partially displacing previous emphasis on germs, enzymes, and biochemical compounds” (Clarke et al., 2010: 68). Indeed, the term biomedicine is used by anthropologists “because it emphasizes the established institutional structure of the dominant profession of medicine in the West” (Kleinman 1995: 25) and identifies that it is, “a body of knowledge and practices often assumed to originate in the bacteriological laboratory in the second half the nineteenth century” (1995: 23). Moreover, the arrangement of “bio” and “medicine” in this term, “while also conjuring the primacy of its epistemological and ontological commitments” to focus its interventions on the material dimensions of bodies (Kleinman 1995: 25). And while there is an attempt to link the effects of social worlds, stratified by race and class, and environmental toxicities, to the molecular and cellular components of diseases such as cancer (Green McDonald 2013: S3), the molecularized view which dominates oncology underscores that interventions scaled at this level will provide the best treatment.

Integrative oncology intervenes in this image of personalized medicine, expanding what it means to make medicine personal by taking a stance on the importance of approaching cancer as a disease that affects the body, mind, and spirit of a person. The formation of this field and its ongoing professionalization, responds to demands for patient, not disease driven care—demands that have opened up new markets and given value to complementary, and alternative medicines.

States and stories of sensitivity

Informed by my ethnographic research on the practice of integrative oncology, I want to suggest that the bodies being imagined and enacted in the treatment practices that bring complementary medical modalities and conventional oncology together are *sensitive*.

In this dissertation, I develop the concept of *sensitivity* to describe how, in using an integrative approach, oncologists are becoming sensitive to different ways of conceiving and treating bodies that have relevancy for the treatment of cancer. Rather than work with *integration* as a concept, I analyze how the practices of “integrating” complementary therapies generates ideas about the sensitivity of bodies. I pay attention to how the separation of mind and body in biomedicine are called into question with the incorporation of these practices in order to understand how diseases affect and are affected by emotions, energetic states, and the disharmonies of bodily substances. Sensitivity names the recognition of these bodily sensitivities and of the subtle dimensions and affective qualities of bodies.⁶ In this sense, sensitivity also speaks to the experiences of patients for whom integrative oncology offers a more sensitive kind of care which they feel is absent in conventional oncology. I pay attention to the differences between integrative and conventional cancer treatment as felt by both practitioners and

⁶ Kelly Ladd, a doctoral candidate in the Graduate Program for Science and Technology Studies at York University, also looks at formations of sensitivity in relation to illness. Her research examines the lives of “sensitives” in North America— people for whom low-level electromagnetic radiation emitted by cell phone towers and other digital devices is toxic.

patients in order to theorize sensitivity. I thus explore how sensitivity matters for how cancer is treated, and for how bodies live and die with cancer in biomedicine. I also attend to how this mattering is constrained by the barriers that integrative oncology faces as an emerging field—of how the evidentiary regimes of clinical research in biomedicine and the political economy of health care in the United States impinge on and contour the promises and possibility of this field.

To explore these questions about bodies from the vantage point of integrative oncology, I take up and engage with literature from the anthropology of bodies and embodiment, theories of affect, medical anthropology, the anthropology science, and feminist studies of technoscience. I analyze ideas concerning bodies and sensitivity in integrative oncology in order to follow how this field is forming. I follow the incorporation of Chinese Medicine, Ayurveda, yoga, herbal medicine, and bodywork therapies, asking: What does integration mean for this field? How are the boundaries between biomedicine and complementary and alternative medicine reconfigured and contested by integrative oncologists? How are existing biomedical ideas about bodies and cancer called into question and reworked through the practices of integrative oncology? What kinds of bodies are being undone, what kinds of bodies are being made, and how do people live those bodies? Further, how does the political economy of health care in the United States shape how integrative care is accessed and delivered?

Indeed, sensitivity is more than a concept that organizes my analytic attentions, it is also an embodied methodology. Becoming sensitive as an ethnographic practice requires being receptive and responsive, and entails taking on, transforming, and transmitting affects encountered in the field (c.f. Helmreich 2007. See also Myers 2006, Myers and Dumit 2011). However, as Donna Haraway reminds readers, the ability to embody a mode of inquiry is always already situated in the partiality of our experiences and perspectives (1988: 582)—that what is possible to think, feel, and say is contingent on the things we have thought, felt, and said (579).

While embodying sensitivity was necessary to and for my movements through the classrooms, laboratories, living rooms, make-shift studios, and cafes where I was told earnest and intense stories about suffering and living on the threshold between life and death, this mode of attention was made possible by my experiences as a caregiver to my mother and other kin who have lived and died with cancer. These experiences sensitized me to a set of concerns relating to the biomedical treatment of cancer which I carried with me into the field. The stories that I became attentive to and have subsequently written in this dissertation refract this positioning—a partial perspective and an ethical commitment to inquiring and imagining how conditions of living with cancer in biomedicine might be otherwise.

In this regard, I am reminded of James Clifford's argument that in ethnographic writing, "every version of an 'other,' wherever found, is also the construction of a 'self'" (1986:

2). I might rephrase this to insist that *every version of a story, wherever found, is also a construction of the storyteller*—that their intent and interests, what affects and is affected by their attention, is always being made and remade through the practice of attending to and telling stories. Taking up issues of the ethics and politics of storytelling, I have endeavoured to both shape and be shaped by what Lochlann Jain and Jackie Stacey call an “‘intimate style’ of theorizing” (2015: 12). As scholars who have lived through the diagnosis and treatment of cancer, Jain and Stacey recognize their unique position as social theorists who have experienced cancer from a position that “would have never been accessible... from a different observational location” (ibid). They, “recognize the ways in which more traditional modes of academic theorizing were not going to get at the horrific and bizarre kinds of social structures were were encountering” (2015: 11) as well as how personal writing on cancer is routinely written off as being overly sentimental or entirely self-indulgent. Working with an idea of intimacy, these scholars share in an “ambition to offer readers *both* critical purchase and affective connection” (2015: 10) by demonstrating the need for situated accounts of cancer in order to tell more complex stories about this disease and its utter imbrication in all forms of American life. Their mode of writing and theorizing thus connects with the efforts of anthropologists like Kathleen Stewart who endeavour to draw poetics and politics together in telling stories that “[grope] toward embodied affective experiences” in order to incite curiosity (2005: 1015, 1029).

My embodied methodology of sensitivity is thus deeply influenced by these attempts to produce intimately-situated works which hold together the political and the poetic in order to comprehend cultural phenomena in complex, contradictory, and creative ways. My ethnographic attention is thus contoured by the partiality and intimacy of my experiences, and I take responsibility for the stories I have chosen to tell in this dissertation, at the expense, and absence, and sometimes difficulty of not telling others.

Outlines

In Chapter One, “Second Opinions” I detail the experiences of medical professionals who take an integrative approach to their work in oncology, exploring what “integration” means for each. With Chapter Two, “Machinations” I situate integrative oncology within the broader cultural, political and economic contexts of American health care. Accounting for the evidentiary regimes of biomedicine, I examine how integrative oncology is pressured to produce particular kinds of evidence for the efficacy of the complementary therapies it utilizes. I pay attention to how professionals in integrative oncology navigate and respond to the demand for clinical trial based evidence as the means of making integrative oncology legible and intelligible to biomedicine. In this chapter I begin to flesh out the concept of sensitivity, which I take up more fully in Chapter Three, “Sensitivity.” I explore how the sensitivity of bodies is modelled in integrative practice, drawing on insights in integrative pedagogy to consider how it is that physicians become sensitive to a different form of cancer treatment. In that chapter I also consider the forms

of insensitivity propagating where the complexities of practices stemming from Chinese and Ayurvedic medicine are simplified for the purposes of instructing medical professionals.

Chapter Four, “Treatment,” is furnished by the stories of patients with cancer who have pursued integrative oncology. With their accounts of the contrasts between conventional and integrative treatment, I also aim to describe how the perceived benefits of this approach are constrained given that many integrative therapies are not covered by health insurance plans. I call into question the promise of integrative oncology for how people might live and die with cancer differently as a potential that only a select few can afford to engage. Following on the heels of these concerns, Chapter Five, “Alternatives”, addresses how the difference between integrative oncology and alternative medicine is envisioned and enacted. I look at the push in integrative oncology to redesignate complementary and alternative medicine (CAM) as complementary and integrative medicine (CIM), and the implications of the suggestion that there are no alternatives to biomedicine, asking what this means for how cancer treatment in biomedicine might be otherwise.

Interspersing these five chapter are two ethnographic vignettes, “Choice” and “Body.” These and the stories that begin each chapter are invested in “combining different modes or ‘registers of writing: personal, political, and theoretical” (Stacey 1997: 24). These are “the stories that make up my story” (Stewart 2005: 1028)—moments of force, impact,

confusion, and trouble which diffract different ways of thinking and feeling through the questions which impel this project.

CHAPTER ONE: SECOND OPINIONS

It's nearing dusk as I pull my bike up the lane of the bungalow where I'm staying in Davis, California. The sky has shifted from cerulean to Prussian blue, the sweetness of the air intensifies, and the green hues of the succulents outside the front door deepen. I've learned from other graduate students that this California Rambler with its composite shingles, mud colour paneling, low pitched gable roof, and much adored Meyer lemon tree, has been a landing site for many students departing and returning from fieldwork. Of the two bedrooms in this house the room I rent feels less like a lodging than it does a living archive—the ethnographic process chronicled in old file folders, discarded notebooks, mismatched clothing hangers, Ethernet cables, lamps, pens, and tiny paper fortunes pinned beside free yoga passes on a thin corkboard. I've learned from those that have taken up residence here that we are kin, connected by shared sleeping surfaces, and committed to shelter one another when research calls us close.

Freira, the one constant in this home, is still on campus. Her friend and former advisor, who is visiting for the weekend, is sitting at the dining room table, sifting through what looks like two years worth of mail. Piles of journals spill into promotional flyers, personal letters, and the occasional postcard. Enzi's stacked silver bracelets chirp and sing as she digs through the large cardboard box beside her, sorting through her correspondence, repeatedly exhaling in frustration when something urgent is unearthed

from a pile purportedly decluttered of important mail. I ask if she's eaten, and begin to make a meal with yesterday's finds from the farmer's market.

We eat among her royalty cheques from Stanford University Press, and bills from various agencies. She asks me carefully phrased questions about the topic of my research, which I fumble to answer with less than a month of fieldwork at my reach. I take a swig of hibiscus flower tea, and begin to ask questions about her developing project when a notice from an electrical company catches her eye.

Holding the paper in her hand, she begins to tell me about her old apartment. Situated in the south of this city, its charms included a fruit tree filled backyard, and lights that only worked in the evening, never in the morning. Enzi describes the conversations she had with her landlord, an electrical engineer, who couldn't quite figure out the problem despite his many assessments. She and the engineer's wife decided that there was a certain "magic" involved in making the lights work—that, "if I waited three seconds or so, they would come on." When they tried to explain this practice and their subtle acknowledgement of the electricity's wiliness to the engineer he laughed, saying that there was "no way that would make a difference." He insisted that there was something mechanical to the matter, and that their method was ineffective, nothing more than a "rain dance."

Barely taking pause for breath, she tells me that this reminds her of a time when her father was ailing with intense back pain:

Nothing in Western medicine could help relieve his pain. He had tried everything. I finally said to him, ‘Why don’t you go to a faith healer, or go for a reiki treatment?’ He said to me, ‘I don’t want to because if I did, and it worked, I’d have to change my whole outlook.’

...

This chapter is contoured by four stories about integration and oncology, expressive of challenges involved in changes of outlook and practice. With the narratives of four clinicians who have been influential in this field, I explore what integration means for oncology, and the various ways the people who take up this practical approach conceive of integration.

Using these accounts, in their particularity and partiality (c.f. Dumit 2004), I endeavour to understand the kinds of ruptures and conflicts at work in this term, and the ways in which these negotiations have shaped the development of this approach to cancer treatment. I take direction in this regard from Joseph Dumit’s work on the social, political, and economic production and circulation of images of the brain made using the functional imaging technique of Positron Emission Topography or PET (2004).

Positioning himself within the community of PET as an “interdisciplinary ethnographer,” Dumit uses both anthropological and historical forms of analysis to tell stories about how

this technology arose, how both PET and brain scans have been made to fashion facts about bodies and brains, and the ways in which these renderings are made meaningful within the contexts of their circulation (2004: 13, 14). Like PET, integrative oncology does not have a singular origin story, and what I take from Dumit is a cautioning against the impulse to craft that kind of narrative. With his insights, I have focused on collecting stories that tell of the life-histories of each clinician—stories that together show up the many instabilities, challenges, and achievements of integrative approaches to oncology and those who take up this practice.

With these stories I thus explore what it means to re-evaluate, or reimagine treating cancer. In this sense, I am less interested in outlining precisely when Chinese, Ayurveda, or botanical medicine were reconfigured as complementary healing modalities for cancer treatment, than I am of how and why oncologists and professionals aligned with this field came to think of these therapies as necessary interventions into existing standards of cancer care.

Berdine

Berdine's office is located beside what looks like a four storey concrete encased waterfall. In actuality, it is the massive cooling system for the backup generator for the UC Davis Health Center where she works. Several doors down from her office is the room where I practice yoga once a week with people recovering from or in active

treatment for cancer. I'm fairly convinced the conference room we rearrange to accommodate our yoga mats is more frequently used for morbidity and mortality meetings, or maybe even tumor boards, but I cannot bring myself to ask for confirmation. I'm not sure what is gained by finding out that where we learn about the importance of child's pose as a posture of recovery and humility is the same room where medical mistakes are put to review, or where physicians meet to discuss the condition and treatment options of patients. To know would only be a matter of nomenclature—it's always already a space haunted with the hope for a different diagnosis, a different outcome.

I met Berdine about a month after I arrived in California. Animated, perspicacious, and kind, she helped me build connections in the UC community, inviting me to many events and always engaging my questions with enthusiasm. With a doctorate in psychology, focusing on behaviour and doctor-patient interactions, as well as masters in public health epidemiology, Berdine is a faculty member in the hematology and oncology division of the UC Davis School of Medicine, and a director of programming. She is responsible for developing distinctive research and education programs as part of the “supportive oncology services” the Center offers. These services strive to treat “the whole person,” a focus Berdine describes as “[believing] that cancer is not just a disease—if effects a person and a whole family. We look at how we can support all of that beyond just the care a person gets with surgery, or chemo, or radiation.” In 2013 this Cancer Center received comprehensive designation from the National Cancer Institute—a status shared among a

mere forty-one cancer centers in the United States.¹ The programs that Berdine developed such as yoga classes for cancer patients and survivors, the “Writing as Healing” program, the cancer walking group, and a fitness program, along with her community based research with indigenous groups in Northern California were instrumental in achieving this important status.

Berdine’s interest in integrative approaches to cancer care is compelling in that it was catalyzed by a recognition of the limitations of conventional oncology for treating the more-than malignant dimensions of the disease; however, Berdine’s investment in whole patient or integrative approaches is grounded in a very visceral encounter with the failings of biomedicine:

I studied the history of medicine, because I wanted to end up teaching at medical school. I was very aware of the split between the mind and body—how this group of specialists get to focus on the mind, and this group of specialists focus on the body. That never made sense to me! The thought of making that connection, and looking at what that means in terms of how you treat a patient, or take care of someone, that made sense to me. And it fit with my own experience. I’d gone through having cancer prior to [graduate school]. I was treated, physiologically for my cancer, but nothing else was addressed because it just wasn’t being done back then.

Everything is so focused on the disease and the doctor’s agenda. When I was diagnosed with cancer at 38, I was a single mother—I had four kids, and I was

¹ This estimate is based on a survey of the NCI listings of Comprehensive Cancer Centers in the United States from their website: <http://www.cancer.gov/researchandfunding/extramural/cancercenters/find-a-cancer-center#cc1> (accessed on June 24, 2014). The NCI defines a comprehensive cancer centers as “[having] demonstrated reasonable depth and breadth of research activities in each of three major areas: laboratory, clinical, and population-based research, with substantial transdisciplinary research that bridges these scientific areas. An NCI-designated Comprehensive Cancer Center must also demonstrate professional and public education and dissemination of clinical and public health advances into the community it serves.” (<http://cancercenters.cancer.gov/about/our-history.html>)

their sole support. I still had two of them living at home. I worked full time. I was concerned that I had advanced cancer, but I had all these other concerns that were kind of taking over: ‘Who’s going to take care of my kids? Can I still work going through treatment? If I can’t, we have no money.’ All those other issues became equally if not more important than ‘I have to fight to live.’ And none of the physicians I had, back at that time asked anything about that—helped in anyway about that. There weren’t any resources. That’s partly why I’m here doing what I’m doing. Every patient comes in with their whole life, and yes, they have this disease now, and they have to deal with that, but there’s all this other life that goes on. To ignore that, and act like the patient will only focus on the disease and getting well, that never happens.

For Berdine, integrative oncology or “whole person” approaches to cancer treatment respond to the systemic problem of mind-body dualism in biomedicine. She contends that the division of treatment between medical professionals who deal with the ‘body’ and those who deal with the ‘mind’ meant that the stresses she encountered with her diagnoses were not taken seriously by her oncologists as affecting her disease progression, or factoring into her survivorship.

It was during her doctoral training in communication psychology in the 1980s that Berdine felt her experience with cancer refracted in and through her reading about the mind-body split in biomedicine. Discussing the literature that helped her think through this fissure, Berdine poses a delightful question to me: “Have you read any of Michel Foucault’s work?” Beaming with excitement at her reference to this historian, I reply that I have, and she begins to unfold why his work was so helpful for her in understanding the treatment she didn’t receive: “Well, *The Birth of the Clinic*, that was a real eye-opener. It describes when things shifted from the healer living with patients and being very much in

their homes, and seeing their whole lives and their relationships, and then having a patient go to a clinic, and the very scientific approach that entailed. And what was lost in that transition.”

Speaking to the implications of that historical shift in medicine, Berdine explains that, I think in medicine there’s this clear divide: psychiatrists and psychologists deal with the mind, and these folks deal with the body. We know, in so many disease, including cancer, that stress is a major contributor, and then physicians are sort stuck with, ‘How do I deal with stress? I can’t give you a pill for it.’ I think its just that—not knowing how, and not having the skills and abilities to deal with things, and thinking its not their area, it’s not what they do.

In asking Berdine about the kinds of critiques she’s encountered from colleagues both throughout her training in the 1980s as she began to broach the problem of the mind-body split with an attention to integrative methods. She tells me that a lot of physicians do not “buy into” this approach: “They’ve talked about it as, ‘I don’t want to open that can of worms,’ ‘I don’t want to get into the emotional side of my patients,’ or ‘I don’t want to know their relationships or their life.’ They just want to deal with the disease.”

For Berdine, integrative oncology “is more than just a theory, or some kind of concept. It’s real life. It’s day to day life.” Gesturing again to the way in which cancer is experienced as a physical and emotional disease, she emphasizes that the attempt to make

the biological dimension more material, or rather, more meaningful for treatment, is where conventional oncology falls short. For Berdine, cancer isn't just a disease that causes abnormal cell growth in the form of tumours—it is a disease whose malignancy diffuses into and affects the whole person—their sense of self, their ability to work, and their social relationships. Berdine wants oncology to recognize these dimensions of cancer, and to treat these seemingly immaterial metastasizations of this disease as consequential and as relevant as its material or biological effects.

In this sense, her conception integration names a kind of embodiment—a mode of treatment rooted in the felt sense of the inseparability of the turbid affective experiences of cancer from the physiology of the disease. Holding close to a “whole patient” perspective sensitizes Berdine to the range of emotional and physiological challenges experienced by cancer patients from diagnosis, through treatment, and into survivorship. It is this kind of attunement that has helped her create effective outreach programming for cancer patients.

Berdine's efforts to develop integrative or “whole person” resources in a conventional oncology setting are unique in that it is her patient experience that informs her work. The spirit of her momentum, that felt need to move toward medical practices that are sensitive and responsive to the social and emotional lives cancer patients in ways that conventional oncology omits, resonates with the accounts that follow.

David

I wake up all too early in an overly priced and heavily air conditioned hotel room. I turn on the news, and sip the coffee I stashed in the mini fridge the night before—a cold brew procured from Peet’s in the belly of Silicon Valley. The granola bar I brought for breakfast resists my bite as I try to coax a nibble or two from its mostly frozen form. This frigid start is far more comfortable than the option of departing from my apartment at 4:00am or bunking with stacks of programmers, designers, and aspiring tech entrepreneurs in one of the overly populated “hacker hostels” plunked across this valley.

With coffee in hand, I make my way to Stanford—the axis point of this city. On roads lined with palms, I pass people commuting in suits and ties on carbon fibre bikes. I watch as they dart through streams of luxury cars and busses dressed with congratulatory banners for the graduating class. I’ve travelled to Palo Alto to interview David—a prominent psychiatrist whose research has influenced the fields of psychiatry and integrative medicine.

I’m surprised to see valet parking available at the medical psychotherapy building where his office is located. My disbelief lessens when I get out of the car, noticing the new hospital being built across the street, and its proximity to the shopping center which graces the edge of the campus—the silver lettering of the Neiman Marcus sign visible from the self-park section.

I find my way up to his office, where his assistant greets me from behind a stack of documents balanced precariously on the edge of her desk. Mary invites me to take a seat in the nook beside his office where a few Time magazines, and a copy of Scientific American rest beside a slightly wilted spider plant. As I start leafing through the magazine she comes out from behind her desk to tell me that David is running late.

I hear David before I meet him. His voice is sonorous, his phrasing efficient. Balancing a travel mug, and a stack of files, he gives me a firm handshake and motions me into his office. There's a warmth to this room. His desk stretches across two of the honey coloured walls in what I expected to be a larger space. We sit adjacent to one another, not across. Mere feet away from my knees rests a burnished leather recliner, beside it, a shelf decorated with beautiful portraiture of his family. The walls are lined with bookshelves, each holding the weight of periodicals and canonical texts ranging from philosophy and psychoanalysis, to hypnosis, of which he is an expert. A framed picture of David with Pope John Paul II comes into view when he stands to receive the copy of my CV that Mary has printed. He leafs back and forth through these unstapled pages, reminded of my discipline, my affiliation with the University of California, and that I'm Canadian. He notes my involvement with the Mind and Life Institute, telling me that he too is a

member.² His demeanour softens with this point of connection, telling me that he thinks I'll be interested in a recent publication of his on hypnosis use in Nepal. He leaves the room to collect a copy. Smiling as he returns, he hands me the paper, still warm from the printer, takes a sip of his coffee and invites me to ask my questions.

I've come to talk with David because of the landmark research he began in the late 1980s exploring the effects of support group interventions for patients with metastatic breast cancer.

A psychiatrist with specialization in hypnotherapy and an interest in “how people deal with real life existential issues” rooted in his reading of Kierkegaard, Heidegger, and Sartre throughout his undergraduate at Yale, David explained that he became involved with this study when he was recruited to Stanford by Irvin D. Yalom. “I was a first or second year Assistant Professor and he said, ‘I’m leading this group of women with metastatic breast cancer—would you like to co-lead with me?’ And when the world’s authority on group therapy asks a young faculty member if they want to co-lead a group with him, you say ‘Yes!’”

² In this moment I detailed my participation in the 2011 Summer Research Institute on “The New Frontiers in the Contemplative Sciences.” I applied for a research fellowship to this intensive program as a preliminary fieldwork exercise, with the hopes that the Mind and Life organization might become a point of focus in understanding how conceptions of ‘mind’ and ‘body’ are made and remade in and through different practical cultures.

The initial findings of his study, published in *The Lancet* in 1989, joined a conversation within biomedical communities linking social and emotional support with disease progress and survivorship.

At that time, I was just very interested in how people could face death and see it from another perspective; not from the one who was dying, but from the one who was losing someone to better understand their family and friends. The old idea was, reduce anxiety and depression. But the newer idea was that maybe people with existential questions don't live authentically until they face the contingency of existence.

David's study sought to examine the psycho-social effects of group therapy for women with metastatic breast cancer. Asking David to clarify this term, he defines psycho-social as,

A broader notion than the psychotherapeutic. The psychotherapeutic is usually a two person, or group interaction, where you're focusing on a problem, trying to help a person see it from a different point of view, come to terms with it, manage the emotions related to it. Psychosocial includes family, and class environment, economic environmental and the idea that there are psychological and social factors that influence people's health.

Situated in his Psychosocial Treatment Laboratory, David developed a seven component Supportive Expressive Therapy (SET) protocol for the study (Spiegel 1999: 276). The approach to psychotherapy outlined by SET focused on "diminishing psychical distress" through the modules of "social support, expression of emotion, detoxifying dying, reordering life priorities, family support, effective communication, and symptom management" (ibid: 277). In the *Lancet* paper, David outlines that he designed SET as therapeutic alternative:

It was meant to counter the overstated claims made by those who teach cancer patients that the right mental attitude will help to conquer the disease. In these interventions patients often devote much time and energy to creating images of their immune cells defeating the cancer cells. At no time did we take such an approach. The emphasis in our programme was on living as fully as possible, improving communication with family members and doctors, facing and mastering fears about death and dying, and controlling pain and the symptoms (Spiegel and Bloom 1989: 890).

The “images” mentioned by David are quite different from the immunological imaginings contained in Emily Martin’s seminal ethnography, *Flexible Bodies* (1994). Exploring how the immune system lives in the popular imagination, Martin and her research assistants encouraged their participants to draw and describe how the immune system functions. These images represent how each person imagines immune system—of how they have learned to make sense of the information they’ve received about its working through medical encounters and popular media. The image that David takes issue with stem from the popular work of radiation oncologist Carl Simonton, psychotherapist Stephanie Matthews-Simonton, and James L. Creighton in *Getting Well Again: A Step-by-step, self-help Guide to Overcoming Cancer for Patients and Their Families* (1978), and by pediatric surgeon Bernie Siegel in *Love, Medicine, and Miracles* (1986). These physicians hold the idea that people are capable of healing themselves if they exercise their will to live. Both *Getting Well Again* (1978) and *Love, Medicine, and Miracles* (1986) assert that this intention can be cultivated through practices of self-awareness that encourage persons with cancer to uncover the thoughts, attitudes, and emotions that have contributed to or created the conditions for their disease. Mobilizing the mind-body

connection and the psychology of stress to make these arguments, both approaches suggest the use of the visualization techniques like those David critiques, positive affirmations, and meditation can help to cure cancer by getting to the psychological seed of this disease.

Sharply contrasting these ideas, David's intervention ran for one year. It began with 109 metastatic breast cancer patients randomized into treatment and control groups; the final samples consisted of 34 and 24 people respectively. Individuals assigned to the treatment intervention were divided into smaller groups of 6 to 10 patients who meet weekly for ninety-minute group therapy sessions, at no charge, in groups directed by a psychiatrist and or a social worker, and a counsellor in remission for breast cancer. In the context of the support group, the patients were encouraged to express their feelings about their cancer and how it affected their lives. They were also taught self-hypnosis techniques to help with pain relief from their conventional treatments. Both groups continued to receive the same conventional oncology treatments throughout the research period, and there was no communication between the experimental team and the patients' oncologists.

Speaking of the criticism he received at the outset of this work,

We were told, 'You're going to make them worse; they're going to watch one another die. The two year survival rate is 50% in metastatic breast cancer. People are going to die in your group; you'll demoralize them!' We were very worried about that. And we measured minute by minute content and affect to see whether they got bad news they got demoralized, and all of which did not happen. They actually grew substantially.

Affect, in David's use here refers to the experience of a feeling or an emotion.³ In order to measure the effects of the support groups for the patients, the study employed questionnaires every four months that collected information about their "social demographic, medical, and psychological data about the patients, their spouses, and family members living in their homes (1983: 335). These questionnaires also made use of the Profile of Mood State (POMS)—a survey that lists 65 adjectives, each on a five point scale, that allowed patients to register emotions such as anger and depression (ibid).

The results of this study indicated that patients in the treatment group felt a reduction in distress associated with their condition, and lived an average of eighteen months longer than those in the control group. Speaking of the effects of these treatment techniques on the personal growth of the study participants, David explains,

I called it a 're-moralizing experience' where people faced their fears of dying and death, and it detoxified them. There's nothing you can do about death, but you can do a lot about how you die, and how you live your life before you die. One woman said that, 'Being in this group is like looking into the grand canyon when you're afraid of heights—it would be a disaster if you fell but you feel better with yourself because you can look.'

³ See APA, 2007. In contrast to the definition of affect being delayed here, my attention to affect is shaped by its conception in Deleuzian (1988; 2005) and Massumiian (1995; 2002; 2005) genealogies of thought. I use affect to refer to the registers of the lived, embodied experiences and everyday practices that are not necessarily shaped or defined by an emotion, but of the sensations and impacts that happen before such an identification—how a body is moved, impacted, by non-discursive means. I develop the concept of affect again in Chapter Two, and develop it ethnographically in Chapters Three and Four.

David and his research team attributed their findings to the experiential tone of group interactions—to the kinds of vulnerable reckoning with cancer supported by this intervention. David developed the term “detoxification” to refer to the way in which the patients in his study let go of their fear of death—that the structure of the therapy, “helps to validate and normalize disease-related feelings and experiences. It also empowers women to develop effective coping strategies” (1999: 277). Put eloquently in one of his publications,

The existential crisis that patients are thrust into as they try to cope with a life-threatening illness can be overwhelming. Exploring fears associated with the process of dying is a powerful therapeutic tool that reduces anxiety experienced by the threat of death. The goal is to help those facing the threat of death by reducing their anxiety about it as well as exploring fears associated with the process of dying. Although the process is difficult, the therapeutic value to patients is tremendous. For example, some patients begin to plan for their deaths by making wills, this enables them to take control over areas of their life where they felt powerless” (1999: 278)

When I asked David about the kinds of critiques he received after the research had been published, he cited psychologists who had attacked his randomization techniques, and oncologists who suggested that each group received different medical treatment: There were some who said, ‘Oh you’re just another Bernie Siegel.’ He is this Yale surgeon who wrote a book called *Love, Medicine, and Miracles* that sold hundreds of thousands of copies. In it he said that, ‘You only die of cancer if you have some unconscious need to die. If you just get rid of your need then you get rid of your cancer.’ Which is pure bullshit.

Drawing a line between his work and Siegel's, David clarifies that "We were trying to study mechanisms that might account for the effect of social support." David indicates that there were those who understood the difference: "Some oncologists said 'Well you know, I always knew there were some intangible differences. I have two women with the same kind of breast cancer and one would do really well and one wouldn't.' So, many oncologists were kind of open to it."

It was precisely a consideration of the "intangible differences" that David wanted to cultivate with his research. His work generated important evidence indicating that thoughts, attitudes, and emotions are not simply the result of physiological processes in bodies—that thoughts, attitudes, and emotions also influence physiological processes. David's seminal research stirred within many medical communities an attention to the need for social, expressive support in treating cancer.

Historicizing the significance of his work and the receptivity of conventional oncologists to his findings, David postulates that,

I think we changed the atmosphere a bit about the importance of emotional support, not being alone with a disease, and about being open with family and friends about what's going on is important. We're now taking seriously the fact that you have to help people emotionally get through, navigate both the acute treatment and then living with the on-going threat that the disease will return, and the long-term late effects of chemotherapy along with the financial and other problems that come with cancer.

For David, it was the recognition not only of the acute, but of the subtle dimensions of cancer—the experiences and realities of the disease that were evident to oncologists but nonetheless not being addressed in their conventional practices that led him to create the Center for Integrative Medicine at Stanford in 1998. An important interlocutor, I address more of his insights into and criticisms of health care and health insurance in the United States in the following chapter.

I think for David, integration references the need for the incorporation of models of bodies and disease into biomedicine that take seriously the inseparability of the physical and embodied experiences of disease. I also get the sense that integration registers a certain imperative for actively engaging, or holding together, ideas about living and living without fear of dying while treating cancer. In this way, the investment that David has in the idea of integration cuts against the fervent discourse of survivorship that all but precludes any discussion of death (see Jain 2013). I think for David, to practice an integrative approach to cancer treatment means asking what support is needed for living and living with the fear of death while receiving treatment for cancer.

Donald

A few weeks after I interviewed David, I met Donald—an oncologist who divides his time between a University of California based center for integrative medicine and one of

the many general hospitals treating the uninsured and homeless in the coastal Californian city where he resides.

In the early 1980s, Donald was a hematology and oncology Fellow working in a retrovirology lab when the initial cases of AIDS were diagnosed in the United States. He was one of the first clinicians to recognize many of the HIV/AIDS related conditions. In a charting room with his hands wrapped around a mug of green tea, he tells me that, “In 1992, somebody challenged me to study cannabis as a treatment for patients with AIDS wasting syndrome. I said, ‘Ok, I can do that. I went to college in the ‘60s!’”

It took Donald five years to convince the National Institute on Drug Abuse to support his clinical trials examining the therapeutic use of cannabis for appetite stimulation in HIV/AIDS patients. This was quite an achievement given the Institute’s strict research mandate which only allowed for the study of cannabis misuse. The positive outcome of these trials inspired Donald to continue to examine other applications of medical cannabis, such as pain relief for people with HIV/AIDS and for people living with cancer. Donald tells me that it was this research, “That changed my life, because it gave me a strong appreciation of the power of plants as medicine.”

This revelation about plants took Donald to the Telluride Mushroom Festival in Telluride, Colorado. Part conference, part celebration, the festival has been running for more than 30 years, bringing together foragers, mycologists, physicians, and many other fungal

enthusiasts invested in the transformative potential of plants for social and environmental change.⁴ It was there that Donald met Andrew Weil—a Harvard trained physician with training in naturopathy. Andrew established one of the first university based training programs in integrative medicine in the United States in 1994 at the University of Arizona. Recounting their meeting, it made Donald realize “[that] I wanted to be a student again. So I said ‘I’m done with HIV/AIDS’, which I’d been doing for 25 years. ‘What I want to do is work with people living with and beyond cancer. And help them to integrate these other modalities into their conventional care.’ So, marijuana changed my life.”

Asking Donald to tell me more about what sprouted during his training to inspire a shift in his career he explained that,

I got exposed to a group of people who were similar to me in thinking that medicine was on the wrong path, and that there were other ways to help people than to write a prescription for a drug. I myself have lived with a macrobiotic chef for nineteen years, and I never learned nutrition in medical school because it is not taught. Everything I learned about nutrition in my fellowship, I’d come home and say ‘You were right!’ and he would say, ‘What did you think? Of Course!’ So my major thrust of what I do with cancer patients is really focused on nutrition and supplements... I’m still a bit western in my belief that the things that work best are often things we ingest.

⁴ See: <http://www.telluridemushroomfest.org/>. The festival is sponsored in part by the Telluride Institute which describes itself as a “germinator,” encouraging sustainable practices for social and environmental change.

Donald's interest in an edible integrative approach evidences his ongoing negotiation as someone who straddles both conventional and integrative oncology and wants to cultivate methods that could work in both practical contexts:

I'm Chief of Oncology at San Francisco General, and after I finished my fellowship in integrative medicine I wanted to see if I could do integrative oncology. But I can't do that at that hospital because, as I often say of most of my patients, cancer is the least of their problems—they're homeless, they're addicted, they're psychotic, or they're undocumented. I can't tell them to go do yoga because they have much more pressing needs.

Donald clarifies that at San Francisco General, he treats “anybody and everybody... we call it a ‘safety-net hospital’ so that people [who don't have insurance] don't fall through the cracks. For every five cancer patients I have, one is black, one is white, one is Latino, one is Chinese, and one is other Asian. There's a lot of cultural diversity, and different beliefs, and I have to do a lot of communicating through an interpreter.” Donald recognizes the ways in which social and economic conditions shape the kinds of medical treatment his patients can access. Ideally, Donald would treat all his patients using an integrative approach, but at San Francisco General, he has to stick to conventional therapies. Using the example of vitamin D, a supplement known to be beneficial in reducing cancer risk, and correcting bone loss (Deng et al., 2009: 105) Donald explains that,

I think it is really important, and it's very cheap. If I tell a patient, ‘Your vitamin D level is very low, you need vitamin D3,’ it's not prescribed, it's not covered by their third-party insurer. I'm asking them to spend \$5. They don't have that. It's a very different world at the Osher Center. Patients come with shopping bags full of supplements that they're taking and I say, ‘Wah! What are you doing?’

The differences between these worlds is of course an issue of socio-economic and political disparities—problems that I analyze with more detail in Chapter Two in my discussion about the political-economy of health care in the United States, and later in Chapter Five where I engage the question of access to medical treatment in relation to alternative medicines.

As Donald explains, it was in 2004 that he began to practice integrative oncology in this “different world” of affluent patients:

I first went to SF General and I said, ‘Can I do integrative oncology here?’ and they started telling me about revenue streams, and you know, that means generating money, and I work at a SF General, and we don't generate revenue. They said, ‘Go over to the Osher Center. It’s just started, see if you can do a clinic there.’ So I came and spoke to the director, and said, ‘I just want to do half a day, you don’t even have to pay me. I’ll just do it to see if I like it.’ And it quickly became my favourite half day, and suddenly I was doing two half days, and the rest is history.

The Osher Center for Integrative Medicine opened in 1998 and is part of the University of California, San Francisco. It is based in a medical building not far from the UCSF campus that also houses the UCSF General Internal Medicine offices and their primary care clinic—a site teeming with the activity of clinical trial coordinators, medical residents, nurse practitioners, office staff, physicians, and patients and their families.

The Osher Center continues to be a leading institution in the development of research and education in integrative medicine, recognized by the National Institutes of Health for its

efforts in this regard.⁵ Known for its exceptional patient care, those interested in accessing integrative medicine at the Osher Center must first consult with one of the Patient Navigators who help to determine which services best suit the health needs of the individual. The Osher Center is unique medical site in that it houses clinical, educational, and research activities in one facility. It seems that the very architecture of this building is expressive of the Center’s mission to provide integrative health resources supporting whole patient treatment in the way it allows for clinicians, researchers, and patients to share quarters. And the range of patient services provided at the Center is extensive—everything from integrative oncology offices, to pediatric pain clinics, to manual medicine services, women’s health services, to educational programming and lectures on yoga, meditation, mindfulness for urban youth, healing through dance are all accessible in one place. However, the Osher Center only accepts insurance claims for appointments with general physicians and nurse practitioners—every other service is a cash expense.

Donald is very much aware of the disparities between the patients he sees at the general hospital and at the Osher Center, and more broadly, troubled by the problem of “the uninsured” in the United States. When I ask him to describe the demographics of the patients he sees at the Osher Center, I’m told, “most of my patients over here are upper middle class white women. Some men, but I think it’s probably 60-30, 55-35, women to men.”

⁵ See <http://www.osher.ucsf.edu/about-us/>

Speaking to his two practices, and the two very different kinds of patients he works with, Donald mentions that, “I tell patients at the San Francisco General I treat cancer, and here, that I treat people living with cancer. And what I tell them is ‘Cancer is like a weed, and someone is taking care of your weed, and it’s my job to work with the garden, and to make your soil as inhospitable as possible to the growth and spread of the weed.’”

Resting his mug on the counter beside his desk, Donald speaks gently and with great focus as he describes this compelling metaphor. He mentions that it resonates deeply with his patients. I imagine that they, predominately white, middle class women, feel this imagery reverberate in their bodies, evoking their own practices of caring for gardens and cherished potted plants. Green thumbs notwithstanding, the promise embedded in this analogy of a garden free of weeds conveys a sense of the labor and dedication commanded of his care.

Further, this metaphor is compelling in that it surfaces a very different terrain on which to engage conventional oncology. There is a tangibility to the therapies that Donald utilizes. He recommends dietary changes and supplement use to “fertilize” his patients with nutrient dense support; or sometimes cannabis for chemotherapy related symptoms such as pain, nausea, and absence of appetite. While these remedies hinge from the “healing power of plants,” these therapies are far more intelligible to oncologists than energy work, guided imagery, or even group therapy. As Donald mentions, “My colleagues across the street at the Cancer Center say ‘You know this is the 21st Century, we don’t

use plants as medicine.’ But they do! I can remind them that they are using chemotherapeutic agents that are derived from plants! The vinca alkaloids, the taxanes are from the bark of the Yew tree, the irinotecans— there’s a lot of the chemotherapeutic agents we use are from plants—plants are very biologically active.”

The potency and substantiality of plants is also present in the way Donald talks about how the integrative oncology that he has come to practice, and the gardening analogies he uses to explain his methods, are translatable and understandable outside of the clinic.

Speaking about his research on cannabis, and how that is part of his integrative “armamentarium” Donald tells me,

When a patient has nausea, loss of appetite, depression, insomnia, and pain, I can say ‘You should try one medicine’ instead of writing them a prescription for five different pharmaceuticals, all of which might interact with each other or the chemotherapy. It is a medicine that the patient can actually grow themselves. If you have cancer and fear that part of you is dead, or part of you is dying, the ability to bring life out of the ground is very empowering, especially if you’re growing your own medicine.

There’s a palpable and unapologetic excitement about what Donald’s integrative practice affords him in the treatment of his patients which speaks both to his felt sense that integrative methods are a necessary intervention in the standardized treatment of cancer, and to the structural limitations he has and continues to encounter in trying to bring these techniques into conventional treatment contexts.

For Donald, practicing integrative oncology allows him to perform a kind of medicine that puts the patient first: “When we talk about integrative medicine, people think about CAM and herbs, and acupuncture, and mindfulness, but it’s really about the relationship. I’m relating to the person living with cancer as opposed to their pancreases, or their left breast. That’s what I’m paying attention to.” Explaining this dynamic further, with particular reference to his patients at the Osher Center,

A diagnosis of cancer is a very troubling and very destabilizing. These are people who are highly functional, and the locus of control has been whipped from underneath them and now they're at the mercy of the surgeon, the radiation therapist, medical oncologist, the chemotherapy nurse, and you know, what can they do? I give them things to do: lose weight, here's what you eat, physical activity, reduce stress, connect with joy.

It is this idea of relating and supporting that makes it possible for Donald to recommend therapies for these patients that might seem too subtle or too intangible to be effective on something as ferociously material as cancer. When he advises his patients to meditate or practice yoga, or to eat organic alongside their courses of chemotherapy or radiation, he is able to present these practices as potent because his patients trust that he is treating them, not their cancer.

Donald is working with a very literal definition of integration. For him, this practice is about bringing together things that have been held separate by biomedicine: body, mind, and spirit. For Donald, this is accomplished with the ingestion of a substance that forges connections. In plants Donald finds remedies that work to bring together mind, body, and

spirit precisely because they are medicinal, nutritious, and imbued with a sense of potential. As Donald mentions, the idea that patients can treat their bodies meaningfully and potently with something they themselves can cultivate is empowering and therapeutic—a form of treatment that leaves his patients feeling whole.

Felix

It's an unusually sunny day in the temperate, fog-swept city of San Francisco when I meet Felix. Both he and Donald trained in integrative medicine at the same program in Arizona, and both work at the Osher Center for Integrative Medicine at UC San Francisco. Felix is a young, bright, and enthusiastic physician. Within minutes of meeting him, I learn that the medical students who helped me find his office on a floor mazed with cubicles are on one of several research teams he's leading in clinical studies on Ayurveda. Felix is the only integrative oncologist I met who incorporates this form of medicine into his oncology work, and indeed, the research projects he is currently undertaking are designed to make this form of medicine more available for use in oncology.

Seating across from Felix in his sparsely furnished office, he leans into the audio recorder I have placed between us to describe for me how he came to practice integrative oncology:

I liked a lot of what I did in medicine, but there were definitely certain parts of medicine that I didn't connect as well with. I found that as I was starting to care for patients, there were certain niches where Western medicine didn't have very good answers. It was great with acute care, and it was even maybe good at treating cancer, but not so good when it came to the so called 'softer side' of things, where a patient has symptoms or a nebulous complaint that we can't diagnose in Western medicine. A lot of those patients didn't end up getting very good care because they didn't fit into the right boxes. I found myself feeling a little bit dissatisfied with the care I was providing because I was trained in Western medicine, and I had a very limited ability to address those kinds of complaints because I didn't have the right tools. So this exploration began with the question, 'What other things are possible?'

When he completed his oncology fellowship in 2006, taking a faculty position in the hematology and medical oncology division at UC San Francisco where he encountered the Osher Center, Felix began to feel that another kind of oncology was possible: "This idea of doing integrative medicine came about and there were people here who were doing it. The Center was already established and [had] been in existence for almost 10 years."

Describing his residency in integrative medicine, Felix recounts that training with Andrew Weil, the same person who trained Donald, gave him, "[an] overview of mind-body medicine, some traditional medicines like Ayurveda, Chinese medicine, and manual medicine. And after doing a program like that, not only do you get a sense of the vast expanse of other possibilities, you also connect with people are also interested in this stuff, and faculty members who have been doing this there for some time. So it's kind of inspiring, and it's motivating."

Asking for more detail about how Ayurveda influenced his turn to integrative oncology,

Felix tells me that,

Being of Indian decent, I always had an interest in Ayurvedic medicine. It was practiced in my household by my grandmothers. With my history, and interest in Ayurveda, I thought, ‘Well, if I can do integrative medicine, why not Ayurveda?’ So then I pursued a two-year training course in Ayurveda to learn the clinical skills, and I’ve never looked back.

Felix became interested in practicing Ayurveda because he has felt the healing effects, and understands firsthand the benefits of this medicine. Practicing Ayurveda allowed him to connect with the medicine practiced in his childhood home, but more than that, it provides the opportunity for him to “expand” his biomedical practice.

Asking Felix why integrative oncology is an important development in the treatment of cancer, he returned to the topic of possibility:

From a patient perspective, they want to have all the options open. Why should they just focus on one [medical] system, when there may be good answers for them in multiple systems or areas. They want to have access to different approaches. I think western medicine is good and its helpful, but I’m also open-minded to other possibilities. If there’s another way of doing something, I’d like to hear about it, and see if it makes sense to me—see if there’s evidence for it.

Indeed, the patients who want to have other options are also those who can afford to choose between conventional and integrative treatment. In his practice, Felix primarily treats white middle class women with breast cancer, although he has a number of male patients with prostate cancer. Where Felix mentions evidence, he is also hinting at the

politics which shape the insuring of integrative oncology therapies, which I attend to in more detail in Chapter Two. In that chapter I will explore how the choice to pursue integrative oncology is always already complicated by the larger political economy of health care and insurance coverage in the United States.

The spirit of possibility that Felix describes—this interest in a different way of approaching the treatment of cancer—is a consistent sentiment with many of the integrative oncologists I spoke with. This question of how the treatment of cancer might be different if other medical modalities are taken seriously is often introduced around the concept of stress. For Felix, integrating Ayurvedic medicine with conventional treatment provided him a way to address the effects of stress on his patients:

In traditional medicines, one of the main causes of disease, in general, not necessarily in cancer, in general, is stress... I always hear stories about, ‘Well, I was healthy but then a series of events occurred which culminated in this cancer diagnosis.’ ‘My parents died, I got divorced, I lost my job, my kids got in trouble, and then I got cancer.’ So yes, of course these are common life events for many people, and you may think they’re not related, but when you start to hear stories like that again and again, you at least have to think that it is possible that these events are related.

Whether or not I believe that stress directly causes cancer, I know stress is a big cause of disease in general. I know its effecting my patients’ health, and I need to address that. I

need to find out ways that they can cope better with stress, and if possible, ways they can reduce their stress.

Integrating Ayurveda into his oncology practice helps Felix to make tangible the possibilities for a different kind of cancer care. In this sense, it seems that integration means bringing the social worlds of patients into the medical worlds of oncology practice in order to take seriously that diseases such as cancer are conditioned by lived experiences. Enacting integration for Felix means connecting with a broader range of therapies in order to address the many different dimensions of cancer avowed by the materialist emphasis of conventional oncology.

After oncology

Present throughout each of these accounts is an interpretation of the way in which the integrative approach addresses how conventional oncology has fallen short treating cancer using only surgery, chemotherapy, and radiation precisely because such cuts, doses, and burns are insensitive to the continuum of emotional peaks and fissures, fears and anxieties, states of suffering and forms of isolation both generated by and surrounding such treatments. Feeling dissatisfied with the disavowal of the existential and experiential facets of cancer treatment, Berdine, David, Donald, and Felix each attempt to connect with forms of medicine differently sensitized to these issues—biological,

pathological, physical, and therapeutic insights that can be integrated into oncology in order to complement conventional procedures.

Each of their stories provides insight into the different meanings at work in the idea of “integration.” What I take from these four accounts is that the focus on the “whole patient” as part of the integrative approach refers to both social wholes and bodily wholes such that integrative care attends to and attempts to treat the many different dimensions of a person affected by and affecting cancer. This is apparent in the way Berdine, David, Donald, and Felix talk about their integrative approaches as being rooted in a refusal of biomedical reductionism—that mind, body, and spirit are connected, and medical interventions must work to address and strengthen those connections.

Integration in their use also signals the incorporation of different medical systems into a biomedical approach. But where Berdine, David, Donald, and Felix each enact a different approach to integrative oncology, I understand that this field is very much in the process of working out its practices of integration. In this sense, it seems that these practitioners are continuously putting their biomedical ideas about bodies, disease, and treatment at risk (c.f. Stengers 2010) long enough to destabilize what it is and how it is they know bodies and cancer. To borrow language from Felix, each is engaged in an ongoing process of becoming sensitive to the possibility that bodies, in health and disease, might be known, and felt, and treated differently. I explore these ideas in more detail over the next two chapters.

Incorporations

At the same time, with these stories I feel the absence of discussion around what it means to integrate medicines and healing modalities from fields outside of biomedicine—what it means that other cultures of medicine are being used to redraw and expand the boundaries of oncology, but that the borders between these fields nevertheless remain porous when convenient, impermeable when not. I want to stay with this trouble (c.f. Haraway 2010), with the discomfort that these registers of integration produce when I hold each definition still enough to feel that the act of importing chunks of practices into biomedicine for the purpose of developing integrative approach is untroubled by the people doing this work.

In his studies of integrative medicine in the United States, critical medical anthropologist Hans Baer describes how important the 1970s grassroots movements of holistic health and new ageism were in shaping biomedical concerns with the subtle aspects of bodies. Baer stresses the point that, “despite the best efforts on the part of proponents of holistic health to develop an alternative to biomedicine, what in reality has occurred has been in large part the co-optation of alternative medicine under the rubrics of CAM (complementary and alternative medicine) and integrative medicine or integrative health care” (2004: 149). As bioethicist Paul Root Wolpe suggests, “over the last thirty years, as

alternative medicine has increased its profile, many of the very therapies that were being continuously ridiculed by orthodox opponents have been finding their way into the orthodox regime. The importance of nutrition, low-fat diets, and vitamin supplements; the concept of stress as a pathogen; techniques like meditation, yoga, massage, and biofeedback; the use of magnets to cure pain, acupuncture, and a host of pharmaceuticals draw from traditional medicines— all were once marginalized ideas that were considered by many as quackery” (Wolpe 1999 in Baer 2004: 89).

For Baer, “integration” when used in the context of biomedicine can only ever register as co-optation because of the ways in which biomedicine “exerts dominance over other medical or therapeutic systems” (2004: xvii). Building on this point, Baer underscores that the idea that, “CAM and integrative medicine are in large part biomedical constructions” (2004: xix) that conceal the selection of the “most attractive components” of other cultures of medicine (114).

Baer’s argument concerning co-optive practices of integrative medicine is important for calling attention to the power of biomedicine to bend other medical practices to fit its needs. Nevertheless, the political-economic framework that informs Baer’s examination of integrative medicine precludes him from attending to the ontological significance of integrative ideas about bodies and health pose for biomedicine— that in integrative oncology where the botanical, humoral, energetic and affective bodies of complementary

and alternative practices intersect with the biomedical modeling of bodies-as-machines, novel configurations of bodies and treatments are being produced.

Curiously, however, Baer is reluctant to excavate the formation of “holistic health” with the same criticality as “integrative medicine” and its connection to the idea of complementary and alternative medicines—as if to suggest that “holistic health,” as a category, existed before or beyond its configuring against biomedicine. If anything, there’s a selective innocence at work in the stories he is telling about “holism.”

Holism in Baer’s usage refers to a radical movement that attempted to resist biomedical hegemony by providing a counter balance of health care practices premised on the idea that mind, body, and spirit are interlaced and matter in their interconnection to health and disease (2004: 20). While Baer treats holism as an object of his analysis in crafting an account of the history of integrative medicine in the United States, he does not fully situate how the idea of holism is and acts in the world—of the different kinds of bodies, images, and ideas adhere to this term and its use.

I want to avoid reproducing any forms of innocence in the account that I am building (c.f. Haraway 1997, Murphy 2015). Indeed, with the research of historian of science, Anne Harrington, I have become more attuned to the imperative of troubling the idea of “holism” — and not just in a Strathernian sense, where the idea of the “whole” is revealed to be composition of inter-and intra-webbed relations (1991). In Harrington’s

analysis of the holistic sciences in Germany between the second and first world wars, she homes in on the “cultural cosmologies,” of sciences that “professed to do justice to the ‘wholeness’ of living organisms and to eschew mechanistic, reductionist caricatures” (1995: 357). By dichotomizing the natural world, these scientists championed the idea of holism seen in the “irreducible unity” of self-directing organisms, and maligned mechanism as being associated with fragmented and chaotic phenomena (1995: 360). Harrington observes that mechanism was figured as the problem, and wholeness, the “flexible currency in a complex conversation about... what was needed to set things right” (1995: 360).

Speaking to the potency of the idea of holism, Harrington explains that this metaphor was “a useful tool for both the sciences and the various other domains of collective life concerned with persuasion and display of claims” because “it allows people to suture new imaginative relationships across domains—to suggest connections between technology and organic process, nature and society, macrocosm and microcosm that may not have been ‘seen’ as likely, appropriate, or possible before” (1995: 359). This need to “recover something called ‘wholeness,’” the need to reclaim German society from the machine, took on political significance for the Nazi state. Harrington explains that, “the binary oppositional trope that saw wholeness as existing in a state of fundamental struggle with mechanism, and the body of racial mythology that imagined a fundamental racial struggle between Germans and Jews” made it possible for Jewish persons to be conceptualized “as direct flesh-and-blood metaphors for the forces of mechanism and chaos, to be contained

and conquered by the answering racial power of German-Aryan ‘wholeness’” (1995: 368). Poignantly, this violent “metaphoric transformation” where holism was imagined in conflict with mechanism, “was due to choices that got made, metaphorical suturings that were sewn, that were not inevitable but that, once established, could work as a powerful independent force” (Harrington 1995: 376). Unearthing this history of this term, Harrington points to how holism is sullied with power and violence—that it doesn’t naturally reference purity or an ennobled perspective, and that its invocation ought to provoke a question of how or why it is being used, and how authority is being imagined in and through its articulation.

Where integrative oncology has taken up the idea of holistic health and the notion that mind, body, and spirit are connected and their tethering matters for disease progression and treatment, it has renamed holism as “whole patient” treatment. I want to stay with the trouble (c.f. Haraway 2010) that Baer and Harrington alert me to in understanding this move. I want to take up these issues with more focus in the next four chapters as I build an analysis of integrative oncology that does not relieve this field of its complications or its problems, but nevertheless holds close to its achievements—to the treatment practices and patient experiences that point to novel configurations of bodies propagating in the this field—to the possibilities and pitfalls it creates for living with cancer differently.

CHAPTER TWO: MACHINATIONS

I drive twenty miles, air conditioning abating the stifling, desiccating heat emanating from the valley. As I push along the interstate, I feel every millimetre of the one hundred mile distance between this city and the ocean—those tempering coastal winds, utterly evaporated.

I park my rental car and wander between taupe coloured buildings, clutching a sticky note with the office and suite number of the nursing coordinator for the UC Davis Health System, located in Sacramento, servicing this city and nine communities in the nearby counties of Yolo and Placer.

I've come to speak with Ruth after hearing praise for her "Writing as Healing" workshop from one of the women in the yoga class for cancer patients and survivors I attend weekly. That same woman cautioned my idea to take public transit to this interview, suggesting that the walking required between bus stops in this part of Sacramento might spur unwelcome attention. The only trouble I encounter is in trying to identify which of the poorly signed buildings in this industrial park is a UC medical office, not wanting to wander into an engineering firm, a computer repair center, a roofing company, or a waste removal service.

When I finally arrive at her office, I find her sipping ice water from a reusable Starbucks tumbler, surrounded by piles of documents, looking visibly exhausted. She took this coordinating position almost immediately after completing her Masters research in Nursing on men's experiences with head and neck cancer. The wear of the transitioning from oncology nurse, to researcher, to administrator is present in her informality, and in her sometimes curt replies.

We chat for two hours. I abandon my list of questions seven minutes into the conversation when she tells me that the "Writing as Healing" workshop she runs is funded entirely out of pocket. Developed around the Amherst Writers and Artists (AWA) methodological assertion that a "writer is someone who writes," the course provides a supportive space for patients to experimentally and non-judgmentally write through the intensities which accompany and precipitate out of surgery, chemotherapy, and radiation. Considering that the offering of this workshop was instrumental in helping this UC Cancer Center achieve comprehensive care designation from the National Cancer Institute (NCI), I ask her to elaborate on her underwriting:

I've been a volunteer since 2008. They don't even pay for pencils and paper. It's not much, it just irritates me. If there was insurance money coming in for it, I could get a grant.

She continues by telling me that integrative interventions in oncology, "Will be recognized more in the future because they will fall into patient satisfaction." Ruth explains that this is the new "buzz word in health care"—it refers to a score derived from

surveys sent by hospitals to patients to be filled out at the end of their treatments. Patients are encouraged to rate their stay and the treatment they received. The data aggregated from these assessments are then used as a way of formulating whether a program or treatment is worthy of continued investment.¹

In the United States, if you finish a hospital visit you'll frequently get a four page survey in the mail, that has little things for you to fill out—‘Did you see this provider? Did you feel like you were treated well, with respect for your privacy?’ They ask all kinds of questions and come up with a score for patient satisfaction. It's a driver for someone opening up their chequebook to say ‘We need to have this if it's important to patients’ because people will get reimbursed. Reimbursements will be tied to patient satisfaction.

I ask Ruth to elaborate on the chequebooks and the reimbursements in question:

“Reimbursements from insurance— medicare, medicaid, those programs. They're going to start setting their reimbursement rates based on some kind of formula that will include patient satisfaction.”

Ruth tells me that insurance programs, those that are operated by partnerships between private companies and the United States Government, and those run without federal

¹ The Patient Satisfaction Questionnaire (PSQ) was developed in the 1970s at the Southern Illinois School of Medicine. The PSQ-III is the third iteration of the survey, composed of fifty items. The PSQ-18 is its shortened version. See http://www.rand.org/health/surveys_tools/psq.html for examples of both PSQ forms.

assistance, don't recognize the value of a treatment program if there isn't enough "data" to prove its efficacy.

Taking a sip of her water, she continues:

Nobody sees any value until they get more and more data about it. But it's a really difficult area to study, to get clinical data. Like measuring the writing group. Do I take blood pressure? What do I take if I want some clinical data that will tell you it's the right thing to do? We have anecdotal data from participants.

Ruth is careful to point out that in addition to the pressure of producing evidence for the effectiveness of integrative programs like her writing group, she notes that there is very little time for physicians to learn about these forms of treatment. Speaking to her own attempts to get oncologists to consider recommending her program to their patients, Ruth explains that "When you're coming into a system that's very clinically focused, science based, that's overwhelmed and overburdened on its own, when is a physician going to have the time to look into the writing program? Or even care about it, when they're still working at 8:00pm at night on their charting."

In the clinical context where she works, physicians are pressed for time, and challenged by their case loads. "The program doesn't come up, they don't think about it because there are a million things that... you know, in our system, we deal with patients, celebrities, CEOs, and homeless people. Sometimes the patients have so many needs that

you don't really have a methodology to sift through other therapies, other than what's right in front of you."

As our conversation progresses, Ruth asks me about my research: "Are you interested in focusing on writing? Or is it one of the components?" I pause and reply, "I'm trying to understand how oncology is taking on these emotional, experiential, mind-body approaches..." Cutting me off, Ruth adjusts her chair and tells me that, "No one is taking it on. It's kind of like, 'Oh and by the way we have this to help you get through it.'"

Flushed, I ask her if she thinks her writing program will ever become something more than the ancillary option she frames it as.

No. And actually I see it getting squeezed out more and more with what's coming with health care in the United States. There's just not going to be money. Hospital margins are dropping. Oncology practices are folding.

I sit. Mouth slightly agape, wondering how this could be when one in four deaths in the United States are the result of cancer.²

"It's the finances of it all." Speaking to the Insurance Benefits Exchange of the Obama Administrations Patient Protection and Affordable Care Act (PPACA), commonly referred to as the ACA or "ObamaCare," Ruth tells me that some of the insurers listed on

² American Cancer Society, "Cancer Facts and Figures 2015" (<http://www.cancer.org/research/cancerfactsstatistics/cancerfactsfigures2015/index>). This report also estimates 1,658,370 Americans will be diagnosed with cancer in 2015.

the online marketplace proposed for this bill, envisioned to create greater access to health insurance for people of many socioeconomic backgrounds by providing them with more coverage options, and plans adjusted to their incomes with the use of government subsidies have,

These ninety-day clauses where the health care provider won't get paid for ninety-days. There's no business that says, 'Ok, I'm happy to take ninety days on my accounts receivable.' It's like, from the perspective of a physician, 'First of all I have to hire employees to make sure I dot all my i's and cross all my t's to meet your insurance requirements for paperwork so that you will in ninety days give me my money. Maybe?'

This is a situation that both hospitals and private oncology practices face, where their patients' insurers hold out on reimbursing for standards of care—treatments that already have a clinical trial derived evidence base.

Speaking to how her writing as healing program could be made to matter in a biomedical landscape, moulded by constraints of time and energy, and the economic pitfalls of insurance coverage, Ruth continues, "The finances of health care are getting really ugly." Referring back to her writing program, "There has to be some other driver that says this is important for oncology, this will prop up the patient satisfaction numbers. But no one is looking out there saying we need this. Until the insurance companies say 'Yes, we'll pay

for chemo but you have to do writing, you have to do spiritual care, you are supposed to have reiki³ while you get your Avastin⁴—it’s not going to happen.”

Pressing for clarification, I ask: “So its not just the clinical research—it’s the insurance side that’s driving this too?”

Nodding, she turns to her computer. “There’s a great graphic in Google.” I watch as she types health care system into its search field, clicking on the third image result. I hear her desktop laser printer begin to warm up. Ruth turns her screen to me and sternly tells me, “you really have to look at that image. Tell me where writing belongs.”

Cheekily I respond by telling her, “I feel like I need a magnifying glass for this. Or some kind of decoder ring.”

Handing me the printout, tone unchanged, “When you go, ‘Well, why isn’t writing important?’ There’s your context. You’re the anthropologist here. This is your context.”

³ Reiki is a form of hands-on-healing or energy work, brought back into practice by Japanese Buddhist Miako Usui in the late 1800s (Herron-Marx et al., 2008: 37). Avastin, the trade name for bevacizumab, produced by the Genentech/Roche pharmaceutical company. This drug is a monoclonal antibody, or rather, an engineered clone of an antibody that inhibits angiogenesis (the growth of new blood vessels). This drug is used to interrupt the vascular endothelial growth factor (VEGF)—a signal protein that stimulates angiogenesis, effectively cutting off the blood supply to a solid cancer growing as a result of the overexertion of VEGF. In this sense, monoclonal antibodies are referred to as “targeted therapies.”

...

Building from Ruth's provocation, this chapter takes up the question of where and how integrative oncology is situated in the political economic context of health care in the United States. In this chapter I ask, how do existing evidentiary regimes condition the possibilities for what integrative practices can be evidenced and insured? Herein, I strive to develop an account of how integrative oncologists respond to the constraints that biomedicine produces in and through the demands for evidence, and in the absence of insurance coverage, exploring how professionals engaged in integrative work strive to make more space for their practice in the context of the American health care system.⁴

Go figure

This is the image Ruth rested in front of me (Figure 2), insisting I focus all my attentions around its mapping in order to understand where and how integrative treatments do and don't matter to the delivery of health care in the United States.

I feel bested by this image, self-conscious about the ways in which I can't, but ought to, be able to understand it as the context I need for my study. I wasn't being facetious when I lamented for something to help me make better sense of it. Maybe it would have been more accurate to ask for something to defuse it, considering it reads like a template for

⁴ See <http://www.jec.senate.gov/public/index.cfm/republicans/committeenews?ID=bb302d88-3d0d-4424-8e33-3c5d2578c2b0>

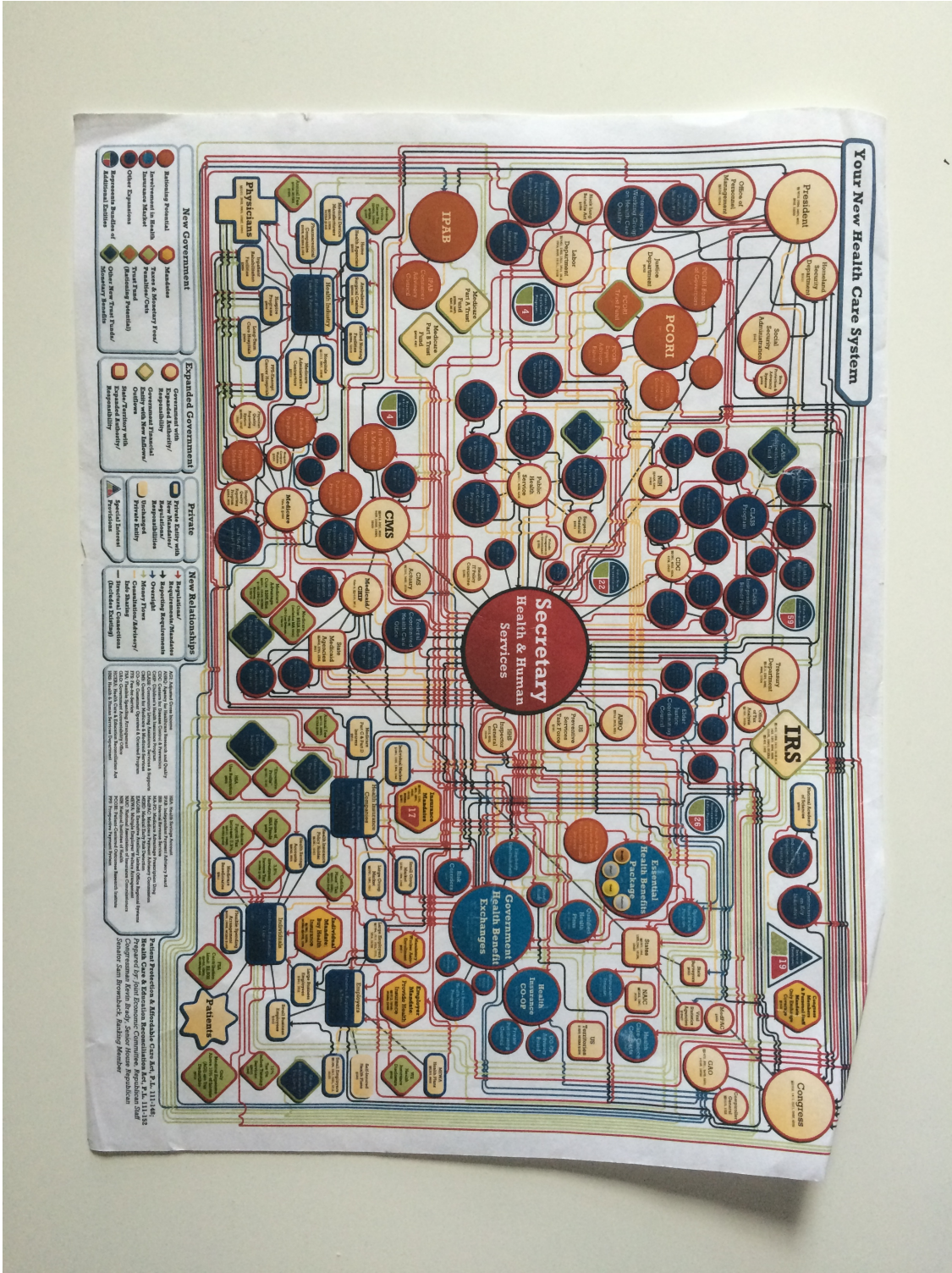


Figure 2: Photograph of the “Patient Protection and Affordable Care Act and Health Care and Education Reconciliation Act prepared by Joint Economic Committee” (2010) chart provided by Ruth.

knob and tube circuitry—the kind of system that might spark, zap, and short when you reach out to assess how it might be rewired.

The lower right hand corner of this image details its production by the “Joint Economic Committee, Republican Staff Congressman Kevin Brady, Senior House Republican Senator Sam Brownback, Ranking Member.” On the website for the Republican members of the Joint Economic Committee (the Democrats have their own site), a “Committee News” post from August 2, 2010 describes Senator Brownback of Kansas and Congressman Brady of Texas as leading the development of this “detailed organizational chart,” which “displays a bewildering array of new government agencies, regulations and mandates” brought about by the Patient Protection and Affordable Care Act (PPACA), signed into law by President Barack Obama earlier that year.

The Patient Protection and Affordable Care Act (PPACA, or ACA), is health reform legislation developed by the Obama Administration, and passed into law by the 111th Congress in March 2010 affecting the financing, organization, and delivery of health care in the United States (Redhead et al., 2012: 1). The major thrust of the ACA was to create legislation to assure the accessibility of health insurance for all American citizens and legal immigrants, regardless of pre-existing conditions or income level (Redhead et al., 2012). The ACA accomplishes this by mandating that all Americans obtain a minimum level of health insurance coverage, by creating tax credits for both individuals and businesses to cushion that cost, by reforming the eligibility criteria of the existing

federally and state funded Medicaid and Medicare programs, by creating standards for health insurance coverage, and by reassembling the private health insurance market (Redhead et al, 2012: 1).

The significance of the ACA for Medicaid reform cannot be understated. Described as the “workhorse of the US health care system” (Rosenbaum and Westmoreland 2012: 1664), Medicaid was established in 1965 as title XVIII of the Social Security Act, and is a federally- sponsored program that provides funding for each state to cover the costs of health insurance for low income families with children, individuals with disabilities, and long term hospital care for the elderly (Schultz and Young 2009: 269). Before the implementation of Medicaid, “health care services for the economically needy were provided through a patchwork of programs sponsored by state and local governments, charitable organizations, and community hospitals” (ibid: 268). Medicare, the partner program to Medicaid, provides medical coverage for individuals over 65, and is similarly structured in its funding. However, these two programs differ in that Medicaid reimburses medical providers directly, while Medicare makes use of intermediary health insurance organizations that works directly with states, such as Blue Cross and Blue Shield (Schultz and Young 2009: 270).

Before the passing of the ACA, there were 41.2 million uninsured adults in the United States, and 21.6 million of those adults did not qualify for Medicaid (The Kaiser Commission 2012: 1). With the ACA, the economic eligibility criteria for Medicaid has

been redrawn to consider a wider range of individuals living up to or at 138% of the federal poverty line or individuals and families who make 38% more than the federal poverty level income. In 2012, the poverty line was drawn at \$11,170 for individuals, and \$19,090 for families of three. With the ACA, individuals with annual incomes up to \$15,415 and families with annual incomes of \$26,344 will now receive Medicaid. This change has opened up the provision of coverage for half of the uninsured adult population in the United States already (The Kaiser Commission, 2013).

In addition to the Medicaid expansion, the ACA also implemented the development of the health insurance marketplaces, or health exchanges. These federally funded, state run platforms are designed to provide affordable coverage plans in line with the bill's mandate that all US citizens must maintain some kind of health insurance coverage. Those who fail to comply will be penalized with what is referred to as a "shared responsibility payment," — "a percentage of household income, subject to a floor and capped at the price of the forgone insurance coverage, assessed and collected by the IRS and reported on federal income tax returns" (The Kaiser Commission, 2012b: 2). This responsibility, and its attendant disciplinary structure, not only speaks to the biopolitics of self care (Foucault 1978); but to how insurance began in the US as a way to offset the "diminished economic production" felt by families and society at the onset of illness (Starr 1982: 236).

The exchanges are designed to provide an affordable range of coverage options from state-approved insurers. Plans are tiered from bronze to platinum, and individuals are also given the option to buy catastrophic health insurance—plans that are essentially for emergency use, characterized by high-deductible, high-cost, low premiums rates, that nevertheless, meet the minimum coverage requirements, of the ACA.⁵ The California health exchange, Covered California, lists platinum plans as covering ninety-percent of health care costs, decreasing in ten percent increments ending with the bronze option at sixty-percent. In each plan the individual is responsible for the paying the percentage difference between their coverage and the cost of their medical care.⁶ The ACA provides tax credits to offset the costs of these plans, scaled according to individual or family incomes with 100-400% of the federal income poverty level—roughly between \$11,1770 and \$44,680 for individuals, and between \$19,090 and \$76,360 for families of three (The Kaiser Commission, 2012: 2). According to data from the National Health Individual Survey conducted in 2012 by the Centers for Disease Control and Prevention for the Department of Health and Human Services, one in six families experience problems paying their medical bills, and one in ten families cannot pay their bills at all (Cohen and Kirzinger 2014: 2).⁷ This report also indicates that families whose income hovers around

⁵ See <https://www.healthcare.gov/choose-a-plan/catastrophic-plans/>

⁶ Figures as of February 2015, <http://www.coveredca.com/individuals-and-families/getting-covered/coverage-levels/>

⁷ The National Health Interview Survey defines family as “an individual or group of two or more related persons living together in the same housing unit” (Cohen and Kirzinger 2014: 1).

⁸ See <https://www.census.gov/content/dam/Census/library/publications/2014/acs/acsbr13-02.pdf>

the national average of \$52,250⁸ experience the highest levels of financial burden when it comes to affording medical care (ibid).

Following the passing of the ACA in 2012, Republicans have tried, unsuccessfully to repeal this bill. Just months after its enactment, the constitutionality of the ACA was challenged, and its legality affirmed by the Supreme Court at the cost of nationally mandated Medicaid reform. The Supreme Court ruled that each state could decide whether to implement the Medicaid expansion without risk to their existing Medicaid funds (Redhead et al., 2012: 5). Since that ruling, only twenty-nine states have adopted the expansion. California, which has the largest Medicaid program in the US, participated in the expansion. As of January 2015, seven states are discussing the option of expanding, and fifteen states are firm in their decision not to expand Medicaid.⁹ In October of 2013, the federal government was shutdown for sixteen days because of a budgetary standoff, instigated by Republicans refusing to allocate funds for the implementation of the ACA reforms. The House of Representatives and Congress resumed budgetary debate on December 12 of 2013, resolving to delay the ACA reforms until 2015 (Lewis 2013; Stein 2013).

⁹ See: <http://kff.org/health-reform/state-indicator/state-activity-around-expanding-medicaid-under-the-affordable-care-act/>.

Even with this cursory contextualization of the ACA, it is clear that the “Your New Health Care System” is less of an effectual aid in understanding the changes and issues at work in this bill, than it is a Republican tactic meant to undermine these health care reforms by rendering them excessive, convoluted, and overwrought.

In making no reference to its own confusing construction, this diagram inveigles its audience further. This original positing of this chart on the Republican Joint Economic Committee website include the comment that with the “Your New Health Care System” chart, “It doesn’t take long to see how the recently signed health care bill causes a hugely expensive and explosive expansion of federal control over health care.” Lamenting the 2,801 page bill, the bulletin quotes Congressman Brady who suggests that, “For Americans, as well as Congressional Democrats who didn’t bother to read the bill, this first look at the final health care law confirms what many fear, that reform morphed into a monstrosity of new bureaucracies, mandates, taxes and forced our most intimate health care choices into the hands of Washington bureaucrats... If this is what passes for health care reform in America, then God help us all.” It strikes me that such assistance might be better directed toward those trying to make sense of this chart—a document which one New York Times writer described as a “monstrosity” and an example of “chart abuse” (Blow 2015).

In the moment where Ruth put this chart in front of me (Figure 2), we weren’t talking about the ACA. When I asked her where this document came from, she told me that she

encountered in it grad school but, “I don't know who created this. You'll have to do some research on that.” The title in the corner, those details about the point and politics of its production escaped us both.

Ruth didn't put this chart in front of me to talk about healthcare reform; she put this chart in front of me because this tangled thicket of lines and shapes is what working toward “whole patient” medicine in the American health care system looks like, and feels like, to her.

As we sat in front of this chart, I remarked at how small the patient shape is, tucked away in the right hand corner. “Yeah, our system is pretty screwy. Got some really good care, but it is designed to move money around, period. End of discussion.” I paused, trying to consider how to get Ruth to say more about this point without annoying her. Before I could assemble a question, she filled this silence by expanding on her comment,

The other problem is that we call it the health care system, but it's really not a system. You define system, it's a bunch of gears moving, but here, they're not connected. There's some touching points, but we still don't have a patient in there. Just a bunch of random wheels moving.

I can see Ruth's comment mapped into this diagram, where patients and physicians are drawn as differently shaped gears with incompatible cogs, separated by spheres and more lines. As someone who advocates for a different kind of medical care for patients than

outlined in this system, this comment also speaks to her felt sense of displacement from its workings.

It strikes me that Ruth continues to return to this chart, or rather, is caught by this chart because it has an affective charge—it irritates her and amplifies her feelings of frustration with a system that does not seem to work.

When Ruth instructs me to tell her where her integrative writing intervention fits in this image, she is speaking about this very affectivity of the chart. This insistence turns to insight when I recognize that this document both resembles and is being positioned by Ruth as a schematic—a blueprint for a mechanized system that affects her with a feeling of displacement. When she asks me where her writing as healing program fits, I hear a question about how her program can be given its own sphere when it does not participate in or reproduce the kinds of political and economic relations that keep this system moving— it isn't easily studied using clinical research methods, it isn't predicated on a modelling of bodies-as-machines, it isn't covered by insurance, and it's not a therapy which lends itself to patent or profit.

This chart may not be my context, but it does contextualize the issues at stake in the development of integrative oncology—problems of finding space for the sensitivities of integrative oncology in the practical culture of biomedicine where machine analogies

organize not only how to treat bodies, but how to make sense of bodies, and what research and coverage parameters are required to produce knowledge about them.

In tracing these challenges I want to use a delicate hand in order to avoid suggesting that integrative oncology is somehow opposed to the biomedical view of bodies. The modeling of bodies-as-machines in biomedicine matters to and for integrative oncology as a field which works to develop healing modalities complementary to existing standards of care. Integrative oncologists work with the mechanically inflected idea that the removal of cancerous parts, by knife, laser, or chemical, is part of the process of bringing a body back to healthy running order. Integrative oncologists do not wish to move away from chemotherapy, radiation, immunotherapy, hormone therapy, or surgery. Rather, they strive to make these treatments more livable for their patients by providing nutritional, emotional, psychosocial, and spiritual support—aspects often overlooked by conventional oncologists as being relevant the treatment of cancer.

In Chapter Three, I develop the notion of sensitivity to analyze how this approach to cancer treatment reconfigures existing biomedical ideas about human bodies, health, and disease. As an idea that builds from, rather than abandons, machine models, it is crucial to first examine where and how mechanical ideas matter in order to understand how integrative oncology responds to and is regulated by this organizing discourse.

Mechanical matters

The entanglement of medicine and capital has created a context in the United States where the body-as-machine analogy is central to the transformation of health care into a commodity. In his canonical text, *The Social Transformation of Medicine* (1982), Paul Starr explains that this market approach to medicine arose with industrialization. For Starr, the development of the American Medical Association (AMA), along with increased medical authority and the licensing of medical practice at the turn of the twentieth century saw the care for the sick and diseased displaced from the home and into the hands of doctors who fit their fees to what patients could afford to pay. In this context, doctors only charged fees to cover the cost associated with their practice (Starr 1982: 60-61, 125-6, 235-6). Starr is also careful to point out that the “changing organization of economic life” at this time placed a different demand on medicine: “In individual households, sickness now interrupted the flow of income as well as the normal routine of domestic life, and it imposed unforeseen expenses for medical care” (1982: 236). What is now a century long debate about the place of social insurance and commercial health insurance in the US arose out of this problem— out of the recognition that the fee-for-service basis of medical care instantiated by the professionalization of medicine meant that the loss of income as the result of illness, or the inaccessibility of medical care because of cost, affected both families and the broader economies of production in the US. The question of reforming health care to alleviate this problem continued to be

critical to the presidencies of Roosevelt, Truman, Nixon, and Clinton—each attempting to build or dismantle social insurance (ibid).

With each of these presidencies, the economic principles driving the American health care system have been further entrenched in a commodity structure. While the history of insurance is certainly not object of this chapter, being attentive to how health insurance has been positioned in the United States tells a story about the value of machine-analogies in biomedicine. It deepens an appreciation of the utility of these configurations for the political economy of medicine in considering that it precisely the idea of the machine-like body that underwrites the idea of insurance— that the costs of medical care can be anticipated because bodies, as machines, require short, efficient, and routine consultations with physicians to assess which parts need fixing or tuning up, and that the resources required for those treatments could be forecasted. Health Maintenance Organizations (HMOs), one of the predominate health insurance delivery systems in the United States, continue to model this view through the process of capitation—“a method for paying for health care under which a service provider [physician or hospital] receives a fixed amount of money per person (the capitation rate) and in return agrees to provide all necessary care to enrolled members” (Barr 2007: 85). HMOs work based on the notion that the provision of medical care is predictable. The inverse, however, is that physicians are limited by the time and attention they can offer patients because it may fall outside of their monthly or yearly capitation rates—the medical services they are paid to, and in a sense, permitted to enact.

Speaking to these tensions, American sociologist and physician Donald A. Barr effectively summarizes that,

Early in the twentieth century, our society elected to approach health care as a market commodity, available to those with the resources to pay for it. Physicians, working through their professional organizations to influence political and legal aspects of health care delivery, were able to attain a position of substantial power. They used that power for much of the twentieth century to ensure that health care remained a market good, with government playing only a minor role. At the beginning of the twenty-first century, we are confronting the policy consequences — cost, quality, and access— that evolved as a result of those earlier policy changes (2007: 19).

While not exhaustive, I nevertheless want to establish that these are the kinds of issues complicating the position that integrative oncology finds itself in confronting a political economic landscape where the kinds of practices that matter to medicine have to make sense to the mechanical modelling of bodies, but be able to participate in the evidentiary circuitry that makes medical procedures insurable and deliverable. These are the tensions which affect the posture with which Ruth insists that I figure out where integrative oncology fits.

The command of evidence

Despite the fact that so much of what is at stake in the development of integrative medicine is conditional to a mechanical view of bodies and the attendant instrumentalization of their care, I did not encounter much talk about this subject. As

described in Chapter One, many integrative oncologists and professionals allied with this field expressed their felt discomfort with the mind-body dualism at work in the conventional treatment of cancer as having catalyzed their movement into integrative oncology. Nevertheless, none identified or made mention that this separation is conditioned by and conditions the extensive and pervasive modelling of bodies as machines—an absence that speaks to how entrenched mechanism is in biomedicine, of how tacit this idea is in medical worlds.

When I did hear talk about mechanism, it was in conversations about how and where integrative oncology sits in biomedicine, and how its place as a legitimate medical field in oncology is both contested and regulated by the requirements for clinical evidence about its therapies—for data derived from clinical trials that could be used to build an evidence-base and to make a case for the efficacy of the many therapies used by integrative oncologists, and the viability of insuring such treatments.

This pressure to produce evidence in such particular terms is intensifying as a condition of the growing embrace of evidence-based medicine (Pope 2003: 269). Synthesized by a group of clinical epidemiologists at McMaster University in Hamilton, Ontario in the 1980s, anthropologists and sociologists suggest that evidence-based medicine be considered “not as a scientific enterprise so much as a pedagogical movement, aimed at unseating the traditional authority of medical consultants through the introduction of rigorous scientific evidence based on epidemiological research” (Lambert 2009: 17).

With their publication of *Clinical epidemiology: a basic science for clinical medicine* (1985), McMaster clinicians David Lawrence Sackett, Brian R Haynes, and Peter Tugwell championed the use of epidemiological quantitative research techniques to determine “the most effective therapies for medical conditions” (Bell 2012: 314). As medical anthropologist Helen Lambert identifies, these evaluative procedures were mobilized in response to the “increasing recognition, probably from the 1960s onwards, within and outside the profession that doctors are not infallible and that many medical interventions have historically been based on tradition or preference, unsupported by any evidence of benefit other than the conviction of the administering practitioner” (2006: 2634). The problem with evidence-based medicine, particularly for fields such as integrative oncology, is not its proposal that research evidence is required for clinical decision making and medical knowledge production. Rather, the issue rests in “how evidence-based medicine as a new social movement has organized to ensure that a particular (explicit) form of evidence, epitomized by the randomized controlled trial, is incorporated in medicine” (Pope 2003: 269). In this sense, evidence, and what counts as evidence, is being refashioned as that which is exclusively produced by clinical trials.

Evidence as it is positioned by this turn is also being used to exert regulatory authority over the complicated, “hands-on,” interpretive work of medical decision making enacted by clinicians (Pope 2003: 273). By championing practical guidelines over professional judgement as the basis for medical conduct and patient treatment, the evidence-based model for medicine has become “attractive to health care policy makers, purchasers and

administrators” because it allows for things like program funding or insurance coverage to be determined by the specific evidence-base supporting a practice or a treatment (Pope 2003: 272).

Felix, an integrative oncologist who incorporates Ayurvedic medicine into his practice, introduced in the previous chapter, has been incredibly helpful in attuning my attentions to these matters. As someone thoroughly committed to his work as a physician and researcher, Felix spent more time talking about his integrative work over the phone and over email than we did in person. During one of our discussions about his clinical research on integrative approaches for alleviating pain, sleep disturbance, and depression related to chemotherapy and radiation treatments, he related to me that,

I think things are shifting, and I'm sure that's why you're doing this work. It may not be as overt, but there is this... let me see what the good way to put this. I think there maybe be a sense among some Western physicians that this is not serious medicine. Sometimes when I'm attending conferences I get the sense that there is this sort of snickering or laughter—that these ideas are amusing to some physicians. I think it's partly because they don't fully understand it, you know, and partly because they have biases against it.

Felix reasoned that he receives such mixed responses to his clinical research because his studies on Ayurveda are, “not like drug development, or its not like studying the molecular biology of the basis of the disease. Like serious medicine. This is seen as not so serious medicine.”

When I ask him about the preponderance of these criticisms, he elaborates that,

I wouldn't say that I get that impression all the time. I think there are a lot of western physicians who would say the same things I'm saying—that they're open minded about it, they want to know if it would help. But if you're asking about the critics, the kinder critics would fall into the category of 'It's fine, it probably helps some patients, but it's not serious medicine.' I would say the harsher critics would maybe even go further and say that 'It's useless, and its a waste of resources, and its quackery.'

The implication of Felix's comments is that research perpetuating, or building from, the existing biomedical model of bodies as machines, exemplified in the life sciences and clinical research, is treated as legitimate. With these comments I also get the impression that the criticisms Felix receives are racially charged—meant to undermine and trivialize the positioning of 'non-Western' practices and bodies in biomedicine (Fausto-Sterling 2004; Reardon 2004). Despite the criticisms his work receives, Felix is committed to producing research that impresses on the medical community a sense of the seriousness of his studies, and the significance of integrative techniques:

I think on a very basic level evidence is required for everything, and I think everything we do should be studied. But I think the question ought to be, 'What's the right way to study something?' and 'What are the results you are getting from the study that you're doing?' The methods of research have to match the thing that's being studied. And that's the challenge we have as researchers in integrative medicine—most of the methodologies in use are more suited to studying other kinds of interventions and drugs. We really have to think about adapting these methods and if that is done, and I think the evidence that's generated would be more useful, and a lot more persuasive to insurers, or medicare, or other policy makers to try to include integrative medicine. The challenge with these kinds of things is that they will take time. It's happening, but it's going to take five to ten more years to see those kinds of results. In the mean time, what can we do?

Asking Felix to elaborate on the need to recalibrate evidence production for integrative methods, he explained that,

I think there is a bit of conflict there about the nature of integrative medicine and that expectation for large studies, and large populations. The whole idea of the journey of doing integrative medicine, and incorporating it into your life is very individualized. Each person is going to have change in a very individual way. Then to say we need large population data on this, I think there's some conflict there that has to be resolved.

Speaking to the problem of the clinical trial for the study of integrative approaches in and beyond oncology, Felix makes clear that the “whole patient” approach to cancer treatment, described by him here as an individualized journey is not something that can be tested using a sample group of randomized individuals. Each of his patients receive a treatment course designed to fit them specifically. This fit, as mentioned in Chapter One, is determined by the kind of cancer the patient has, and the kinds of the therapies required to support the patient through conventional treatment are determined by the patient’s social life, emotional wellbeing, stress levels, their environments (with consideration for toxicities they might encounter), diet, and exercise level.

This question of where and how to fit integrative medicines into the biomedical machinery of the randomized clinical trial (RCT) is one that echoes throughout the fields of complementary and alternative medicine—reverberating like radar, pinging as it identifies the obstacles that evidence-based medicine, predicated on a view of the body-

as-machine, poses for practices trying to find space to move in this landscape (Barry 2005).

Indeed, evidence-based medicine promotes the idea that medical practice and therapeutic decision making should be based on “the best evidence” obtained from randomized controlled trials. Referred to as the gold standard in medical research, clinical trials are used in “evaluating the efficacy and safety of newly devised medicines, and for researching new indications of existing ones” (Applebaum 2012; see also Petryna 2009, Dumit 2012, Jain 2013). In her analysis of the recent past of the clinical trial, Petryna notes that the randomized controlled trial was given gilded status in the 1970s by the Food and Drug Association (FDA). Critical to this methodology is the randomization of participants at each phase. Randomization is a statistical protocol which involves randomly assigning trial participants to either a treatment or control group. The treatment groups receive the drug being tested, while the control group either receives an existing drug against which the new drug is tested, or a placebo drug. In some trials patients and their medical teams are aware of the randomization, and in other situations, only the researchers running the trial will know which participant belongs to which group (Petryna 2009: 23).

Clinical trial research in conventional oncology is typically developed over three phases. In Phase I the “maximally tolerable dose” is determined by gradually increasing the dose of a drug in patients with cancer to the point that it is intolerable (Price et al., 2008: 12).

Phase II tests the maximal dose on patients with solid cancers that can be easily measured using medical imaging in order to see the cytotoxic effect of the drug on the tumor—of whether the drug has an effect on decreasing the growth rate of cancer cells (ibid). If the drug is found to have some effect in Phase II, Phase III trials proceed and at this stage, patients with cancer are randomized to either receive the drug being tested or the best available treatment in order to compare the effects of the new drug on “long-term survival” (ibid).

In *Cancer on Trial: Oncology as a New Style of Practice* (2012), historian Peter Keating and sociologist of medicine Alberto Cambrosio elucidate that oncology and the experimental format of the clinical trial were mutually productive—that the development of clinical testing protocols for the use of chemical agents for the treatment of cancer in the postwar period simultaneously anchored the utility of clinical trial methodologies for medicine, materializing oncology as a field defined by these experimental specializations. Before the first World War, cancer treatment belonged to the domain of surgeons and general practitioners who treated cancer by excising or x-raying tumors. In 1941, the United States army contracted Yale biologists Louis Goodman and Alfred Gilman to study the biological mechanisms of mustard gas in order to better understand and better weaponize the compound (Keating and Cambrosio 2012: 40). Goodman and Gilman used mice to study the effects of nitrogen mustards, and during the course of their experiments they noticed that these gases “destroyed” both the lymph nodes and bone marrow of mice (ibid). A year after these experiments, Goodman and Gilman injected a nitrogen

compound into a person who was terminally ill with lymphoma. This test was considered to be a successful application of a chemical in the treatment of cancer in that the compound shrunk the patient's tumor, providing a short remission before their death. Out of this success arose an effort to create standardized ways of treating cancer, rather than waiting for standards to emerge through the aggregation and analysis of cases in which cancer was successfully treated (Keating and Cambrosio 2012: 52).

It was precisely this need to create standards for the treatment of cancer that shaped oncology. As Keating and Cambrosio contend, "medical oncology is built around the performance of clinical trials, the principle vector for the development of chemotherapy" (2012: 16). These scholars point to a landmark clinical trial conducted at the National Institutes of Health (NIH) Clinical Center in the early 1950s that established the utility of this experimental method for establishing standards of chemotherapy treatment for oncology. The VAMP trial entailed the testing of a chemotherapy regime combining four different drugs for the treatment of children with lymphocytic leukaemia: "vincristine (V) and amethopterin (A, also called methotrexate), were given every four days intravenously; mercaptopurine (M) and prednisone (P) were to be administered orally on a daily basis" (Keating and Cambrosio 2012:5 6). The trial involved sixteen children with lymphocytic leukaemia, and required that the children continue to received this regimen until they entered remission, outlined as "the abatement of the leukemic symptoms but also as the reduction of the proportion of leukemic cells in the bone marrow to below 5% of the total number of cells contained therein" (ibid). The initial

results of the VAMP protocol were so successful that the trial stopped with those sixteen subjects, and this combination of chemotherapy drugs was established as the first standardized cure for this disease (ibid).

The VAMP trial was also critical in establishing what trials were needed to further to understand how chemotherapy drugs work at different stages in the development of cancer. Critical here, according to Keating and Cambrosio, is that “clinical trials began co-producing the diseases stages against which a particular chemotherapy regime was tested, in the same sense that they led the clinical redefinition or reinforcement of nosological categories (e.g., “leukemia” was shown to consist of two distinct entities, childhood and adult leukemia, that responded differently to treatment and could be correlated to the involvement of different cell types) and to the production of clinically relevant subdivisions of those categories based on the (treated) disease trajectory. Maintenance of remission, for example, used therapies different from those used in remission induction” (2012: 71-72). It becomes clear that how cancer is known and how cancer is treated was shaped simultaneously in the turn to developing chemotherapy using clinical trials. It is not difficult to see why it would be so challenging for integrative oncologists, who understand cancer to be a disease that is at once physical, emotional, and social, to use clinical trial methodologies that focus on finding the biological effects of cancer therapies to demonstrate the efficacy of complementary modalities in these specific terms.

Further compounding this question of fit are the actual requirements of large-scale clinical trials. As Keating and Cambrosio elucidate, it takes an estimated, “810 steps to open a Phase III trial, implicating as many as thirty-eight different individuals and groups in the decision-making process. With these time delays and the sometimes-baroque additions to the original protocol, it is little wonder that 64% of all Phase III cancer trials sponsored by the NCI [National Cancer Institute] between 2000 and 2007 failed to meet their minimum accruals” (2012: 361). They also mention that the FDA has become aware of just how difficult it is to organize and complete all four phases of clinical trial protocol. In 2006 it created “Phase 0” or “microdosing studies” which allow for the testing of a “subtherapeutic doses of an experimental drug” to “gather data on the drug’s behaviour in the human body, in particular to assess whether the drug has had an impact on its intended molecular target” (Keating and Cambrosio 2012: 362). This Phase attempts, “to pry open the bottleneck located between the isolating of a promising compound in a screening system and its first use in human beings in Phase I trial” but even then, this phase remains inaccessible for the testing of integrative oncology interventions that do not have molecular targets.

The experimental format of the clinical trial is not only predisposed to make sense of treatments that are based on a material or biological modeling of disease, it is a knowledge-making technique in and for the production of capital (Dumit 2013). The market for anti-cancer pharmaceuticals alone was estimated to be worth \$70 billion in 2008. Focusing on the triad of risk, treatment, and consumption in biomedicine, in his

ethnography *Drugs For Life: How Pharmaceutical Companies Define our Health* (2012), Dumit contends that pharmaceutical companies, through their use of clinical trials, have played a critical role in redefining illness. For Dumit, viewing “clinical trials as investments, pharma companies start with the question of how to research a treatment so it can be indicated for the largest possible market. They do this because they measure the value of clinical trial research via the total number of potential treatments that can be sold over the patent life of the drug” (2013: 5). Dumit shows that in the 1990s, “a very different notion of illness took center stage, one in which bodies are inherently ill” (2013: 7)—a notion that was contrived by the logic of risk which meant that health became a matter of staving off illness—a process that required constant medical and pharmaceutical intervention. Indeed, Dumit identifies that things like vaccines, or treatments that produce cures have little to no long term market value in what he calls the “mass health model”—a state in which “clinical trials indicate treatments” and treatments, instead of returning a patient to health, become organized around the “indefinite” process warding off the risk of illness (2013: 8). Through this remodelling of health as a matter of reducing the risk of illness, rather than curing, the pharmaceutical industry has modified the clinical trial to serve in the production of evidence for drugs that will expand markets and modes of consumption.

At what cost?

In *Malignant: How Cancer Becomes Us* (2013) anthropologist and cancer survivor Lochlann Jain indicates that the clinical trial has been instrumental in developing “oncology as a professional field” (113). Jain suggests that there is, “a deeply embedded paradox” at work in the relationships between the protocols and participants of the clinical trial. For an experimental methodology which is supposed to evaluate and support the development of better cancer therapies, “the trials need—indeed await—the cancer recurrence of their participants” (Jain 2013: 114). Jain makes clear that the clinical trial in oncology is not so gold insofar as the physicians who conduct these investigations, “stand in the awkward and horrible position of needing their subject’s deaths, sometimes withholding treatment, even when the treatment in question clearly extended lives” (2013: 120). The clinical trial as a research methodology in oncology, “asks its subjects to partake in the higher calling of what the philosopher Michel Foucault might have called ‘collective living on’— the sacrifice of oneself for the possibility of a social group” (Jain 2013: 118). As Jain elaborates, “by promising a future it cannot know and asking patients to hurry to a sacrificial conclusion, the RCT ignores its own forms of violence and permission to harm. Its varied uses for science, capital, and professional advancement do not in themselves correspond with cures or better treatments” (2013: 118). Indeed, Jain figures that, “the number of true [RCT] breakthroughs can be counted on one’s finger and toes” (2013: 115).

In considering how the clinical trial has been positioned as the standardized mode of evaluating and producing evidence for the use of medical therapies, Jain speculates that, “the present-day appeal of the RCT surely lies in its elegant simplicity. Its commonsensical grounding remains so beyond reproach that even as physicians hotly contest the relevance of results and specific trials, the method offered medical practitioners a tightly shut black box; the method itself barely requires comment in the scientific literature” (2013: 116). This resonates with conversations I had with integrative oncologists who consistently questioned how to make integrative therapies intelligible to the clinical trial format—questions which show up the limitations of this methodology for evaluating medical methods that are not explicitly pharmacological in nature.

Returning to Felix’s comments concerning how the integrative approach is not generalizable because it is a treatment approach based on the individual being treated, he gestures to the way in which the clinical trial generalizes cancer—that the treatment standardization that trials strive for functions by stripping cancer of its particularities such that “the cancers affecting all patients in a trial” are construed as “similar enough that the patients can be said to have the same diseases” (Jain 2013: 124)—an idea which is antithetical to integrative oncology.

In my conversations with Donald, a colleague of Felix’s also introduced in Chapter One, the difficulty of producing evidence for integrative therapies came up in our time

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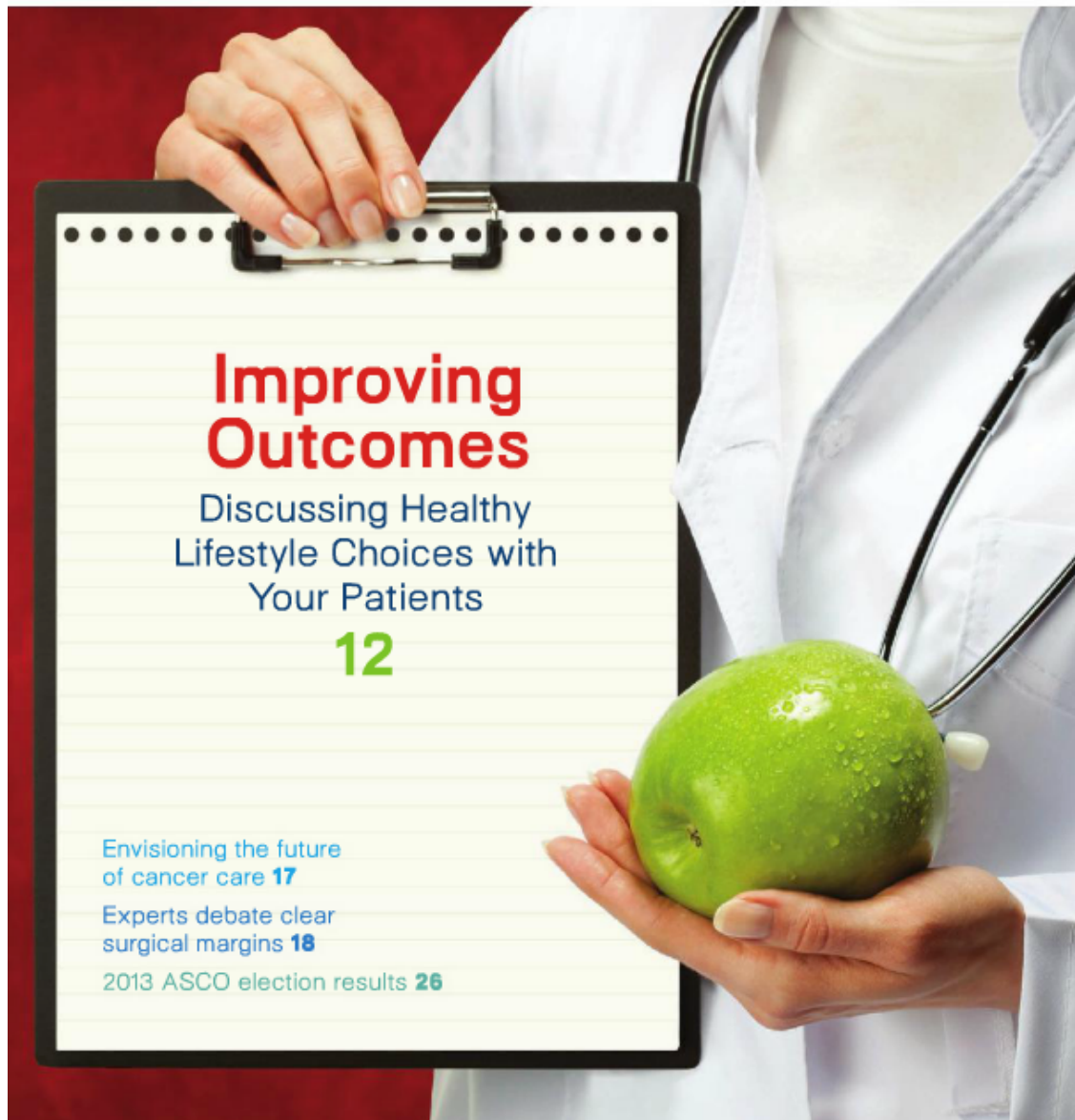


Figure 2.1: ASCO Connection cover, January 2013

together. In his office at the Osher Center, Donald made similar comments about the pressures to legitimate integrative oncology. Unlike Felix, Donald is already imagining movement on this issue. Making reference to a recent cover of the ASCO Connection, what he describes as a “chatty magazine for oncologists” published by the American Society for Clinical Oncology (ASCO), Donald mentions that,

They just had a cover of their ASCO Connection which showed a person with in a white coat holding an apple in their hand, saying ‘Talk to patients about lifestyle.’ Maybe there is some hope, that mainstream oncologists are going to start to think about this.

Indeed, Donald tells me that he often begins presentations on integrative oncology with this image (Figure 2.1)— a catalyst for creating connection in the company of conventional, and skeptical, oncologists.

The article associated with this cover image, “Improving Outcomes: Discussing Healthy Lifestyle Choices with Your Patients” by Virginia Anders (2013), addresses cancer prevention in relation to tobacco cessation and the importance of “energy balance,” a catchy shorthand used to talk about monitoring calories as there are correlations between obesity and cancer. It advises oncologists to assist their patients in understanding the importance of lifestyle interventions, suggesting that tobacco cessation and changes in nutrition and diet are beneficial even after a cancer diagnosis. One of the pull quotes in the article, formatted in a colour of green reminiscent of the dewy granny smith adorning its title page, cites an ASCO Cancer Prevention Committee

Figure 2.1: ASCO Connection January 2013 cover image (<http://read.uberflip.com/i/98825>) member arguing that, “We need real research to determine what human behaviours make a difference after a cancer diagnosis and what changes are most effective” (Anders 2013: 14, emphasis mine). For Donald, this article and apple-in-hand image is a kind of olive branch.

When I ask Donald what would be required to extend these ideas about lifestyle and nutrition beyond the ASCO monthly newsletter, as if echoing the sentiments of the article, his immediate response was “evidence.”

That's the big thing. Oncologists are very evidence-based—all of medicine is very evidence-based. That's the big buzz word. What I like to say is that integrative oncology is evidence informed as opposed to based.

Donald calls on his training in integrative medicine with Andrew Weil to explain this point:

One of Andrew's great teachings is ‘The degree of evidence should be directly proportional to the potential of the intervention to do harm.’ So if I say I'm going to give you chemotherapy, your hair is going to fall out, you're going to be vomiting for three days, and your bone marrow is going to be depressed, you're going to want to say, ‘Show me the evidence that's its going to benefit me.’ But if I say eat more blueberries and broccoli and get a massage twice a month, how much evidence do I really need to generate to say that's going to be beneficial? The potential for any of those do harm is pretty low. And how do we conduct those experiments, anyway? Blueberries vs non-blueberries? There's no such thing as a placebo blueberry, so how can I randomize this half of the group to eat blueberries three times a week, and this half to eat placebo.

Walking me through an example of how an “evidence-informed” practice might be used to structure integrative practice, Donald elucidates that,

I know patients should not take St. John's Wort—which is a mild to moderate botanical anti-depressant—when they're taking chemotherapy because St. John's Wort is an inducer of the liver enzyme system that also metabolizes chemotherapy drugs. Two studies were done with St. John's Wort in combination with chemotherapy— it showed that it lowered the concentration of the chemotherapy. It's sort of, intuitive. Do I know that St. John's Wort should not be taken with cyclophosphamide? No, because it was only studied with irinotecan and erlotinib. But I can use that evidence to inform my recommendation. That's what it's all about—we have some evidence but not the type of evidence that oncologists really want.

Here David points out the critical problem that many complementary therapies that have an evidence-based in biomedicine nonetheless have not been examined for their interactions with chemotherapy, radiation, immune and hormone therapies used in treating cancer. Moreover, the “type of evidence” desired by oncologists, and the political-economy of their health care practices, is predicated on a view of bodies as machines. The application of complementary healing techniques in integrative oncology isn't directed by an idea about fixing the person as a machine, but rather, is directed by supporting the person through their treatment. Integrative methods are about helping to hold the body together against the disintegrating and dividing forces of chemotherapy, surgery, and radiation by providing therapeutic support for all those parts of the body that are overlooked by the disease-focus in conventional cancer treatment.

Donald's comments thus reveal how the turn to evidenced-based medicine and the positioning of the clinical trial as the principle means of developing oncological therapies, procedures, or pharmaceuticals, degrades the value of experience, improvisation, and, in his words, intuition in medical practice and decision making. This is a pressing problem for integrative oncologists who work to incorporate healing techniques that are based on carefully cultivated practices of diagnosis and treatment—modes of medicine that are meant to meet the individual needs of their patients to help them feel “whole” within themselves, and cared for within their patient-physician relationship.

In discussing blueberries, and informed decision making, Donald expresses different ideas about efficacy at work in the demand for clinical evidence. The evidence required to deem a new chemotherapeutic drug, or combination of drugs, effective in the treatment of cancer, thus justifying the cost of its synthesis, its therapeutic utility, and its insuring, must demonstrate, within the context of a clinical trial, measurable effects. In this sense, efficacy might be determined by the quantifiable reduction in tumor size after treatment or a significant diminution of the number and presence of tumor markers—proteins found in the blood produced by cancerous cells or cells responding to cancer. But for integrative oncology, the efficacy of complementary healing modalities lies in how these forms of treatment help patients to live with cancer and its treatment. Thinking with Jain, this intention is deeply incommensurate with the paradox of oncology clinical trials—a

technique of knowledge production which relies on recurrence and death to demonstrate the effect of a new treatments.

The problem of evidence for integrative oncology is not that there is a dearth of research to support these techniques in the treatment of cancer. The Society for Integrative Oncology (SIO) has been engaged in producing comprehensive evidence-based clinical practical guidelines reflecting the current state of knowledge, and on-going research, regarding the use of an extensive array of complementary therapies (see Deng et al., 2009). The guidelines are written with an, “awareness of and sensitivity to the mental, emotional, and spiritual needs of a patient, combining the best of evidence-based, complementary therapies and mainstream care in a multidisciplinary approach to evaluate and treat the whole person” (Deng et al., 2009: 87, emphasis mine). This document, and others like it reference hundreds of peer reviewed articles published in conventional oncology and medical journals. The pressure that Donald and Felix, and many of the professionals I spoke with involved in integrative practices feel is related to the politics of the dominant evidentiary regimes in biomedicine.

I use this term with particular reference to its conceptualization by Natasha Myers and the METALab at York University in their organization of the Activating Evidence speaker series hosted in 2014 by the Technoscience Salon. They began the series with a premise that, “evidence is activated in contested fields of power” and that evidence takes on

“messy and multiple lives” with “historical, epistemic, and material contingencies.”¹⁰ In this sense, evidence is anything but a neutral measurement derived from unbiased studies—it is always already connected to regimes which condition and constrain what kinds of knowledge gets to count. The conflicts concerning the production of evidence for integrative therapies points to a tension between existing and emerging evidentiary regimes—forms of power and authority conditioned by the ongoing refashioning of medical knowledge and decision making as that which must be based in and on evidence derived from randomized controlled trials.

Disturbing evidence

In her research on the alternative medicine of homeopathy in the United Kingdom—a system of medicine that uses natural remedies to treat illness based on the guiding principle that like cures like—anthropologist Christine Anne Barry reminds that “the production of scientific evidence is a social as well as scientific process” (2005: 2648). Coproduction, as it is conceptualized by scholars of science and technology suggests that, “knowledge and its material embodiments are at one products of social work and constitutive of forms of social life; society cannot function without knowledge any more than knowledge can exist without appropriate social supports” (Jasanoff 2004: 2; see also Reardon 2004). Coproductive analyses resist separating “domains of nature, facts, objectivity, reason and policy from those of culture, values, subjectivity, emotion and

¹⁰ See <https://technosalon.wordpress.com/2008-9-salon/2014-15-activating-evidence/>

politics” (Jasanoff 2004: 3). Barry does just this in taking issue with the politics of evidence in the context of alternative medicines. She suggests that the call for clinical trial evidence, “originates in part from the motive of ensuring that alternative medicine ‘works’ before providing it in a publicly funded service,” but more importantly, “this call is also, in part, political and creates the agenda of controlling the threat posed by alternative medicine to the long-standing hegemony of biomedicine in the west” (2005: 2646). Amplifying the concerns of Felix and Donald, Barry argues that clinical trials, “necessarily entail reducing the complexity of the intervention to fit the reductionist nature of the RCT method” meaning that in practice several modalities might be combined for therapeutic purposes, but for the purposes of a trial, only one treatment can be tested at a time (2005: 2648).

This reductionism is precisely what is at issue for Gemma. Known within the North American oncology community for her non-profit organization which provides accessible reviews of scientific and medical research on complementary and alternative cancer treatments for patients, Gemma has been living cancer free for the past fourteen years after pursuing alternative treatment for metastasized breast cancer. Spirited and spunky, I met Gemma at the Society for Integrative Oncology (SIO) meeting in Vancouver, British Columbia in October of 2013.

Attended by a oncologists, physicians, pharmacists, patient advocates, nurse practitioners, naturopaths, acupuncturists, massage therapists, and herbal supplement representatives,

this conference took place in an luxury hotel in the West-end of Vancouver. The venue for these plenary lectures was almost comical, held in an overly ostentatious ballroom—its windows and main stage framed with towering cascades of gold brocade curtains, held in place with tasseled ropes of golden velvet. Breakout sessions, smaller workshops, and lunch lectures were held in adjacent rooms equally baroque in their styling.

Gemma was the first to the microphone during the question period, consistently asking for clarification, drawing comparisons between studies, and insisting on more accounting for the patient experience. I spent most of my free time during the conference trying to find her—my efforts largely truncated by the lineup of people who too wanted to talk to her. Gemma’s sense of what it means to produce evidence of the efficacy of integrative approaches is particularly compelling because she is someone who does not possess formalized training in medicine. She hasn’t been taught the same kind of fidelity to scientific methods, or interpellated by mechanical ideas about bodies in quite the same way. She came to her work as a patient advocate in and through her own experience of cancer, and the difficulty she had in obtaining information on alternative treatments.

In a conversation over Skype after the SIO meeting, which was conveniently enough convened around the theme of evidence-based medicine in integrative oncology, I asked what kinds of requirements she has for efficacy—what kinds of evidence she looks for in recommending or informing her readers about an integrative treatment.

I need a certain amount of evidence. It has to be enough that I can say ‘There's something here, we'll look further.’ I'm not interested in testimonies per say, but the only kind of testimony I'm interested in is what we call ‘patient centered’—that's when a person says to you, ‘Chinese herbs, I personally took them. I personally benefited.’ That's different than hearing a story on the internet, where you don't hear exactly the whole story—I don't accept that as evidence.

The stories that Gemma does accept as evidentiary she finds in oncology periodicals, on PubMed, at conferences where she networks with other patient advocates, physicians, and oncologists interested and aligned with integrative and alternative approaches. Telling me about how she reviews and makes decisions about what content to share with her patient audience, Gemma explains that,

After a while, they'll be a preponderance of people in real life who say ‘I tried this and I'm here.’ Or some variation on that, then we'll put that information on the website. For me, I'm not asking for level one. I'm not waiting for that. I will look at how much evidence, what kind of evidence, if the treatment is toxic, what the downside might be if we go with the treatment, how its presented in publications, those kinds of things.

Before I could ask her to clarify her use of the term ‘level one’—a shorthand I later learn that refers to Phase I of clinical trial testing—Gemma asks if I saw her speak at the SIO. I did a presentation called ‘Disturbing Evidence’ and it's about the loop holes that, you know, the gentlemen's agreement that we have we're just going to ignore the fact that some things don't fit into the way in which we're supposed to talk about evidence, but we ignore that. I'm very concerned about that because it affects so much—it's seriously problematic.

She continues,

I'm writing a paper that I've actually worked on since the conference. I want to show people that the reason that evidence is not all its cracked up to be has to be challenged because it's not quite right. I'm also pointing out that level one cannot be required because it will never happen no matter what we we're doing. We can't be saying 'You can't do this, you can't do that'— we can't have everyone saying, 'I can't recommend that because I don't have level one.' At the SIO when this would come up I would say, 'You're not going to have level one so what are we waiting for? What's the plan?' I don't know if you saw at the end of meeting with the executive board presentation, but they put something I said up on the last slide, which is 'What's the evidence for saying no?'

At that presentation, Gary Deng, a physician and integrative medicine specialist at Memorial Sloan Kettering Cancer Center in New York City, and one of the former board members of the Society for Integrative Oncology — a council composed of physicians and nurses with appointments at leading medical campuses in the United States and Canada — projected the most recent draft of the evidence-based clinical practical guidelines for integrative oncology (see Deng et al., 2009). Deng, who also happened to be the lead author on the guideline, invited the relatively scant audience to provide feedback on the evaluation criteria used in the guidelines—to help craft the most comprehensive recommendations possible. These guidelines use a grading recommendation scale from 1A to 2C, where 1A refers to “strong recommendation, high-quality evidence” and 2C references a “weak recommendation, low- or very-low quality evidence.” Very few of the complementary or botanical therapies listed in the guidelines received a grade of 1A, precisely because this grade is reserved for therapies that have completed all phases of clinical trial evaluation.

Reiterating Gemma’s remarks, Phase I clinical trials are notoriously challenging for studies of complementary and alternative medicine. Speaking of his own clinical research, Felix explained to me that many clinical trials on integrative interventions begin as small, generative pilot studies. These trials are seldom randomized, in part because of their experimental quality and because of the costs associated with such a measure. For these reasons, findings in these preliminary studies do not qualify as medical “evidence” for the intervention in question. Further many attempts at conducting randomized clinical trials on integrative therapies are stymied because of funding biases which favour trials that will sustain pharmaceutical interests, expressive of disease categories such as depression that can be treated with drugs (Dumit 2013; Barry 2005). According to Felix, getting to and past Phase I trials is increasingly difficult because many clinical trials in integrative oncology rely on the participation of patients who have completed conventional cancer treatment. As he thoughtfully says, “these patients are still overwhelmed from the whole experience of having cancer, and getting treatment. Even at the end of their treatment, they’re sort of like ‘I don’t know if I can handle this right now; maybe in a little while,’” hinting at the problem of participant retention.

While Gemma is unconvinced that complementary and alternative medicines, applied in integrative oncology, can be adequately studied using the clinical trial as a measurement, she nonetheless wants evidence for cancer therapies— a kind of evidence that might allow for kinder, more sensitive imbrications of medicine and capital in the US:

I want the standardization of the reporting of adverse effects. I want drugs that work better than the current. Right now, if you put an oncology drug through FDA it basically has to meet the qualifications of a two to three month disease free period. It may or may not pan out into overall survival, there's no guarantee. I just wonder how that happens—how can that be? It's wrong.

For Gemma, it is imperative to keep an open dialogue about the challenges of producing clinical trial derived evidence for integrative oncology:

And I think, again, if you're never going to get that level one, how can you ask for it? It doesn't make any sense. You have to go with some other stuff. That, in my mind, would be the preponderance of evidence of value. That we often have.

In what Gemma describes as a health care system where chemotherapy drugs can be put to market and incorporated in treatment regimens having only demonstrated evidence of an effect, not a cure, she shares a line of agitation with Donald: “So blueberries need a randomized clinical trial? I don't think so, but there is demand for that. We just have such a stupid system, we really do.”

But it is because of this stupidity, because of the rigidity imposed by evidentiary regimes that novel arrangements of evidence are forming. In integrative oncology we can see emerging formulations that broaden what counts as evidence. David's idea of evidence-informed decision making in the use of integrative regimens, or Felix's interest in

developing clinical trial methodologies attuned to the highly individualized qualities of integrative care point to this. Further, the continued attempt to find ways to measure the molecular or cellular effects of therapeutic practices like writing programs, yoga, or Chinese herbs that are otherwise rendered immeasurable by clinical trial studies is a defiant gesture against the politics of the current regimes of evidence.

Rewiring

I carried the “Your New Health Care System” chart around in my notebook for weeks after Ruth charged me with its care. The edges of the sheet bear the traces of its movement with me, my fumbling over and with it. By providing me with this piece of context, Ruth helped me adjust to studying a medical practice in a country that did not have socialized health care—a comfort I have come to know as a Canadian, and a security that initially prevented me from fully appreciating the problem of health care access in the United States.

When I asked Felix how the system of health insurance affects his integrative practice, he made clear to me that “It does.”

As you know, many of the things that we do at the Osher Center are not covered by insurance. Patients can see me, insurance will pay for that because it's still considered a medical visit, and I frame it in that way. But if I want to send a patient for acupuncture, or massage, or individualized yoga sessions, or anything else, the patient has to pay out of pocket. And that can be costly. Acupuncture is reasonable considering how helpful it is, how non-toxic it is, but it's still an out of pocket cost.

I have many patients who don't make a lot of income, so for them it's really challenging to do some of these treatments effectively. For example, they might do acupuncture only once every other week, when what might be required is once a week, or maybe even twice a week. We do what we can, but that probably limits some of the efficacy.

Clarifying that the frequency and consistency of treatment is more therapeutically effective, Felix expands on his point by offering a critique of evidence-based medicine that destabilizes its rhetorical charm of efficiency and efficacy:

I think it would be great if these services were covered by insurance. There's a bit of irony there too because their insurance will pay for very expensive conventional treatments, some of which don't have a high evidence-base, or a very good evidence-base. But you have some of these other things in integrative medicine which by comparison are very inexpensive that are not covered. There's a disconnect there between what's really practical and might actually be cost efficient for insurers and the companies that pay for that health insurance.

Felix comments in this regard are quite poignant, sounding the depths of just how deliberately managed that disconnect has been—a detachment that organizes the context of health care in the United States, where the availability of treatment options for people living with and dying of cancer is shaped by whether or not these therapies comply with the complex and specific interactions of knowledge and practice shaped by the evidentiary regimes of biomedicine.

In sum, the impediments of evidence and insurance that integrative oncologists encounter have more to do with stabilizing the health care system and its interfacing with the machineries of trial technologies used to produce market expanding facts about health and treatment than it is with assessing the safety and therapeutic efficacy of complementary, alternative, and integrative medicines. Surely the \$33.9 billion spent out-of-pocket on complementary and alternative medicine in 2007, accounting for 11.2 percent of the total health care expenditures in the United States, speaks to the confidence Americans have in these health care modalities (Barnes et al., 2008).

In her paper on “The Ethnography of Infrastructure” sociologist of science Susan Leigh Star argued the point that “when large epistemological stakes are at issue in the development of a system, one political tactic is to focus away from the larger question, and instead to seize control of the indicators” (1999: 388). The pressure placed on integrative oncologists to produce evidence supporting the efficacy of complementary healing techniques alongside conventional cancer treatments indicates this tactic—it diminishes the fact that patients are pursuing integrative approaches because they are dissatisfied with the treatment they receive in biomedicine or because conventional therapies tested by trials do not work. This move is evident in Ruth’s suggestion that writing as a form of healing does not fit in the current health care system because its an uninsured and unevidenced form of care—a position which dismisses the formidable proof evident in the consistent attendance of patients who bring their own pens and notebooks, who make clear that this intervention changed their lives, who write letters in

support of the program, and who articulate emphatically that learning how to write with the support of an oncology nurse provided them with the means to begin to heal after receiving their sixth consecutive cancer diagnosis. In this case the problem of evidence might be understood not only as a question of the kind of evidence needed, but of what quantity is required. When is there enough evidence?

The practice of integrative oncology is constrained by the political economies of evidence production and insurance in the context of the US health care system precisely because the challenges of making these healing techniques make sense to the measurements of the clinical trial makes evident the tarnish on this gilded standard, questioning what is knowable and indeed what can be known about cancer and its treatment—a disease that already confounds American medical communities.

In responding to Ruth's question about where integrative oncology fits within the US health care system I have explored how the process of integrating this field into biomedicine is constrained by existing regimes of evidence production. But I have also attempted to demonstrate that the recognition of the sensitivity of bodies to therapies that work on a subtle level poses epistemological and ontological issues which call into question the limits of evidence as it is conceived in and through the randomized controlled trial. In this sense, it is not that writing groups and or blueberries are incommensurate with clinical research; it is rather that the effects of these therapies are

not detectable using the forms of measurement predicated on mechanical ideas about bodies that constitute the evaluative methods of evidence-based medicine.

In the following chapter I continue to theorize the significance of the sensitive modelling of bodies and health at work in integrative oncology.

CHOICE

In a cafe just blocks from the capitol building in Sacramento, I sit sipping on an iced Americano, waiting for Nissa to arrive. I've grown fond of this space—it rests between the bus and light rail stops I use to get between several of my research sites. It is also an incredible intersection of interactions—the kind of place where government employees in pressed suits gather to talk shop beside women with newly manicured nails socializing over non-fat lattes while rocking their babies in thousand-dollar strollers, curtailing their cries so as to not disturb the writers in wrinkled shirts, protectively hovering over their MacBooks, performing productivity. It's also the kind of place where the baristas ask you to chose which of the several single-origin, fairly-traded coffees you'd like for your drink—the curated list of selections from regions in Africa and Latin America, artfully inscribed on the poured concrete wall behind the front counter.

Nissa enters the cafe dressed in charcoal grey yoga pants, a white tank-top, and a flowing linen sweater. Her look, her confident movement into this space resonates with the gendered, racialized, and classed assumptions we tend to tether to white women clothed in what we take to signify the privilege of unstructured afternoons organized by wealth and whim.

Seeing her scanning the room for me, I wave, collect my things, and nod toward a small table in the window. As we cross paths, she embraces me and expresses how happy she is

to have finally found time to get together. She and I met months ago when I began attending the free yoga class for cancer patients and survivors that Berdine developed as part of the supportive services programming at the UC Davis Comprehensive Cancer Center. Since then, we've been trying to find a time to meet and talk about her pursuit of integrative therapies throughout her treatment for breast cancer.

A single mother to a child with special needs, Nissa splits her time between caring for her son and volunteering at a women's shelter. Passionate, intelligent, and kind, Nissa has a fae like quality about her—a condition born of the blond pixie cut she keeps in celebration of recently returned hair, and by the intuition she carries into every conversation—acuteness without imposition. She's the kind of person who always brings an extra yoga mat “just in case someone needs it,” checks on everyone who participates in the class, and emphatically insists that, “there's no such thing as coincidences.”

Asking what she'd like to drink, she confesses to me that she's “never been in a place like this—I usually just go to Starbucks.” Slightly surprised, I suggest that we consult the barista for a suggestion. Deciding on an iced earl grey tea with frothed soy milk, we wait for her drink to be made. Standing at the bar, I compliment Nissa on her leggings, asking where she found them. “I bought these at Marshall's. All the other yoga clothing stores are too expensive.” Walking back to the table I notice that the edges of the handbag resting on her shoulder are frayed in a way that belies the brand—wear that would be repaired without question by the company.

Taking a few sips of her tea, Nissa asks me how my research is progressing, excitedly inquiring about all the new ideas I'm learning. I disclose that I'm currently trying to understand how integrative treatments fit into the political economy of health insurance in the US. With a knowing nod, Nissa tells me that insurance coverage means everything for the treatment a person can receive, "there is a big difference between the kinds of treatment you get at a state or government run hospital, university run, and private hospital."

Taking another sip of her drink, Nissa tells me that she has benefited immensely from having health insurance from a Preferred Provider Organization (PPO) rather than an Health Maintenance Organization (HMO):

That's like the top-tier insurance you can have. It means you can pick your own doctor—it doesn't have to be in a certain network, it doesn't have to be ok'd by the insurance company. With an HMO, it's restricted to a list of doctors, or a certain facility. But I can go anywhere.

Expounding on the process of selecting an oncologist, Nissa describes that,

Initially my primary care physician referred me to an oncologist who was a friend and colleague that he admired. I'm sure she was very intelligent and she would be a good doctor. But, I couldn't get my phone calls into her. The office staff was kind of bumbling, and not coordinated. I was very sick, I didn't have a lot of energy, and I was emotionally distraught. It's hard to follow-up, to call five times to get the nurse to take care of something when I was having an issue.

Pausing for breath and composure, I watched as Nissa straightened her back and folded her hands into her lap.

That office, didn't catch.... *they didn't even catch* the fact that I was going to have a double mastectomy. The oncologist scheduled me for a biopsy on my left breast, and it was really painful. I didn't even need to have that because I was going to have the whole breast removed anyway. She wasn't on top of that. Then when I went to have my mastectomy, she was supposed to have told my surgeon whether I was going to have chemo so they could put in a port.¹ She never got back to the surgeon, so by the time I went in she still had not gotten back. The surgeon was conservative and did not put a port in because they couldn't get a hold of the oncologist.

Requiring a course of chemotherapy after her surgery in order to reduce the chance of the cancer returning, Nissa sought a recommendation for a different oncologist from her surgeon. Finding an oncologist who would communicate effectively with Nissa and the medical team responsible for her treatments was critical. However, as a Reiki practitioner, Nissa also wanted an oncologist who understood and supported the ideas she held about her body and about health as someone already sensitized and invested in her capacity to be affected by positive thinking and energy work. Reiki is a Japanese healing practice premised on the idea that all living beings are inspirited with a “universal” life energy referred to as Ki (Herron-Marx 2008: 37). Illness and disease in the context of this modality are the result of the imbalance of this energy which courses through and surrounds bodies. Attuned to these worldly energies, Reiki practitioners act as facilitators,

¹ Port, short for portacath, refers to a medical device used on patients receiving frequent or high doses of chemotherapy. By connecting a catheter directly to one of three veins located below the clavicle (either the jugular, subclavian, or superior vena cava), the port allows for the immediate delivery of chemotherapy drugs to the circulatory system without incurring chemical damage to skin or muscle tissues. In the context of Nissa's treatments, a port would have made her chemotherapy appointments much simpler.

rather than healers—sensitized to these ebullient forces, in practice they become conduits, using their hands to realign the energies of their patients (ibid).

With the referral for a second oncologist, Nissa tells me that,

I went into that consultation thinking, ‘I’m going to screen this person because they’re going to work for me, and I need to make sure they’re like a match for me.’ I wanted to be positive. I didn’t want them to go in and go ‘You have this percent change of dying; you have to do this and that.’ I wanted someone who would support me in the mind-body connection, in wanting to heal, and wanting to do it positively. The oncologist I found was really great for that.

In contrast to her experiences with a conventional oncologist, Nissa detailed that her integrative oncologist,

Actually, spent time asking me how my family was—how my son was—how my relationships were. She really wanted to know the whole me. I guess, that’s not that common, and she’s known for that. She had previous experience in working with at-risk families. She was familiar with the kinds of issues where mental-emotional health really matters. She was very attentive to that part. On days when I would go in there crying, or worried that I’m going to have a bad hair day because I’m not going to have any hair, she was there and would spend all her time, and would really take care of all of that for me. She treated me as a whole person.

The sense of being treated as a “whole person” was also made possible by the resources available to Nissa under the integrated “globular health care” treatment model. At the cancer center where she received treatment, Nissa had access to a social worker and a psychologist. These professionals were provided without the financial or energetic costs of coordinating such council.

What's really great is that social worker is a survivor herself. She can empathize, and she has so many resources. It's been so great because, I found out from her about the yoga class, and I found out from her about the no-cost oncology massage. Otherwise, people are piecing it together, trying to grab from here and there because it's not all in one place.

Nissa's comments track through the different kinds of care she received from both conventional and integrative treatment for cancer. With an integrative oncologist, Nissa felt as though the emotional and experiential dimensions of her cancer were not treated separately from the cancerous growths in her breast—a quality that was instrumental in her living through cancer.

The choice to pursue integrative oncology was afforded to Nissa because of the patient-consumer model of health care at work in the US, where for those who can pay for medical treatment is rendered a commodity, what a patient can pay determines the quality of care they receive.

It might seem that Nissa was able to access integrative care because of her wealth—that she has the economic resources to purchase exceptional insurance coverage and leverage that to make demands for better or different treatment—her economic privilege, a catalyst in deciding to find a physician who would treat her on her own terms. This is too easily read onto her body.

What I learn over coffee, and what I become aware of in our subsequent time together over lunches, text messages, and in the intervals before and after yoga class, is that Nissa's pursuit of integrative oncology was less a choice enacted by her purchasing power than it was of favourable conditions—that she happened to receive her diagnosis while she was still married and able to access the health insurance provided by her husband's employer. Without these benefits, there would have been no choice for Nissa to engage in integrative treatment—it would have cost too much.

While some insurance providers in the US cover complementary therapies such as acupuncture, many of the therapies that integrative oncologists practice or recommend to their patients are not covered. The implementation of the Patient Protection and Affordable Care Act (PPACA) is changing and will continue to change the landscape of insurance coverage in the US. Expanding eligibility criteria for state-sponsored and private insurance will provide many people with coverage, and the resource to make choices regarding their care. Nevertheless, there have been and will continue to be people who will be diagnosed with cancer and who will have to pay for their conventional care, and its associated expenses of lab testing, medical imaging, and prescription medications, out of pocket. What choice do they have to pursue the promise of integrative oncology?

With Nissa's account, the choice to seek integrative treatment is here understood as governed by class, which is itself always already conditioned by race and gender. In the context of the American health care system, it seems that integrative oncology is

something only those with economic resources can access—a practice which interpellates those poised to pay cash for their medical care, particularly those already investing in complementary and alternative medicine. That this choice should be so contained by economic privilege is deeply troubling when held alongside the testimonies of so many who have suggested that integrative interventions makes a difference for how people live and die with cancer.

CHAPTER THREE: SENSITIVITY

On Monday nights around 4:00pm I still feel a mixture of excitement and trepidation stirring in my tissues. These forms of anticipation and uncertainty erupted during my fieldwork, and linger on despite distance and time—the affective charge of having practiced yoga on a weekly basis with people in recovery and in active treatment for cancer

The moments before class were always animated by conversations between participants concerning the events of the previous week—checkups, deals found in department stores, smoothie recipes, family outings, and complaints about the weather. An important space for the seven women who regularly attended this class, many of these discussions would happen with yoga mats in hand—everyone too excited by their company, their return, to drop their things before catching up.

These exchanges would begin to dissipate when Anna turned on instrumental music, signalling the impending start to class and the time to set up one's mat. Each of these women had a designated spot that was left untouched if someone was absent—an informal kind of attendance keeping.

Two months after I began attending the class, a new participant joined the group. She arrived in all black with a taupe coloured scarf shrouding her head. Gregarious and kind,

Jacqui introduced herself first by her name and then by her cancer. When Anna asked how she found out about the class, Jacqui mentioned that there was flyer in the information packet she received from her oncologist after learning of her diagnosis. With a knowing nod, she and Anna began to joke:

“Oh you have cancer, here's a booklet!”

“Yeah, oh perfect! Just what I needed—a reading package!”

I listened as dry humour turned to tumor stories exchanged between Jacqui, Anna, and the other regular participants, Holle and Nissa. At one point Jacqui turned to me, inviting me to tell my neoplastic narrative. I redirected the conversation to my project, and she lit up hearing that I was participating as part of my research on integrative oncology. “That is so great. I’m really glad you’re studying that!” Her sentiments echoed those I’ve heard from the others—a sense of relief and recompenses in knowing that people outside of this room, and this Cancer Center, are taking seriously that there is more to treating this disease than cuts, burns, and packages of poison.

As Anna motioned to begin the class, Jacqui unrolled her mat where I normally practiced—a spot beside Nissa, designated for me on my first day. Smiling, Nissa motioned me to the space behind her and beside Holle who practiced with the help of two chairs.

Unfurling my mat and finding my way to a seated pose, I noticed that Jacqui had

removed her sweater revealing a black canvas pouch around her waist. A thin piece of medical tubing stemmed from the pack, stretching up and under her tank top, connecting to a small port tapped just below her clavicle. In seated pose, we drew in several breaths, chanting together. As the class continued, Anna took us through a flow of poses, the pace between each slowed to accommodate healing bodies. I watched Jacqui bend and fold with pieces attached to her body.

As the class came to a close, Anna asked the room to find their way to Savasana (*Shavasana*)—a position which takes its name from the Sanskrit words *śava* for corpse, and *āsana* meaning seated pose.¹ Savasana is often practiced at the end of yoga sessions as repose from all the stretching, twisting, contracting, and inverting constitutive of yogic movement. It involves lying on one's back, eyes closed, arms and legs released to make contact with the mat, palms facing up, feet gently turned out. In my experiences of practicing many different kinds of yoga in and beyond this class, savasana has been positioned as a kind of surrendering into stillness—a gesturing toward death, toward the end of the body in order to understand how it was lived and experienced through the practice. This symbolic ending gives way to a beginning, or rather, a coming into an awareness of the sensations of being in and of a body as breath slows and tissues soften. As a liminal state, savasana cultivates sensuous forms of attention required to embody the

¹ This pose is also called *Mrtasana*, meaning death pose. *Mṛta* is the Sanskrit word for death.

connections between mind, body, and spirit pivotal to the projects of modern postural yoga.²

When instructing the class to move into this pose, Anna often offered the gentle reminder that this supine position is one of the most challenging to hold—that many people feel discomfort or disinterest in being asked to remain still and to calm their mind—to focus on their bodies as opposed to their grocery lists. She sounds these reminders as a form of encouragement, soliciting the class to capitulate to the difficulty of savasana—careful to only ever refer to this position by its Sanskrit name, avoiding the anxiety of asking a group cut by cancer to perform the corpse pose.

Lying in savasana, I could feel the heat between my body and the mat, the film of sweat along my back beginning to evaporate. In the quiet that descended over the room as each person acquiesced to the demands of this pose, I heard a new sound. Amongst the breathing of these seven women, I could discern a different pace of inhalation and exhalation. Focusing my attention on the rhythmic clicks at the ends of this breath, I realized it was emanating from the plastic lungs in Jacqui's pouch. It was as if the pump contained in her pouch, the thing treating her cancer with a constant infusion of chemotherapy, was participating in and with this pose through its mechanical respiration.

² 'Modern postural yoga' is a term which speaks to the uptake and practice of yoga in western/ized contexts over the last one hundred and fifty years (White 2012; De Michelis 2004). These forms of yoga are distinguished by their emphasis on the *āsanas* (postures) and the physicality of yoga practice (ibid).

I was struck by the intimacies between this practice, that machine, and her body—distracted by the presence of a device that was keeping Jacqui alive and able to attend yoga class—engrossed by the thought that a conventional oncologist had supported her interest in attending this class, pump and all.

In the company of that metered breath, I became attuned to how integrative approaches to oncology reconfigure biomedical bodies. With Jacqui's presence, I began to understand that the integration of yoga and Ayurvedic medicine, Chinese medicine and acupuncture, botanicals and supplements in the integrative treatment of cancer does not require that patients leave their machines at the door or abandon their mechanical embodiments. Nor are physicians compelled to discard their mechanized and reductive medical models or methods. Rather, the use of these complementary healing modalities alongside conventional oncological treatments pulls biomedical models into relation with other ideas about bodies and disease—models that consider the psychosomatic, affective, nutritional, and spiritual dimensions of cancer. It is in this encounter between biomedicine and complementary therapies in integrative oncology where different kinds of bodies are being made, and different paths to treatment are being taken—materializations that do not require mind and body to be oppositional, or that spirit and flesh be separated. These engagements, which I began exploring in the previous chapter as frictive and tense (c.f. Tsing 2005) concerns for the evidence and efficacy of integrative interventions, reveal productive proliferation of ideas about the sensitivity of

bodies propagating in these encounters—ideas about treatment that offer an otherwise for how it is that people might survive oncology.

...

In this chapter I follow formations of *sensitivity* by examining how integrative oncologists become *sensitive* to different models of bodies and disease derived from Ayurveda and Chinese medicine through integrative training. I focus on these medicines specifically because they have been the most influential in the modelling of bodies, disease, and treatment in integrative oncology. In this sense I take direction from anthropological literature on bodies and embodiment in the context of medicine, science and technology, that suggests understanding how bodies are conceived requires analyzing the disciplinary practices and institutional spaces pivotal to producing such ideas as well as reviewing the metaphors and imagery which connect social symbolic orders and biological materialities (Lock and Scheper-Hughes 1987; Martin 1994).

I develop the idea of *sensitivity* as a means of marking the multiplication of ways of knowing and treating bodies propagating in integrative oncology. Returning to Tsing's notion of the frontier I explored in the Introduction, I want to consider how the idea of integration is itself a force of friction, creating a space of encounter where “new arrangements of culture and power” (2005: 5) are made in the meeting of conventional oncology and complementary medicines. In the messy, bumpy, and ongoing work of

making complementary modalities make sense in the biomedical treatment of cancer, sensitivity takes shape as a quality or condition of being responsive to the need for different ideas about bodies and their treatment. I attempt to tease out how this regard for the possibility for an otherwise of oncological treatment is experienced by integrative oncologists in and beyond their training.

In this chapter I also examine what it means to activate the medical modalities of Ayurveda and Chinese medicine in the service of sensitizing oncologists to ideas about bodies, disease, and treatment. I also consider what gets overlooked or problematically positioned in the packaging of these practices of integrative oncology, asking what expressions and forces of *insensitivity* also arise with the incorporation of these fields into biomedicine?

Contact

Recall from the previous chapters my conversations with Felix and Donald—two oncologists practicing integrative cancer care at the the Osher Center for Integrative Medicine in San Francisco. Felix and Donald are both graduates of a two year fellowship in integrative medicine offered by the Arizona Center for Integrative Medicine (ACIM) at the University of Arizona. The leading program of this kind in the United States, the fellowship is a combination of distance learning and residency available to physicians, pharmacists, nurse practitioners, nurse-midwives, medical students, medical residents,

and osteopaths. Speaking to its prospective students, the program’s website outlines this program as that which,

Re-energizes, restructures and reframes your perspective of medicine. It teaches a new way of caring for patients, with emphasis on the individual, not simply the disease - and on prevention, not just treatment. Through the Fellowship, you will be able to continue your medical practice while studying, and apply what you learn immediately.³

Felix and Donald each pursued training in integrative medicine because of a felt sense that what they had learned in medical school limited the kind of treatment they could provide for their patients—a feeling that sat with them, weighing on their practice, until they encountered ideas and opportunities that resonated with their reservations.

In Chapter One I described how Felix felt compelled by the “idea of incorporating other medical traditions”—a notion that was conditioned in part by his upbringing in a household where Ayurvedic medicine was practiced. Felix revealed that there were dimensions of his medical training he “didn’t connect with” and as a result he found himself “feeling a little bit unsatisfied with the care I was providing because I was trained in Western medicine.” Similarly, Donald told me that in the middle of his medical career—one that began much earlier than Felix’s—he started to think that “medicine was on the wrong path”—“that there were other ways to help people than to write a prescription for a drug.” It was after meeting Andrew Weil, the physician who founded the ACIM, that Donald was presented with the possibility of getting on a different path, one which began

³ See <http://integrativemedicine.arizona.edu/education/fellowship/>

with the fellowship. Felix would also follow this route years later during his hematology and medical oncology fellowship at the University of California at San Francisco where he met oncologists who had been trained at the ACIM and were practicing integrative cancer treatment. In Andrew Weil, I find a common connecting point between these integrative oncologists, and a foundational figure in the shaping of this field.

Weil of fortune

In his writing on integrative medicine, Baer describes Weil as one of the “most visible spokespersons of the holistic health movement” (2004: 119)—a prominence that might account for the difficulty I had getting a hold of him for an interview.

Weil established the ACIM in 1994 in response to the growing interest in integrative medicine in the United States, and the need for an institutional context in which to professionalize this approach to practice. Baer’s description here betrays some of the particularity of how Weil positions integrative medicine in the holistic health landscape. Weil contends that integrative medicine has developed in relation to biomedicine as that which responds to the escalating costs of high-tech medicine, and the dissatisfaction of patients with the quality and calibre of care they receive (Abrams and Weil 2009: vii). In a volume on integrative medicine that he edited with Donald, Weil distinguishes integrative medicine from holistic health by arguing that integrative medicine “is not synonymous with alternative medicine or with CAM (complementary and alternative

medicine),” rather it makes use of “ideas and practices currently beyond the scope of the conventional, but it neither rejects conventional therapies nor accepts alternative ones uncritically” (Abrams and Weil 2009: vii, 3). By adapting medical modalities categorized as complementary into biomedical practice, Weil suggests that integrative approaches, “seek to restore core values of the profession that have eroded in recent times,” by practicing patient-focused rather than disease-focused medicine, and promoting the importance of supportive doctor-physical relationships (Abrams and Weil 2009: 4).

I sent a lot of requests to speak with Weil, and neither he nor his staff sent me a reply. But after navigating through countless websites and articles speaking to his prominence in and for integrative medicine, I felt like I’d met him. It’s no exaggeration to say that there is an abundance of information produced by and about him that conjures his physicality — a sense instantiated by all the articles adorned with images of Weil gazing toward the future, his mirthful grin visible through his large bushy white beard, enacting yoga postures in short sleeve linen shirts, standing in Birkenstock sandals, jeans, and a tie-dye shirt beside garden beds lush with leafy greens, or set against the tents of a farmers’ market, visibly delighted to be holding a freshly carved coconut, the airbrushed image of a wolf in a lightening storm on his t-shirt discernible behind his proud display of the fruit.

The information attached to his name figures Weil as every bit the embodiment of the things about “holistic health” that make people itchy and interested. He has the affective charge of someone who cares deeply for and about his practices, the people he treats, and

the plants he uses as medicine. Consistently documented in casual dress, there's an air of approachability to his image. Leaving his white coat and stethoscope outside the frame, it is as though he has cultivated this appearance for audiences whose conventional medical experiences have made them cautious of formalities, or for those who distrust that biomedicine has their best interests in mind. His website is a labyrinth, rich with material categorized under the topics of *healthy aging*, *spontaneous happiness*, and *balanced living*.⁴ His website also provides more personalized content: the "Ask Dr. Weil" section allows readers to solicit responses for their health queries—answers which are archived under groupings such as *foot health*, *gardening*, and *colds and flu*. His website is further segmented by the "Dr. Weil's Blog"—a compilation of daily responses to popular press provocations regarding the benefits and risk of natural health products and practices, as well as more advice, videos, and updates regarding the science of supplements. This website also offers a marketplace where readers can purchase his brand of supplements and other forms of content curated by Weil. And if all of these forms of exposure weren't enough, every section, tab, and post of this elaborate realm is punctuated with links to his social media securings on Facebook, Twitter, YouTube, Flickr, Vimeo, and Pinterest.

In charting Weil's integrative trajectory, Baer notes that the physician studied biology and medicine at Harvard in the 1960s, interned at Mount Zion hospital in San Francisco, and worked at the National Institute of Mental Health (NIMH), where he began to study the medical application of cannabis, leaving shortly after his appointment when this research

⁴ See www.drweil.com

interest was met with resistance (Baer 2004: 120). I learned from my discussions with Donald—whose studies in 1990s on the use of cannabis in the treatment of AIDS wasting syndrome were instrumental in shifting the tone of research regarding these plants—that during Weil’s tenure at the NIMH, the only way to access cannabis for research purposes was through the National Institute on Drug Abuse, and for projects focused on examining the plant as a “substance of abuse.”

After leaving the NIMH, Baer describes that Weil took up practices of yoga, vegetarianism, and meditation. In 1972, Weil wrote his first book *The Natural Mind: An Investigation of Drugs and the Higher Consciousness*— his treatise on the use of alternative healing methods, including the benefits of occasionally using consciousness raising or psychoactive substances. In this and the twelve books that he has since published, he has variously elaborated on his view that diseases are rooted in lifestyle and that coming into practices of healthy living condition the possibility for “spontaneous healing.” For Weil, this idea refers to the way in which “the body has an innate capacity for healing, self-diagnosis, self-repair, regeneration, and adaptation to injury and loss” and that the “excessive” use of surgery and prescription drugs in the biomedical treatment of illness and disease diminishes this ability to self-heal possessed of all bodies (2009: 3). It is this evocative perspective, along with the focus on the “whole person,” lifestyle, and the importance of supportive doctor-patient relationships which ground his conception of integrative medicine and his conviction that, “the primary goal of treatment should be to support, facilitate, and augment that innate capacity” by utilizing the healing methods

from complementary medicines (2009: 3). Where Weil's writings give way to captivating ideas about the importance of "the wisdom of religion, and all the techniques of magic" to and for medicine, Baer's reading of his work points to the way in which Weil also draws on, rather than against, biomedical models of bodies to make his arguments (2004: 124). Baer cites one particularly interesting example where Weil conceptualizes health as,

The efficient operation of all of [the body's] systems. A useful analogy is the engine of a car. When all components are doing what they should be doing in just the right way, efficiency is maximal, and operation is quiet, producing a 'contented' purr that you rarely notice (Weil in Baer 2004: 124).

The presence of mechanical metaphor in this definition certainly speaks to the hold of mechanistic thinking over how biomedical practitioners make sense of bodies and health discussed in the Introduction and in Chapter Two. It provides a reminder of his medical training and his argument that integrative medicine is "conservative in practice, favouring less invasive and drastic treatments over more invasive and drastic ones whenever possible, and it is fiscally conservative in relying less on expensive technology and more on simpler methods, *as appropriate to the circumstances of illness*" (Abrams and Weil 2009: 4). Moreover, the presence of this analogy signals a significant commingling of ideas that are critical to the kind of pedagogy that Weil has developed for the ACIM, and critical for how the sensitivity of the body-machine of biomedicine is being recognized in the practice of integrative oncology.

Programming possibility

Under Weil’s directorship, the ACIM developed its unique two year fellowship in integrative medicine, taking on its first cohort in 2000. The fellowship involves one thousand hours of “blended learning,” incorporating three weeks of residency with web-based modules utilizing videos and podcasts, research reviews, and case studies to explain and teach the application of different medical modalities within biomedical practice. As mentioned previously, this program is oriented toward biomedical professionals as a form of continuing education. Since the inception of the fellowship, the ACIM has developed an integrative medicine distinction program for medical students at the University of Arizona College of Medicine—an independent learning program meant to supplement conventional curriculums with information on many integrative medical modalities and their medical application. The ACIM has also created the curricula for several integrative medicine residency programs that have been implemented in major medical centers across the United States, designed to educate and support residents interested in incorporating integrative practices into their residencies in primary care, pediatrics, and family medicine.

Writing as the director and as an instructor at the ACIM, Weil describes the curriculum as that which,

Covers the philosophy of integrative medicine as well as broad subject areas currently slighted or omitted entirely from conventional medical education. These include nutritional medicine (e.g., designing an optimum diet for health and longevity; using dietary supplements appropriately; using dietary change as a primary therapeutic strategy, etc.), botanical medicine, mind-body medicine,

manual medicine (such as osteopathic manipulative therapy), spirituality in health and illness, environmental medicine, and overviews of traditional systems of medicine (like Chinese medicine and Ayurveda) and CAM (ibid).

With regard to “traditional medicine and CAM” Weil suggests that the program in integrative medicine teaches, “the philosophies behind these approaches, the evidence base for them, their strength and weakness, and their appropriateness or inappropriateness in specific health conditions. We also cover the training and credentialing of CAM practitioners and information on how to find and refer to competent ones when appropriate” (ibid). Weil also emphasizes that, “Training at ACIM requires fellows to assess the evidence-base for all recommended treatments, including conventional ones,” aiming to cultivate “future researchers” who will go on to generate “new measures” for assessing integrative treatments regimens (Abrams and Weil 2009: 5). This training enjoins students to look at conventional medicine to see where it could be open to reinterpretation in and through therapeutic insights derived from complementary medicines. Thinking back to chapter three, I read this instruction as revealing the importance of making integrative oncologists who will both participate in and push back against the evidentiary regimes of biomedicine.

In my conversations with Donald, he was somewhat reluctant to talk about his training experiences at the ACIM, redirecting the discussion to focus on how he educates his patients on healthy eating and living as part of his integrative practice. As evidence of this, he provided me with the same information packet he gives to all his patients—a

thick blue and white folder inscribed with the Osher Center's insignia, filled with photocopied articles on a range of topics such as nutrition, anti-inflammatory diets, and organic food, several of which bear Weil's authorship. The folder also contains lists of stress reduction techniques, Donald's favourite books on integrative oncology, a product guide for medicinal mushroom supplements, and catalogues of guided imagery and meditation DVDs for a range of afflictions. Underscoring his instructional intent, Donald explained that he gives this package to patients after their first consultation in order to help them learn more about his approach to integrative oncology. The tone of the pieces speak to this as each article is written in a clear, accessible language, organized into small, digestible paragraphs perfect for the swipe of a highlighter. The folder even reads like a course pack, each article building and extending the content of the previous piece.

Inasmuch as this kit provides insight into the kind of patient Donald is try to make, this package is demonstrative of the kind of physician Donald has become, and of the kinds of sensitivities he has cultivated in and through his integrative training. This folder has been curated with an attention to the experiences of living with cancer, providing information that speaks to the dimensions of the disease unaddressed in conventional oncology.

Pulling together pieces on diet, exercise, and spiritual counselling, Donald's efforts here reveal how his training sensitized him to the manifolded needs of his patients. Donald knows that his patients with estrogen-receptor-positive (ER+) breast cancer need hormone therapy, provided by drugs like Tamoxifen, to block the estrogen receptors on the surface of the tumor which account for its growth—but he also knows that these

patients will require surgery to remove their tumors, and that talking to each about their fears around this procedure will ease their anxieties. Moreover, he knows that the hormone-blocking drugs he will prescribe to these patients will cause fatigue, and that some of his patients will experience a shift in their mood or outlook on life such that recommending acupuncture or encouraging his patients to pursue gentle forms of exercise like walking and yoga will help to alleviate the effects of these treatments. Donald's approach then treats both the mechanics of the disease and well as its intangible, emotional dimensions.

Felix, on the other hand, spoke more directly about his training at the ACIM, and how it changed his oncology practice. Describing the fellowship, he explained that,

It gives you an overview of mind-body medicine, some traditional medicines like Ayurveda, Chinese medicine, and manual medicine. After completing the program, not only do you get a sense of the vast expanse of other possibilities, but you also connect with people who are also interested in this stuff, and faculty members there who have been doing this there for some time. It's kind of is inspiring, and its motivating—it tells you and shows you that you can do this, because there are other people doing this, and it's a field in and of itself.

The possibilities that Felix speaks of concern the many ways of understanding and treating bodies revealed to him in his integrative training:

Coming out of that fellowship I had that energy, and that inspiration that I can use these things in my practice and I can help patients with them. And then, with my history, and interest in Ayurveda, I thought well, if I can do integrative medicine, why not Ayurveda? So then I pursued a two year training course in Ayurveda to learn the clinical skills, and I haven't looked back since.

Integrative training affirmed for Felix that there are different explanations for illness and disease, and that other therapeutic models could be combined with the material focus of biomedicine to generate an approach to treating cancer that does not treat the body as separate from the mind or spirit.

Integrative instruction

In order to develop a more nuanced sense of how integrative training attunes practitioners to the “possibilities” that other forms of medicine pose for their oncology practices, I enrolled in two online continuing education courses on integrative oncology offered by the *ACIM: Introduction to Integrative Oncology* and *Breast Cancer: An Integrative Approach*. While these courses are open to the public, they are designed for medical professionals and make extensive use of technical language as they provide an “overview of integrative modalities and treatments that are beneficial for cancer care for patients in active treatment and survivorship, as well as prevention strategies.”⁵

Mirroring the “blended learning” of the fellowship program, the content for both classes is composed of written descriptions, case studies, anatomical illustrations, instructional lectures and videos, and photographic images of people, foods, and supplements. For the Breast Cancer course, each of its seven modules are directed by different virtual

⁵ See http://integrativemedicine.arizona.edu/online_courses/intro_oncology.html#credits. The quoted material that follows is taken from online course content that I had access with my course enrolment.

instructors—fellows of the ACIM whose images and credentials anchor the start of each section. Revealing his prominence within the field and within the ACIM, Donald was the only instructor for the nine sections of the *Introduction to Integrative Oncology* course.

These courses each begin with a short explanation of integrative oncology, leading into a discussion of the value of this practical perspective. Expressive of a pedagogical concern for how the integrative approach can be applied in the treatment of cancer, both courses stress the point that many patients are already pursuing complementary and alternative health care modalities out of personal interest and are not disclosing their activities for fear of derision or the pressure of cessation. Both courses suggest that patients seek medical care in these fields as a means of regaining control in the destabilizing wake of a cancer diagnosis and the clutching currents of predetermined treatment protocols—that being able to choose a therapy based on interest or perceived benefit provides patients with a modicum of agency. In this regard, the courses underscore the idea that if an oncologist possesses training in integrative medicine, their patients will confide such activities, creating a working relationship where possible “drug-CAM therapy interactions” can be avoided. With training in integrative oncology, the oncologist will be able to recommend evidence-based, or evidence-informed, therapies that are compatible with conventional treatment regimens, perhaps proving to be more potent than what the patient might have selected on their own.

Moreover, the discussion of the importance of integrative training also allows for the drawing of boundaries between complementary and alternative medicine. Positioning integrative oncology as “combining of complementary and conventional therapies,” the courses make clear that alternative medicine or any therapy “eschewing conventional cancer treatment,” not only falls beyond the purview of this practice, but is deemed unsafe by the standards of this field.

For the purposes of understanding how sensitivity is cultivated in integrative training, I hold more closely to the *Breast Cancer* course as it provided a depth of content and detail not present in the introductory course. To that end, the course begins by emphasizing that in order to use an integrative approach, the oncologist must “deeply understand how patients live their lives—their diet, exercise and habits, day after day, week after week—through careful interviewing, questionnaires, and other information gathering.” The course instructs practitioners learn to “express empathy” in order to “create a foundation for the physician-patient partnership” that is pivotal to integrative oncology. This practice of listening and avoiding imposition requires that the oncologist share in the feelings and everyday experiences of their patients, getting to know how they live and how they want to continue living with and through cancer. This helps to shift treatment practices from being disease focused to patient focus, enabling the oncologist to begin to learn what complementary therapies and supplements would work best for their patient. With this mode of relating, the oncologist is more clearly positioned as a facilitator, and in that

sense, better able to motivate the patient to make changes in diet, lifestyle, and behaviour toward integrative ends.

The *Breast Cancer* course in particular focuses on the contribution that integrative methods can make in treating the stress experienced by patients with cancer. It suggests that, “stress is a major factor in the life of people living with, and even beyond cancer.” Stress here is understood as a feeling that does something to the matter of the body—an experience of intensity that has bearing for how cells, tissues, and organs function. While stress has long been an object of medical concern (see Cannon 1927, Selye [1956] 1978, Maté 2003), the idea that oncologists ought to “honour” and develop an “attention” to how stress affects their patients’ lives and provide interventions for those effects as part of an oncological treatment regimen is a novel configuration of concern. Returning to my conversations with Felix, he explains how this regard for stress is both significant and contentious:

I think that's a controversial issue in oncology, right because a lot of people don't want the idea out there that stress can be linked to cancer. And people have different reasons for that. Patient advocates don't actually want that out there because they don't want patients to think they to blame for their disease. Even though, truly, how can we be blamed for stress because so much of it is out of our control. But there is this sense, or at least, I used to hear this more years past, that you know, ‘How can you blame the patient for their cancer?’ And that's not exactly what that research is saying, but that's one of things that's been raised. And then other people will argue that ‘Well stress is so common, and cancer is so common, but that doesn't mean they're causally related.’ But then you see all of this research that is coming out, showing in animal models, and even in human studies, that there is this emerging evidence that stress does play a role, may play a role in cancer, that there's more and more evidence for that.

In the pedagogical materials of the *Breast Cancer* course, stress is positioned as having a “complex relationship” with cancer—that “how we eat, move and handle stress can create cellular and systemic disturbances that eventually lead to this disease.” The course indicates that the cascade of biological changes in the immune and endocrine systems of human bodies generated by feelings of stress, anxiety, and fear can create conditions for the onset of cancer. It also argues that, “Patients who are finally diagnosed with breast cancer have suffered from the stress generated by diagnostic procedures, making decisions about treatment options, and the impact of a cancer diagnosis on professional and personal life. The stress can generate multiple systemic biological changes that cause physical and emotional dysfunction.” Where these ideas were raised in the instructional material, recommendations for mitigating stress derived from complementary medicines were offered. Indeed, the very idea that stress could be toxic for human bodies is an idea that seems to have taken shape in relation to the incorporation of complementary medicines—of practices that extol treating diseases by bringing bodies back into balance—into even-keeled states where mind and body are renewed in their connection.

The influence of Ayurveda and Chinese medicine in these ideas is especially salient. Ayurveda derives its name from the words *ayur* (life) and *veda* (knowledge). In contrast to the contained bodies of biomedicine, it conceives of bodies as “fluid and penetrable, engaged in a continuous interchange with the social and natural environment” (Langford 2002: 11) Ayurvedic bodies are fluid, “streaming with temperatures and aromas, eloquent with densities and moistures, where illness is communicated in a teeming polysemic

lexicon of air currents and blockages, emotions, and digestive fire” (Langford 2002: 22). Disease in Ayurveda is produced when the *doshas* (doṣas) of *vata*, *pitta*, and *kapha* become unbalanced—when one or more of the substances which constitute the body become “angry” or “overwrought” (Trawick 2010). Treatment in Ayurveda thus requires bringing these doshas back into balance. The bodies of Ayurveda are mercurial—no two are the same precisely because the configuration of the doshas is different for each person.

In Chinese medicine, bodies are animated by *qi* (chi)—a form of energy that circulates through systems of meridians located in organs of the body. Qi is understood as the “origin of the world, its material [makeup], that which fills out the entire universe, the finest matter whose movement does not cease—these [all] are generated by the interactive transformations of qi” (Yumin in Barnes 2009: 147). Qi reveals a conception of the dynamic quality of matter insofar as the qi that animates the world is the same qi that animates the life processes of bodies. Disease in the body is not separate from how a body is in the world—not separate from what is experienced, felt, or ingested— because both are animated by the same energy.

In various sections throughout the course, “mind-body” techniques such as meditation, mindfulness-based stress reduction, support groups, yoga, self-hypnosis, deep breathing, and guided-imagery are offered as useful interventions. These methods also appear in other sections alongside herbal supplements as tools for alleviating the pain, and fatigue

brought about by chemotherapy and radiation treatments. The positioning of these therapies as useful interventions in the treatment of cancer demonstrates an emergent consideration of the sensitivity of the biomedical body. By incorporating different ideas about bodies that populate the Chinese and Ayurvedic medicine, biomedical practitioners can begin to consider how the physical machinery of the biomedical body might be affected by intangible things—dimensions that matter in the treatment of cancer.

The whole difference

Here again I come back to Jacqui, her pump, and her presence in the yoga class. The idea that someone in active and audible treatment for cancer would benefit from participating in a yoga class gestures to the formations of sensitivity that I see in integrative oncology. Sensitivity signals an active and ongoing negotiation concerning the limits of the biomedical model for helping oncologists apprehend and treat cancer. It also gestures to the need for more than one form of treatment, more than one conception of bodies and disease. In this way, I want to suggest that the “whole patient” or “whole system approach” central to integrative oncology signals the sensitivities being formed in integrative oncology. Like stress, the idea of conventional cancer treatment methods only address a part of the person, the “whole patient” approach is influenced by complementary practices that treat disease as affecting the whole.

The “whole system approach” modelled in the pedagogical materials that I examined was particularly informed by Chinese medicine. In these courses, Chinese medicine is framed as a “whole medical system,” because it “naturally views the human body systematically through its unique perception of human physiology at the energetic level, called chi [qi]”— a conception that “perceives the human body beyond the structural anatomy.” The course material described Chinese medicine as being “all about balance,” and a practice that is focused on “expelling evil while supporting the good,” unlike biomedicine which, “is focused heavily on expelling evil.”

Moreover, the instructional material on “whole system” approach to medicine teaches practitioners that how a body is conceived informs the kinds of treatments that modality can provide—here again signalling the limitations of the biomedical view of bodies which dismisses so many subtle dimensions, such as stress and mood, which impact cancer.

These instructions to approach cancer as a disease affecting the the “whole system,” or rather the “whole patient” are atypical of medical pedagogy. In *Medicine, Rationality, and Experience: An Anthropological Perspective* (1994), Bryon Good provides a detailed account of how physicians are made in and through pedagogical practices at Harvard Medical School. Working with Michel Foucault’s concept of the clinical gaze (1973), Good argues that this training is a process of learning how to take on this penetrating power of sight in order to disarticulate the patient from their body for the purposes of

diagnosing and intervening in the mechanisms of disease (1994: 71). For Good, the cultivation of this skill begins in the anatomy laboratory where medical students must detach the bodies they dissect from any and all cultural webs—that ideas about or feelings for the animate lives the cadavers once lived have to be cut away in order for the students to make “entry into the human body” (Good 1994: 72), following generalized routes carved by biomechanical models of biology, physiology, and pathology. In this context, there is no space for identifying with or relating to the the bodies encountered in medical school: they are objects through which and for which medical modes of seeing, thinking, and writing are trained.

Further to this point, for anthropologist Daniel Segal, “medical education resolutely maintains a *double image* of the physician’s relationship to the bodies of others” (1988: 17, emphasis added). Segal describes that physicians are taught to think of the patient as “an object that can be known and handled through technical routines,” and themselves as “the agent who performs these routines impersonally and *unemotionally*” (ibid). It is this reification of patient-object, physician-subject that makes medical training, particularly the dissection of human cadavers, possible—an imparting of the “signifiant message” that physicians are “privileged” to handle bodies in particular ways (Segal 1988: 22). As Segal’s research with medical students indicates, becoming “a physician requires learning ‘to control’ one’s ‘feelings’” because a “physician should never be ‘emotionally involved’ or ‘callous’” but “must react ‘professionally,’ always fulfilling his or her duties regardless of any ‘personal feelings’ or ‘emotions’” (1988: 18).

Sociologists Stefan Hirschauer also speaks to this dynamic in his piece, “The Manufacturing of Bodies in Surgery” (1991), arguing that in order for surgical operations to proceed, the patient body must be divested of its “life-world” (282). This is accomplished by reducing the patient to “the area of operation,” a division that results in patients being referred to by the procedure they’ll be undergoing or the part of their body requiring surgery (Hirschauer 1991: 288). In their paper “You are a Number, Not a Human Being” (1999) Anthropologists Susan Sered and Ephraim Tabory speak to this reductionism in their accounts of the experiences of Israeli women receiving conventional oncology treatment. The patients they interviewed described instances where they were referred to as “room five” and “the third-stage cancer” (ibid). These patients expressed their frustrations that their physicians were relating to them “like a number and not a person. Like a machine that part of it is damaged” (ibid). Hirschauer suggests that this dematerializing and desensitizing move allows surgeons to then project anatomical images of parts and procedures learned in medical school into and onto the interior of the patient body, making its structures, cavities and coursing fluid channels traversable and operable.

While Good, Segal, and Hirschauer’s work was written over ten years ago, these descriptions continue to resonate with the stories I heard about medical education, particularly from Felix. Having finished his residency in the mid 2000s, he recounted that, “medical school can be difficult, and medical training is so brutal” precisely for the

reasons identified in this literature—that it not only encourages conceiving of patients as their ailments, so tightly structuring the relation a physician can have with a patient; this mode of operation also disrupts the ability of the physician to conceive of different means of treatment:

I was talking to a medical student in his first year about this indoctrination process that happens—I was telling him, ‘You have this fresh perspective right now, try to hang on to it as you go through the process because you will start to get indoctrinated into a particular way of thinking, and this fresh perspective you have right now, it could be valuable to you later if you can hold onto some aspect of it.’

That fresh perspective is for Felix critical to conceiving of new “possibilities” for medical practices—of finding different ways to treat patients. It is also one that he found in taking an integrative approach to oncology. “One of the reasons I went into integrative medicine is that it's practical. I think it goes along with keeping these perspectives open—it’s just a good practice, you know, to not get stuck in a particular way of thinking.”

The stickiness that Felix points to is the adherence to the idea that medicine is best conceived as a practice of reducing a whole body down to the tissue, cell, or molecule to find the cause of an ailment. Held alongside the pedagogical insistence of integrative oncology to scale up—to think of the whole rather than the part in understanding disease—Felix’s comments here point to the way in which modes of thinking are always already about modes of sensing (Kuriyama 1999). And that his frustrations with biomedicine are

related to the limitations that reductionism places on what is sensible in understanding and treating cancer.

Historian Shigehisa Kuriyama writes about this very idea—about how conceptions of bodies define what is knowable and sensible about bodies and disease. He suggests that, “when we study conceptions of the body, we are examining constructions not just in the mind, but also in the senses” (1999: 60). In tracing the historical divergences between Greek and Chinese medicine in and through their respective practices of pulse palpation, Kuriyama indicates that what a practitioner is able to diagnose is “bound up with different ways of being bodies” (1999: 13). The senses required to feel a pulse in Greek medicine were entirely different than those required of Chinese traditions. Kuriyama explains how this was a matter of the way in which each form of medicine conceived of bodies. In Chinese medicine, “winds sculpted the shape and possibilities of the body, folded desires and dispositions, infused a person’s entire being” (Kuriyama 1999: 235). The properties of these winds were revealed by palpating the various pulses of this body, deriving diagnostic information based on their directions, volumes, and intensities. On the other hand, Greek medicine, conditioned by an anatomical view of its body as a set of organized structures, approached the pulse in its singularity, as an indicator of “the activity of the heart and arteries” (Kuriyama 1999: 33). Despite a shared physical form, Kuriyama notes that “the divergence was as much a matter of experience as it was of theory. Greek and Chinese doctors knew the body differently because they felt it differently” (1999: 55).

Kuriyama also points to the influence of dissection practices on Greek medicine and the body of this practice. He indicates that the ability to cut into bodies to touch their muscles, organs, and tissues established a particular trajectory for Western medicine (1999: 119-120). As Kuriyama explains, “anatomists eyed the body *as* the body” (120). Dissection focused their sight, and their sense of the body and its aliments as having to do with its makeup—of what was inside and visible its form. This developed in stark contrast to Chinese medicine, with its attention to how outside forces impacted the body and influenced disease.

It seems that the intent of these courses, and indeed, integrative training at the ACIM is to attune oncologists to the sensitivity of bodies—to create treatment protocols that are responsive to different ideas about what a body can do, sense, and be affected by (c.f. Spinoza 1677). This training in some senses loosens the grasp of the biomedical model as the only means of knowing bodies by drawing attention to the ways in which tissues, malignant and otherwise, are affected by emotions, their surroundings, and the ideas they possess about self, spirit, and worth. Indeed this training multiplies how it is that bodies can be known and treated precisely because it emphasizes that each patient requires a different approach to treatment. Sensitivity is thus located in a sense of and for difference. Whole patient care in integrative oncology does not endeavour to make patients whole. Rather, it emphasizes the open-ended work of treating patients as more than their parts—as complex social and emotional beings whose needs shift and change,

and whose social and emotional states have bearing for their treatment. matter to their treatment of cancer. Integration is then always already about a sensitivity to the different needs and conditions which emerge in treating the social, emotional, and physical dimensions of cancer.

This training also endeavours to reconfigure the sterilized boundaries between the physician and the patient. The integrative approach thus encourages a consideration of what the patient is feeling—their stress, their fears, their doubts about their doctors, their treatments and their ability to outlive the cancers growing in their bodies. Sensitivity is something extended to bodies in integrative oncology through pedagogies that connect oncologists to different means of making sense—to different ways of feeling and modelling bodies that can then be used to understand the discomforts, pains, and stresses experienced as a part of cancer. As an intervention into the practice of conventional oncology, part of the friction produced by integrative approaches is its requirement that physicians get mixed up in the lives of their patients—that becoming *sensitive* to what their patients *feel* is critical for how their patients heal.

My attention to the sensitivity in this regard is something that I have come to know through the suffering of my mother and the stories I have collected throughout my fieldwork; but it is also something I've experienced in my receiving and researching of the bodywork practice of craniosacral therapy (Atkinson-Graham 2009). This field is premised on the idea that the human body is energetically animated by the circulation of

the cerebrospinal fluid in the dura membrane—the outermost layer of the meninges membranes which encase the head, spine, and sacrum. The wave like motion of the rise and fall of this fluid between the head and sacrum is often referred to as the “breath of life” as its uninhibited movement in the cranial system, and throughout the body, is essential for health. Things like physical injuries or the experiences of stress can disrupt its movements and bring about larger health issues. But this rhythm is intensely subtle, almost imperceptible—it resonates at a register which is softer than the breath or the pulse. Craniosacral therapists must learn to feel for this rhythm by becoming sensitive to its presence—a kinaesthetic and affective learning which involves feeling for the rhythm and feeling the rhythm reverberate in their own bodies. Sensitivity in this practice means not only extending the possibility that a body can be known to have such subtle dimensions, but feeling and being affected by those dimensions in order to comprehend them.

Sensitivity as I am conceiving it in the context of integrative oncology is influenced by the previous research I conducted, and what it has meant for me as a patient of craniosacral therapy to have another person treat me by being affected by me—by *feeling for* my afflictions as a mode of treating them. Sensitivity in this sense I think speaks to the kind of physician being made in integrative oncology—one who is required to conceive of and respond to bodies and disease in terms that differ from conventional biomedical practice.

Moreover, sensitivity, as I consider it emerging in integrative oncology, is a mode of care that understands that biomedicine needs more than one model of the body— it needs ideas about the subtlety of energies, molecular pathways, the porousness of bodies to toxicity, and the physical impacts of stress. It takes a particular kind of sensitivity in the sense of being receptive and responsive (Haraway 2008, Schrader 2010, Barad 2012) to understand that we inhabit many bodies simultaneously.

Insensitivity

The content of these two online courses, and the stories I have heard from Felix and Donald about their integrative education, reveal the efforts of pedagogy in integrative oncology to sensitize biomedical practitioners to different models, modes, and means of treating bodies with cancer. But what these courses and these stories do not reveal is any consideration of what it means to import ideas and practices from other medical modalities in integrative oncology. In this regard, I feel waves of *insensitivity* inside in the fragmented representations of the many modalities recommended to treat the “whole patient” in both the *Introduction to Integrative Oncology and Breast Cancer: An Integrative Approach*. Techniques such as yoga, meditation, acupuncture, and even herbal supplements, are advised based on their biomedical utility, and inadequate consideration is given to how these healing methods fit within their practical cultures of Ayurveda, Chinese medicine, and botanical medicine. In these courses it seems that biomedicine is engulfing these practices.

Reading over an outline of the ACIM Fellowship in Integrative Medicine, I get the sense that there's a depth of detail missing from this program as well. This overview lists eleven units of material scheduled for one and three month intervals, spread across two years. Indeed, Unit 3 provides one month for fellows to learn "Spirituality and Health Care/ Mind-Body Medicine Practice/ Introduction to Integrative Mental Health/ Interactive Case/ Sleep Health Case Study/ Introduction to Contemplative Care/Death and Dying" and Unit 6 provides three months for "Whole Systems Introduction/ Homeopathy/ Naturopathy/ Traditional Chinese Medicine or Ayurveda (choose 1)/ Case Study" — the requirement to *choose one* of these modalities seems curious given these fields provide the principles and techniques upon which integrative medicine is based. That Felix went on to pursue training in Ayurvedic science is perhaps indicative of the need to supplement this training. As a point of comparison, Masters and Doctoral training in Traditional Chinese Medicine at the San Francisco based American College of Chinese Medicine — one of thirty-six training programs in the United States and approved by the Californian Department of Consumer Affairs Acupuncture Board — are both four year programs, requiring both classroom and clinical work.⁶

At issue in integrative training then is the particular packaging of complementary therapies—that knowing of their existence, and knowing to recommend them in relation

⁶ See <http://www.acupuncture.ca.gov/students/schools.shtml> for other approved training programs, and <https://www.actcm.edu/> for the American College of Chinese Medicine Masters and Doctoral curricula.

to conventional oncology, is positioned enough knowing. There are some sections in the online courses I took where the critical differences between complementary practices aren't even explained. Sentences that read "Some approaches to consider include: Traditional Chinese Medicine or Ayurveda, exercise, yoga, meditation, clinical hypnosis, nutritional changes, or other integrative modalities" lump different genealogies of practice together without requiring that the physician learn how those therapies are situated in their respective fields.

Yoga, and its attendant practices of meditation, exemplified in this problematic packing as both are conceived without reference to their multiplicity or history. It is described as "a component of Ayurvedic medicine that uses breath control, meditation, and physical movement and can be helpful in treating anxiety and depression, nausea, including anticipatory nausea, insomnia, and supporting the immune system." As a technique, there is little consideration given for the many different styles of yoga practice that existed previous to and after Swami Vivekananda modernized and introduced yoga to the West in the 1920s (White 2012; De Michelis 2004). In studying the content of my interviews, fieldnotes, and the collections of references before and after taking the integrative courses, yoga is always referred to as *yoga*. There is no mention of how this practice is varied in form and focus by its articulation in Buddhist, Hindu, Janist, Tantric, and Sikh genealogies, or that each of these conventions of practice have been repackaged countless times for consumption in North America. Ayurveda, on the other hand, is mentioned only as a medicine—no detail about its history or conception is given.

There does, however, seem to be more careful representation of Chinese medicine in integrative oncology. It receives slightly more detail defined as, “a whole medical system that naturally views the human body systematically through its unique perception of human physiology at the energetic level, called chi, and pathways called meridians. Acupuncture is one of the therapeutic tools of Traditional Chinese Medicine and the aspect most widely used in the West.” The idea of food as medicine central to this practice fits comfortably within biomedicine insofar as both fields share in the practice of selecting tangible remedies based on physical symptoms (see Farquhar 1994). Less emphasized in the literature is the idea that Chinese medicine involves a different temporality of treatment. As anthropologist Judith Farquhar has ascertained in her sustained research on Chinese medicine, “it is not a quick fix or powerful drug. It takes time, and it teaches you to pay attention to your body” (1994: 489). The timeframe required of Chinese medicine and the management of herbal remedies seems somewhat overlooked in its import into integrative approaches to cancer— a disease that requires quick response because it consumes *time*.

There more time I spend in the space of integrative education, the more it seems that to activate Ayurveda and Chinese medicine for Western audiences means to making these fields fit within biomedicine. In this regard, the category of complementary medicine more accurately names the work of using these procedures and approaches as a means to

extend and enhance the reach of biomedicine—to give it longer arms and more leverage, rather than put biomedical conceptions of bodies and health at risk for redefinition.

But where anthropologists, like Hans Baer, make the argument that integrative medicine is engaged in a “process of co-opting CAM” (2004: 53), I want to suggest that the sensitivities produced of the re-presentation and reformulations of Chinese and Ayurvedic medicine for biomedical audiences are still important. It seems that the project of the integrative approach is to make different ideas about bodies perceptible, sensible, to biomedicine as a means of encouraging a change in its practice. I do not mean to relieve integrative oncology of the trouble it generates in simplifying Ayurveda and Chinese medicine in its pedagogical contexts; but rather to suggest that the notion of co-optation disregards the attempts and achievements of this approach in trying to find ways of improving cancer treatment. That in the “awkward engagements” (Tsing 2005: ix) involved in integrating these systems into biomedicine, important ideas are emerging that concern an otherwise for how people live and die with cancer. The sensitivity produced of these frictions makes the conventional treatments of oncology more livable for patients.

Moreover, the criticism of “co-optation” overlooks the many routes that Chinese medicine and Ayurveda have already taken. In her work on the globalization of Chinese Medicine, anthropologist Mei Zhan provides the helpful insight that, “from the 1960s to the early 1970s, the Chinese government organized and promoted the export of traditional Chinese medicine as low-cost, low-technology, preventive medicine that is Chinese in

essence and at the same time suitable for health care in third-world countries, including those in Africa” (2009: 169). To this end, Mei indicates that forms of Chinese medical practice were being made to move across the globe well before this practice was made relevant to the counter-culture and holistic movements of the 1970s. She also indicates that trade relations more than expropriative intentions created the conditions for Chinese medicine to be taken up in biomedicine, citing President Nixon’s historic trip to the People’s Republic of China in 1972 as opening up the public to this practice (2009: 174).

Mei’s work in this regard troubles the criticisms of co-optation in integrative medicine, and by extension, integrative oncology. Further to figuring out the tensions at work in integrating “traditional” medicines into biomedicine, Jean Langford cautions against thinking that aligns a set of practice with the cultures of its conceptions. In resisting the interpretation of Ayurveda as a “cultural artefact” or a static symbol of Indian culture, Langford points to the ways in which, “the (re)invention of Ayurveda as a system of medicine in parallel to biomedicine serves to highlight certain peculiar features of a modern organization of knowledge” (2002: 9). She argues, “that even as practitioners give Ayurveda a modern institutional framework, they also implicitly criticize many of the philosophical premises underlying that framework” (ibid). Relating back to the stories that Felix and Donald have told me about their integrative practice, learning about and beginning to work with this and other healing techniques helped them to build their own critiques of biomedicine, and flag its failures in treating cancer.

Sensitizing practice

Combining ideas about stress and the imperative of treating the “whole patient,” and incorporating complementary medicine with conventional treatment practices, integrative oncology is generating novel modes of sensitivity and sensing that are changing ideas about cancer and its treatment. These changes arise out of the idea that it takes multiple ideas about bodies and multiple models of treatment in order to care for cancer. Cancer in integrative oncology is understood as a disease that affects and is affected by the “whole person” imagined as a configuration of mind, body, and spirit. Indeed, being sensitive to the needs of patients is what pulls all the bodies of these different practices together, creating an integrative form that enables oncologists to treat cancer as something that is embodied (c.f. Mol 2002). In the next chapter I examine how sensitivity is enacted in the treatment practices of integrative oncology.

CHAPTER FOUR: TREATMENT

“Sometimes a ‘cure’ for whatever kills us is just not enough reason to keep the killing machines going at the scale to which we (who?) have become accustomed.” -Donna Haraway

Having realized that I am thirty minutes early for a meeting with Felix, I walk to the nearest café. I pass surgeons in green scrubs darting into amber lit crosswalks and clinicians whose hurried paces cause their white coats to billow like full spinnakers. With files in arm, they walk past men with cupped hands who sit next to shopping carts draped with blankets and piled high with irregularly shaped garbage bags. This movement of running shoes, tattered and new, and the jostling ID badges against hips and chests spans the seven-block stretch of medical buildings I wander through to kill time.

The wind in San Francisco is strong, and as I near Felix’s office my coffee turns cool. Moving through the labyrinthine-like halls of his building, I silently count the number of hand sanitizer dispensers adorning the walls. I knock on his office door, and find him part way through his lunch. Apologizing for a morning that has escaped him, he asks me to wait while he finishes eating and responding to a few pressing emails. He offers water, walks me over to a work area where he invites me to make myself comfortable.

I swivel on an office chair and play with its height until I’m tall enough to gaze over the edge of the cubicles. I see a head in front of a monitor, clicking through screens of data, quiet and focused. I pivot again, returning my attention to desk in front of me, empty of

all accoutrement. The chair quietly hisses as I return it to a reasonable height. Pulling out my notebook, I see Felix as he turns the corner, coming to collect me.

Cast against a postcard view of the steep inclines and Victorian inspired architecture of the city, Felix is seated at a desk anchored by two very large volumes on Ayurvedic medicine. Taking a sip of tea, he tells me that,

I've just started a new qualitative project. The medical student you were sitting beside was working on it. Its about trying to understand patient decision making around alternative cancer treatments, which as you know, are the ones that are separate from western medicine, not integration. No integration, but separate. There's a larger group than we recognize of patients who refuse, or decide not to pursue, chemo, radiation, or surgery, and instead, do a lot of alternatives. I'm very interested to study that group, because, obviously, it has a lot of serious implications because many of the alternative treatments are not effective, and so that leads to recurrences and relapses. But more importantly, I'm interested to know why they're choosing alternatives.

Responding, I mention that that I'd be curious to know what kinds of stories these patients are hearing about alternative medicines—what these stories reveal about the promised effectiveness of alternative medicine over conventional oncology, or even integrative approaches? I ask Felix whether these accounts, found in books and online, are selective in their storytelling, focusing on those who survive rather than those who die pursuing the assurance that alternatives could rid them of their cancers.

Hearing these questions, his face softens.

I have patients for whom, unfortunately, that happened. But then that will never make it on a website. And it's not that I'm suspicious of people who offer

alternatives, I'm sure that many of them have good intentions, and they're trying to help; but at the same time, it's completely unstudied and uncertain, and I don't think that they are honest, maybe, to patients about that. There are some dangers there.

This morning, I learn that Felix is developing a manualization program on “Ayurvedic interventions for supportive care for cancer patients.” Felix explains that he and his research team of medical students interviewed Ayurvedic healers in order to ascertain “how they understand cancer, and how they would use their approach to support patients with cancer.” These insights are being implemented as a manual for the application of Ayurveda in an oncology setting:

It is now being used in a clinical trial as the protocol for the nutritional, lifestyle, and yoga intervention... for women with breast cancer who have just finished their chemotherapy, radiation, and surgery. So they're potentially cured, but they have a lot of residual side effects, and not good quality of life. The idea is that an intervention like this can help them return to good health, and maybe better and quicker.

Felix's comments about the “dangers” of treating cancer with “alternatives,” and his concerns with finding supportive evidence for integrative treatments derived from complementary healing modalities expresses a solicitude for his patients well being. He doesn't want to see patients forego conventional forms of cancer treatment in favour of alternative treatments such as detoxifying juice cleanses, or high dose vitamin injections. Instead, he wants to support his patients through conventional treatment by making recommendations such as practicing yoga to alleviate fatigue brought on by many of the drugs used in treating cancer or by asking his patients to incorporate foods filled with

curcumin into their diets—a compound found in turmeric that has anti-tumor properties, particularly against colon cancer.¹ “I want to be able to give my patients the best care that I can. I think western medicine is good and it's helpful, but I’m also open-minded to other possibilities.” With fingers laced and forearms resting on his desk, Felix leans in:

I tell this to medical students too—what I love about having these two systems, Western medicine and Ayurvedic medicine to use in my practice is that it really expands my possibilities with a person. I was giving the example earlier that when a person comes with a complaint where in Western medicine there's not a good way to think about it, like fibromyalgia. For many years these complaints were not really considered, sort of like, ‘It's not a rheumatologic disease, it's not rheumatoid arthritis, it's not lupus, so I don't know what this is and I don't know how to help this person.’ And so many physicians get frustrated with these patients with fibromyalgia because they don't have a framework for it, and they don't have good treatments for it. But, for me, now with Ayurveda, there's an exact diagnosis that fits with fibromyalgia, there's exact way of understanding that condition in that patient, and there's a very specific treatment plan I can offer based on the diagnosis. I find with these two different skill sets it just opens up the possibilities of how I can think about something and what I can do for that person.

With the example of fibromyalgia, Felix draws attention to the limitations of the biomedicine, suggesting that such a “framework” cannot adequately diagnosis or treat the symptoms of chronic pain. Fibromyalgia poses a problem to biomedicine because the widespread musculoskeletal pain associated with this condition has no root that biomedical diagnostic technologies can identify. It’s causes are undetectable.

In Western medicine, if someone breaks their hip and they have hip pain we can say, ‘Ok, yes, that’s the spot. That we understand.’ But pain as we know is multi-factorial—there’s physical, psychological, maybe even spiritual components to

¹Information taken from content of the integrative oncology courses I took online through the Arizona Center for Integrative Medicine at the University of Arizona.

pain. When it comes to these other non-physical components of pain, I think in Western medicine, perhaps we're less comfortable with that, and less willing to treat it as seriously.

Recall that for historian, Shigehisa Kuriyama, diagnostic and treatment practices in Western medicine are conditional to and conditioned by sensing practices (1999, 2002). Kuriyama makes the argument that if a Western physician cannot touch or see an symptom, whether using their own facilities or a diagnostic technology, they are not able to grasp what is being expressed by the patient's body (2002: 271). The expression of non-localizable pain associated with Fibromyalgia is imperceptible to biomedicine precisely because it challenges the conventions of diagnostic sensing in this field. Medical anthropologists have studied this difficulty extensively (see Kleinman 1988, Csordas and Clark 1992, Csordas 1994, DelVecchio Good et al., 1994, Jackson 2000, 2005).

While conducting ethnographic research at a pain management center in the United States, Jean E. Jackson was told repeatedly by patients that having “cancer was preferable... because it is a known diagnosis with treatment possibilities” (2005: 340). Speaking to the poignancy of such a statement, Jackson clarifies that syndromes with chronic pain are an issue in biomedicine because there are invisible to a biomedical view of the body. She suggests that chronic pain is a liminal phenomena— it “threaten[s] the logic of the classification system by straddling the mind–body boundary and revealing its inadequacies” (345). It is precisely the liminality of the patient with chronic pain that

frustrates physicians. Not having a standard treatment, or even a “universally accepted definition of pain,” Jackson indicates that “chronic pain patients rather easily fall out of the category of patients physicians are eager to treat and into the category of being ‘a pain’ themselves—a ‘crock’” (338).

One of the things that motivates Felix to practice Ayurveda is that this field takes the multiplicity and complexity of pain seriously:

If a person has a huge psychological component to their pain, Western physicians are going to be hesitant to prescribe narcotics, naturally, because narcotics are addictive, and have side-effects. They’re not comfortable with the type of pain this person has. But if I bring into bear Ayurveda, I don't give narcotics. I can treat that pain using other methods. I'm not going to create an addiction, I'm not going to create dependency, I'm not going to cause side effects necessarily, and I might be able to help that person.

Felix is able to do this because pain in Ayurvedic medicine is not understood as an explicitly physical phenomena. It is of both the mind and the body, and the experience of pain invites an Ayurvedic practitioner to find out about the conditions that person is living in that could manifest pain in their bodies. And for Ayurveda, everything from social relationships to diet has bearing.

For his patients with cancer, his training in Ayurveda provides him with possibility to address their acute and chronic pain and to treat it effectively. In positing the possible, Felix is expressing a different set of concerns about what it means to care for patients

using an integrative approach to oncology. His example gestures to the kinds of sensitivities that his practice enacts.

When I ask him to elaborate on the difference between practicing integrative and conventional oncology, Felix describes a contrast in time:

I felt dissatisfied with the model of clinical practice.. you may have twenty minutes to spend with somebody, maybe less. It's usually, actually, less by the time the patient gets into the room and gets settled. It often ends up being ten minutes in Western medicine. They may have like six or seven very complicated medical problems, and you can't adequately address any of those. Maybe even just one. You can't really get at very much and, so again, that interaction often becomes dissatisfying. You may appreciate the human interaction, but medically, you're maybe not really doing much for that person. All you can really do is write a prescription and then have them go home. You know that diet and exercise are really important and impact on that problem, but you have no time to talk about it. That's also a struggle. Now I spend two hours with new patients, and one hour on follow-ups

Felix requires more time with his patients because as an oncologist who is providing both conventional and complementary treatments for cancer, his integrative practice necessitates “two assessments in one visit.” Particularly in the case of first appointments, Felix explains that,

I'll do a completely Western medical assessment and intake—history of illness, physical, social history— and an Ayurvedic evaluation as well. There is some overlap. When I talk to the patient I can get a sense of their constitution, but there are certain questions that I will ask that are more specific to Ayurveda.

Felix must ask several different questions during the intake to get a better sense of his patient's constitution. This constitution, as explored in Chapter Three, is highly

individualized, and disease in Ayurveda is understood as the production of a disruption in the interconnected processes of mind and body (Pole 2013: xviii). Because no two bodies are alike, even if all of Felix's patients share a biomedical disease category or a set of similar symptoms, they will each receive different treatments particular to their constitution.

The longer window of patient-physician interaction required by an integrative practice also shifts the very terms of that relationship:

Because I have that time, I can get to know that person better. I find that my suggestions to them are better. Also, they're not just suggestions that are generic, I can make it a little more specific. Like, 'I know that this person has been eating this diet for like 20 years, so I know that based on the diet they are eating, I need to make slow changes in this direction', rather than just saying 'Let's stop and try something brand new.' Probably they wouldn't be able to do it if they've been eating this way for twenty years. I needed that time to really understand where they were to be able to help them to make changes.

When Felix describes wanting to know how and what his patients eat, how much stress they feel in their lives, what kind of family support they have, and what emotions they feel around their diagnosis, he is positioning a different approach to treating cancer. With Felix's remarks, I sense that integrative oncology is being imagined as a practice of caring for and about patients with cancer.

Pressing him on this point, I ask, "Is there a difference for you in terms of care and treatment?" As with all of my questions, he thoughtfully pauses and then replies: "I don't

know that I consciously thought of it as such, but I suppose that they are different. When I think of treatment I think of treatment of a disease, and when I think of care I think it's more global—care could include the treatment of a disease or things that aren't directly treating the disease.”

Referencing the “global” difference between treatment and care, Felix uses scalar imagery as a way of tapping into the comprehensive qualities of the integrative oncology he practices—those realms of therapeutic possibilities made accessible by being attentive to the many different models of bodies required to begin to imagine “whole” patient treatment.

Explaining this point further, Felix points out that cancer is a difficult disease for biomedicine to treat because,

It's psychological and physical. I can't say that anyone has ever explicitly told me in my training that mind and body are separate, but its again, it's just sort of there. And if you think about it, it's clear that's how it is in that model. Mind and body are clearly one entity, or at the very least, very closely interconnected and one influences the other. I've observed in my interactions with patients, and in my own life, how, mind affects body, and body affects mind. If for example I had a physical disease, then that will affect my state of mind. Some people might be more anxious or irritable, or whatever it is, its affecting their mind. Or visa versa, if they have a psychological condition they may have physical symptoms that come from it. You kind of come up against the limitations of the existing framework to treat these dimensions. At that point, you start to think that there has to be other ways of thinking about this that are not so dichotomized, that are more integrated.

Felix's training in integrative medicine revealed to him the dualism implicit in biomedicine. As an integrative oncologist, Felix performs a kind of care which he describes as "global" precisely because it spans the chasm between mind and body by incorporating medical models which are not dualistic. Moreover, rather than dismiss the biomedical model, his integrative perspective enables him to question whether this view of bodies is *the* most effective model for cancer treatment. In this regard, the kind of care he provides by using both conventional and Ayurvedic treatments for cancer allows him to *respond* to the limitations of oncology to adequately support worlds of need expressed by his patients.

...

In this chapter I explore how integrative approaches to oncology are imagined as practices of care. Rather than suggest that care is absent in conventional oncology, I want to consider that the kind of care being enacted in integrative oncology is connected the ways sensitivity is being modelled as a form of response in this field. Formations of care as compassionate, empathetic, personalized, and personable in integrative oncology are also present in the treatment practices I observed in conventional oncology. Stories about these enactments of care are necessary for complicating talk about integrative oncology in a way that appreciates the differences between these and conventional practices.

Drawing on literature from the anthropology of medicine, the anthropology of science, and feminist studies of technoscience on care, I hope to tease out the particular qualities

of integrative care in and through a consideration of the forms of responsibility and “response-ability” (Haraway 2008; Barad 2007, Schrader 2010) being cultivated in this field.

Convention

In a wing of the Stanford Cancer Center, I follow Peter on his afternoon rounds. A renowned hematologist and researcher, recognized for developing cellular therapies for the treatment of complex hematological cancers, he is every part the charismatic physician one might assume to find on the edge of the Silicone Valley. Dressed in black slacks, a crisp oxford shirt, and red pattern tie, stethoscope draped around his neck, he wears wire framed glasses and a one shouldered satchel containing an iPad and patient files. His breast pocket holds his iPhone, winsomely referred to as his “second brain,” and business cards which he hands out to each patient and all their family members. He jokes: “I have tons of them because I only ever give them to my mom.”

Before entering the first consultation, Peter tells me that he’s going to be discussing treatment options for a patient with “double hit, with Myc” lymphoma diagnosis. His consistent and generous presumption that I know more oncological shorthand than I actually do has me asking for clarification at the threshold of many exam room doors throughout the day. In this moment, he clarifies that this is a cancer with no known standards of care, which is precisely why this patient has been sent to him.

Indeed, the double hit refers to a high-grade B-cell lymphoma with dual chromosomal rearrangements of the Myc and Bcl-2 genes. These proteins code for transcription factors or rather the regulation of gene expression that directs the growth and function of a cell. These genes are present in all cells, and are responsible for ensuring that a cell goes through the process of apoptosis or “programmed cell death.” Apoptosis is critical because it is induced when there is something wrong with the normal functioning of a cell, whether because of a virus or because of a mutation. When the ability of a cell to die is compromised by mutation of the genes that regulate apoptosis, that cell will continue to grow abnormally. Cells with compromised apoptotic function can become cancerous.

The term “high-grade” refers to the grade of the tumor. Tumors are assigned grades of cellular differentiation in order to predict their spread and growth. These grades, ranging from G1 or differentiated low grade, to G4 or undifferentiated high grade, are assigned by a pathologist after examining biopsied cells under a microscope to see how closely the tumor cells resemble the healthy cells of the tissues from which they developed. If a tumor is “well-differentiated” that means the cells of the tumor resemble the structure of normal cells, and the tumor is considered low-grade and slow in its growth and spread. If a tumor is “poorly differentiated” or “undifferentiated” that means the cells are abnormal in shape. Undifferentiated tumors tend to grow more rapidly and expand beyond their initial site of inception.

So when Peter calls this cancer a “double hit” and “high grade” he is describing the intense challenge this cancer presents as that which is growing quickly and already spreading throughout his patient’s body. The difficulty of treating this kind of cancer doubles again as many chemotherapy treatments work by inducing apoptosis (cell death), and in this particular case, those drugs will not work.

Because of the complexities of this diagnosis, this patient is an apt candidate for an treatment protocol that Peter is currently studying using a clinical trial model. David is researching allogeneic and autogenetic hematopoietic stem cell transplantation (allo- and auto-HSCT) for this type of lymphoma. Used in the treatment of aggressive cancers of the blood such as such as non-Hodgkin’s lymphoma, Hodgkin’s lymphoma, leukemia, and multiple myeloma, this treatment involves transplanting stem cells taken from a donor (allo-) or derived from the bone marrow of the patient (auto-). The idea behind this procedure is to attempt to destroy all the cancer cells by first administering a nearly-lethal dose of chemotherapy, which also has the effect of killing the stem cells in the patients bone marrow. Stem cells are then intravenously injected, effectively kick starting the growth of a new, cancer free immune system. In successful cases, this eradicates the cancer; however, there is the possibility that a patient will react to the cells derived from a matched donor, developing graft versus host disease (GVHD)—a condition in which the donated cells begin to attack the recipients organs and tissues, putting them at increased risk for infection. GVHD can be treated using immunosuppressive drugs.

As he is about to open the door, one of Peter's residents, recently returned from maternity leave, asks to join the meeting. Peter is known for providing clear and concise explanations of transplant procedures, and she is eager to learn from his delivery.

Opening the door, we find a retired attorney, the patient, and his two daughters sitting nervously with notebooks in hand. After establishing a rapport with the family, Peter begins to explain that this case of B-cell lymphoma would be best treated with allogeneic hematopoietic stem cell transplantation.

Positioning this treatment as the most viable option for the patient, Peter takes a seat on a wheeled stool at the base of the examination table and begins to write on the tissue paper cover (Figure 3). The resident holds the top of the paper still as Peter writes *total lymphoid irradiation and anti-thymocyte globulin: TLI-ATG*. He then jots *Acute GVHD 5% and chronic*. Moving his hand down the sheet, he fleshes out a biomechanical rendering of this procedure, starting with stem cells that will be injected into the patient, illustrated as the encircled acronym of *HSC*, and ending with the desired effect of a *T-cell*, bred of the pluripotency of the stem cells, expressing its compatibility with the patient.

As his hand moves across the sheet, he explains that because lymphoma is a cancer of the lymphocytes, affecting the production of stem cells in the bone marrow which then differentiate into B and T cells, the patient will need a transplant of healthy stem cells

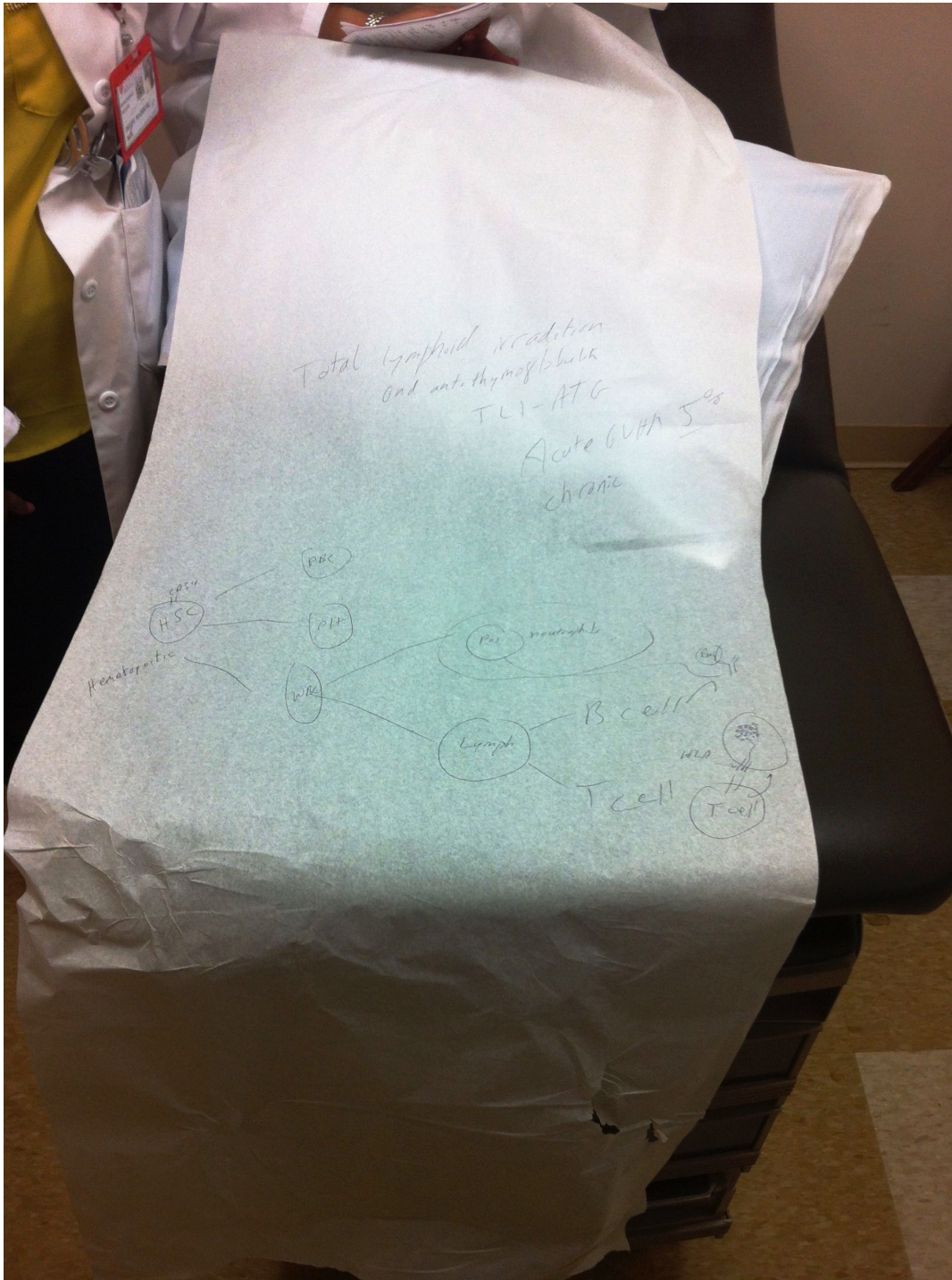


Figure 3: A sketch produced during a conventional oncology consultation concerning the procedure for a hematopoietic cell transplantation, and its associated risks, in the treatment of lymphoma.

from a donor, thus giving the procedure the designation of *allo* (meaning other), rather than *auto* (meaning self). Looking at the patient's daughters, Peter clarifies: in order for the procedure to work, the donor must have a matching HLA, or human leukocyte antigen. The HLA is the human designation for the major histocompatibility complex (MHC)—a series of molecules that process and present antigens to T cells, which then regulate the response of the immune system to these foreign bodies (Parham 2009: 146-149, 460). MHC molecules are encoded and clustered as a group of closely linked genes located on chromosome 6 in humans. David assures his patient that the HLA is a measurement used to establish a genetic match in tissues between donor and recipient.

Reaching up to where he has written *Acute GVHD*, Peter underlines the 5%, communicating that there is a chance the graft will be rejected, and the health of his patient might be compromised by GVHD. I watch as the daughters make eye contact, perhaps sharing in the recognition that their bone marrow might contain suitable stem cells.

Motioning to where he's written TLI-ATG, Peter explains that before the patient can receive the transplant, steps must be taken to prepare for the engraftment and to prevent GVHD. David describes that this will involve the patient undergoing total lymphoid irradiation (TLI)—the administering of full body radiation treatments over a course of a month, the alternative to the extremely high dose chemotherapy mentioned above. After the TLI, and infusion of anti-thymocyte globulin (ATG) will be administered. This is a

mixture of antibodies used to prevent the rejection of tissue and organ transplantation. Taking his hand off the paper, Peter wheels away from the table and closer to his patient, telling him that following these stages he will receive a transfusion of stem cells derived from the bone marrow of a healthy donor. Peter explains that if the graft is successful, these donor stem cells will replenish his immune system, leading to the production of cancer free B cells—lymphocytes, or white blood cells, that are critical to a healthy immune system as they respond to antigens and produce antibodies. Cancer free B cells in this case would mean the end to the cancer compromising this man's life.

Throughout this discussion, the patient sat relatively motionless, nodding when prompted by an inflection of Peter's pen in his direction. Asking for questions from the family, one of the daughters immediately replied with a query about the survival rate for this cancer. Peter, somber in his tone, tells her that this will be an arduous process that will be very hard on her father, but that this transplant is the best treatment option he has. Peter assures the daughters and his patient that he is their "partner," and that he is committed to providing the best possible treatment he can. That said, he offers the reminder that this procedure will cost upwards of \$50,000—a fee this family must leverage without insurance support because of the experimental nature of the procedure. The family agrees to proceed with the treatment, and the patient consents to participate in Peter's research. Shaking hands, and handing out cards, Peter invites the oncology care coordinator into the room to begin the process of arranging appointments and establishing payment plans.

As the care coordinator ushers the family out of the consulting room and down the hall to her office, Peter, the resident, and I linger in the room. As they debrief, Peter tells his resident “not to talk about or stress the numbers because patients get hooked on percentages of survival. I want the patients to understand the concepts that propel the treatment, and that I’m their partner.” Peter’s diagram speaks to this tactic. Rather than simply rhyming off the terms related to this procedure, Peter provides this family with an illustrated explanation of a very technical procedure—something they can relate to, something that hails their medical literacy and familiarity with popular imaginings of science (c.f. Martin 1994). This act of care provides something tangible for this family to relate to in a moment where everything is made immaterial—as slight as this seems, this thin piece of wax paper is a considerable gesture of care.

I ask to photograph what Peter has drawn, and he enthusiastically rips off the sheet and hands it to me. As he and I leave and walk toward the charting room to see who he’s meeting with next, he tells me that the lawyer “looked weak,” and that he was worried that he won’t survive the TIG. He tells me that he encounters many cases in which patients feel pressure to undertake treatment, despite the risks or the costs, and that there is very little room to talk about the possibility of death in a space pressurized by the hopes and fears of a family.

It’s clear to me that Peter cares about his patients. As I shadow him through four more follow-up appointments with patients recovering from both auto and allo HSTC

treatments for leukemia, lymphoma, and autoimmune disorders, he spends half an hour to an hour with each patient—more than double the time required of, or scheduled for, him. Pulling their charts out of his bag, he only has to glance at their name to recall details of their medical and social lives. Entering the room, he expresses concern for their wellbeing beyond their disease by posing considerate and playful comments: So are you surfing yet? How's your first year at Berkeley going? Did you decide on a major? Where's your niece this time—is she in the waiting room?

As he listens attentively to his patient's answers to these seemingly mundane questions, picking up on how their daily practices have changed—if they're paddle boarding instead of surfing because their arms are too swollen by the immunosuppressive steroids to prop themselves up on the crest of a wave, enjoying school but having trouble making it to classes because they're feeling lethargic, or if family members have been asked to stay in the waiting room because something embarrassing or confusing that needs to be discussed.

But as “a doctor and a scientist” he makes no recommendations beyond the boundaries of biomedicine for interventions that might help his patients to live with and beyond their cancer. Sitting in front of a computer terminal, its screen saver composed of scrolling text instructing physicians to Start in the heart. Make a human connection, and to ask What are the feelings between the words, Peter takes vitals, palpates for signs of increased

GVHD reactions on the skin and in joint mobility, checks in about medication use, and adjusts doses where necessary.

Peter is sensitive to the experiences of his patients as they live with and through treatment for cancer. However, he's ambivalent when it comes to considering what practices beyond the standard of conventional care can do. He tells me that he sees “desperation in alternatives,” but with the same breath, he yields that yoga and meditation might be useful. Nevertheless, for Peter, caring as an oncologist does not mean making recommendations for his patients to pursue practices beyond convention.

My time with Peter makes clear that the dichotomization of treatment and care as a way of identifying the difference between conventional and integrative oncology is too simple a construction. I want to hold my experience with Peter alongside what I've learned about integrative oncology through the stories of its practitioners and its patients, not to dichotomize these fields, but to appreciate their differences—to understand the subtle contrasts in treatment.

Careful stories

As discussed in previous chapters, Donald's integrative approach to oncology draws on nutrition and plant-based remedies in his practice as an integrative oncologist. Like Felix, he too is concerned with providing therapeutic support for the physical, psychological,

and even spiritual facets of his patients and their cancers. In the charting room of his clinic at the Osher Center, Donald and I sit and discuss how his consultation practice differs from conventional oncologists.

“Do you know the average duration that a physician allows a patient to speak before interrupting them?” Caught by the sapphire eyes of the ouroboros ring on his right middle finger that comes into view as he twists this piece waiting for my reply, I blurt out, “is it five minutes?” Cracking a smile, he replies, “eighteen seconds.”

In order to develop a sense of what compels his patients to pursue integrative oncology, Donald explains that he starts “by asking my patients to tell me a story... I sit there and I listen.” The stories that he solicits invariably detail a cancer diagnosis, but in not asking specifically for that account, his patients end up describing their social and emotional lives, particularly how their jobs, and their relationships with family and friends shaped or were affected by the onset or discovery of their disease. Here again care is revealed as being made possible by time—by physicians taking and making time for their patients. Indeed, the care-filled extension of more time than typically allotted for appointments allows Donald to hear stories that provide him with an incredible amount of insight into the habits, sites of stress, and coping behaviours that his patients have in place.

Continuing to explain his method, Donald tells me that,

At the end of the interview before I examine patients I say, ‘Were you raised with any religious beliefs?’ and ‘Do you have any currently?’ Because, people often were, or no longer, and often change. And I say ‘Do you consider yourself spiritual?’ and then I ask three questions: ‘What brings you joy? What are your hopes? Where does your strength come from?’ And very often one of those three will make people cry depending on where they are in their journey. But at the end of the day, I remind them that they still have joy, hopes, and strength, and that they need to tap into that.

In asking these questions, Donald cares for his patients by supporting them to remember all the things they have to live for—encouragements that rarely get spoken in conventional offices. Resonating with Felix’s approach, these questions help Donald ascertain what treatments are possible. If a patient identifies as spiritual, Donald knows they will be receptive to guided meditation, or his recommendation to seek more regularly scheduled spiritual council. The care of attention and time that contours Donald’s intake process allows him to build an integrative treatment plan specific to the needs of each patient. The complementary treatments he recommends work as an extension of this care:

I give my patients things they can do themselves. You know, how they eat, physical activity, some breathing work—that’s the mind-body link—that empowers people. A lot of people leave after an hour saying, ‘Donald, you’re the first person that’s given me any hope.’ I’m not saying ‘You don’t have cancer’ or ‘You’re not going to die, or ‘We’re going to cure this.’ I just give them hope, by giving them things that empower them, and that they themselves can do in their path.

That idea of helping a person with cancer along their path is precisely how Berdine, a programming coordinator at the UC Davis Comprehensive Cancer Center, positions the

kind of “whole patient” care she provides in developing outreach programming for cancer patients and survivors. Speaking to Berdine about the kinds of barriers to getting whole patient care programs running, she explains that many physicians resist the idea that mind and body are connected, or that supporting the integration of mind and body with complementary healing modalities might be of importance in the treatment of cancer.

In her office, a teal coloured room, adorned with grey furniture angel figurines, she explains that,

Oncologists just want to deal with the disease. They're very disease focused. I think the other problem is, you know, very basic economics—they aren't paid to learn that about a patient, or work with a patient in that way. Which is really why I think what we're trying to do is so important because we can sort of pick-up those pieces. We can meet the patient before they start treatment, during, and after, and sort of introduce some of these ideas, and activities, and services that will help address those needs.

In sharp contrast to the care that Felix and Donald enact, Berdine makes clear that there are oncologists who, “don't want to engage the patient in decision making, shared decision making, they don't want to get into their life, and their relationships, they just want to do whatever needs to be done.” And that doing is often disease, not patient focused.

Living on

The felt difference between integrative and conventional oncology was also something that Holle and I spoke about at length. A gregarious and compelling speaker, I met Holle in the yoga class for cancer patients and survivors. Holle and I often gather to talk at a diner off the I-80—a highway that connects the East and West coasts, beginning in New Jersey, running West through Reno, Nevada, and into Sacramento, California where it dips slightly south to end in the San Francisco Bay Area. On benches of red vinyl, surrounded by tchotchkes, we poked at plates of eggs and potatoes, and talked about her life with and beyond cancer. A retired Director of Communications for one of the largest facilities at UC Davis, Holle has undergone surgery, chemotherapy, and radiation for lymphoma, colon cancer, and four instances of skin cancer. When I first met her she was waiting for the biopsy results of a possible seventh cancer and living with heart disease as a side effect of the various medications administered throughout her treatments.

Holle has not been treated by integrative oncologists, but she participates in outreach programming organized by UC Davis Health in order to support patients. Describing her rather circuitous path to integrative care, Holle clarifies that a few years ago,

I was talking to the nurse manager at my oncologist's office about something, and suddenly he said, 'You need to meet Ruth!' While I waited for my doctor to come in because he was running late, Ruth and I stood in the doorway for about fifteen minutes, and chatted and talked. She told me about her Writing as Healing class for cancer patients, and that's how I learned about this stuff.. not through the doctor.

Ruth, who set the tone for Chapter Two, is a coordinator for the UC Davis Cancer Care Network. Recall from that chapter the Writing as Healing course she developed, offering a supportive space for patients to experimentally and non-judgmentally write through the intensities which accompany and precipitate out of surgery, chemotherapy, and radiation. Ruth volunteers her time, and provides all the resources required to implement this class on a weekly basis, which is striking considering the offering of this workshop was instrumental in helping the UC Davis Cancer Center achieve comprehensive care designation in 2013 from the National Cancer Institute (NCI).

Holle believes that her oncologists didn't make any recommendations to attend this class or to access patient programming because of a "breakdown" in communication and an undervaluing of supportive services. Speaking to a difference in perspectives, and imagining herself in Ruth's position, she explains that,

I can also see how it would be really hard to get the doctor's attention to say, 'Excuse me, could you just listen to this little pitch for ten minutes about why this is of value to your patients?' I can see why that doctor is not going to sit around and do that, or consider that part of his job description. It's clutter as far as he is concerned.

In addition to the Writing as Healing course and the yoga class, Holle also participates in a yoga class for cardiac patients, organized, financed, and taught by Linda—one of the most intrepid nurses working in conventional clinical contexts that I've ever met, but whose schedule was impervious to conversations requiring more time than afforded by the length of hallways between patients. Clarifying the importance of this kind of

programming, Holle contends that, “my having gotten into Writing as Healing, the cancer yoga programs, has made the quality of my life, as a survivor, so much better. I mean, I can't even tell you, the quality of my life hasn't come from the treatment that saved my life.”

Having been treated by many kinds of health professionals, Holle suggests that there is “a cultural difference” between conventional and integrative approaches to medicine:

I have a lot of doctors. My radiation oncologist, is a fabulous doctor. He saved my life. He was in charge of all the treatment around my radiation. But never in all the times that I've seen him, and I've seen him over fifty times, has he touched me. His demeanour is totally clinical. He didn't even get within an energy range with me even when it was the scariest— when we weren't sure I was going to live, or when I finished treatment and I couldn't swallow for six months because the inside of my throat was burnt so badly, it was just raw. His ability to be able to be so scientific makes him a really good doctor, but from a patient's perspective, it's hard.

This absence of touch registered for Holle as a lack of compassion or acknowledgement for her suffering. However, in the writing course, crafting and sharing stories about the difficulties of treatment, she became part of a conversation about conventional cancer treatment. Speaking to those discussions, Holle indicates that, “Ruth helped me see [that] all the doctors are different.” What might read as an obvious statement, Holle's participation in the Writing as Healing program has helped her make sense of the treatment she received from her oncologist.

Participating in courses where the modelling of sensitive bodies informed integrative interventions that complement conventional oncology, Holle felt a kind of support for her embodied experience that allowed her to recognize not only the technological achievements that biomedicine has made, but as well, that she was being cared for even if the treatment she received felt impersonal, and focused on her disease. In relation to her most recent radiation treatments, Holle described radiotherapy as, “extraordinary” explaining that the oncologists and medical professionals who work in this field, “what they know, what they can do with the technology... what they do, it is so important.” Nevertheless, “going in for radiation, everyday, psychologically it was killer. It was killer... they got it down to a system that works really well for them, but it’s really impersonal for a patient.”

For Holle, the “impersonal” characteristics of her radiation treatment were carved into the chambered landscape of the clinic—of the way she was moved through various rooms, holding, changing, waiting—of hallways lined with radiotherapy masks, their perforated surfaces contoured to the faces of many others, the haunting and haunted quality of their shape. Her sense of being cared for in these spaces was particularly eroded by the way she was prepped for her radiation treatments. She spoke of the consistency of nurses who would unflinchingly bolt her to the radiotherapy machine using the mask made to shield the parts of Holle’s head and neck that were not meant to receive radiation treatment. She described the terror she felt being fastened to a table, her skin pulled taught by the plastic contours of her mask. She expressed how confused she was that her fear wasn’t registered

by the nurses or anyone around her—that she only ever heard the word “ok,” as the nurses each day would pat on her leg before leaving the room to start the treatment leaving Holle alone with the intimidating whirl of the radiotherapy machine.

I have never felt so vulnerable in my life. I’ve never felt so exposed, in my *whole life*. No one deals with that. I mean they have this wonderful system, the nurses are nice, but you know, they’re doing their job. There’s a total disconnect, not with every doctor, but with the vast majority. And now, I understand why. They’re scientists to begin with; they have expectations for how many patients they need to see, for how much time they can allot to each patient. I know that they have a lot of challenges.

With Ruth’s facilitation, the Writing as Healing program helped Holle to understand that the conventional oncologists do care about her, but are faced with limitations conditioned by their training, but also by the practical and institutional constraints that they work in. Holle’s involvement in whole patient interventions has provided her with a glimmer of encouragement that oncology is “moving toward a more compassionate, kind of sensitivity, around cancer.”

Ever considerate of others, Holle explained that,

My fear is that, most people who are treated, have never had an experience of anything other than clinical, and they don’t have an expectation that it would be any other way. It’s been that next step above the clinical that has really helped me accept that even now, five years later, one more time, when my oncologists office called to tell me, ‘Yes it came back cancer,’ I can handle that in a whole different way.

Finding spaces like the writing course, and practices like yoga that strengthen Holle by providing her with support and expressive outlet for the emotions, questions, agitations,

and uncertainties she feels, make it possible for her to live despite the cancer diagnoses and the health complications that keep piling on. These integrative interventions have,

Given me a tremendous compassion for people, and a tremendous ability to be able to say. Today is Wednesday. I'm going to yoga at 2:00pm...It doesn't have to be bigger than that. And tomorrow will be Thursday. And that's the way I learned to look at things.

The compassion that Holle was able to cultivate through her involvement in integrative programming flags an important distinction for understanding further the difference between conventional and integrative approaches.

Integrative responses

In the accounts provided by Felix, Donald, and Holle, integrative oncology is imagined as a caring and compassionate practice—one that creates time to understand what patients need to live well through their treatments. This practice registers as caring and compassionate not because integrative oncologists necessarily care more or are more careful. Indeed, Peter, a conventional hematologist certainly makes time for his patients and endeavours to understand their lives, and the integrative approach still requires that patients undergo the painful procedures of surgery, chemotherapy, and or radiation.

Rather, what I want to suggest is that integrative oncology is imagined in these terms because it provides a quality of care different in its sensitivities—it is a kind of caring

that *responds* to and takes *responsibility* for the dichotomizing and alienating treatment of cancer in biomedicine.

My invocation of responsibility here is influenced by the work of feminist scholars Karen Barad (2007, 2012) and Donna Haraway (2008, 2012). Responsibility is part of the story of “agential realism” that Barad crafts as a framework for understanding how “practices of knowing are specific material engagements that participate in (re)configuring the world” (2007: 91). Barad uses the term “intra-action” to describe how matter is produced in the actions of ongoing and contingent entanglements of apparatuses and phenomena. Barad states that, “In an agential realist account, matter does not refer to a fixed substance; rather, *matter is substance in its intra-active becoming—not a thing but a doing, a congealing of agency. Matter is a stabilizing and destabilizing process of iterative intra-activity*” (2007: 151, emphasis in original). For Barad, the substances of the universe—facts, objects, and beings human and non, are all mutually and constantly constituted through intra-actions. Part of accounting for these intra-actions involves attending to how phenomena and apparatuses have been arranged—how the possibilities of intra-action are conditioned and constrained by expressions of agency. Barad refers to this as the “cut”—the “marks left on bodies” which reveal “particular patterns of the world as a result of the specific cuts and reconfigurations that are enacted” (2007: 176). The cut thus expresses how agentic enactments have created relations between one thing over and sometimes at the expense of another thing. For Barad, responsibility is a form of

attending to these cuts—an “accountability for the lively relationalities of becoming of which we are a part” (2012: 393).

In chorus with Barad, Haraway suggests that responsibility—the accountability of “caring for and being affected” (2008: 36)—concerns the “capacity to respond” (71). Thinking with Barad, Haraway suggests that “responsibility is a relationship crafted in intra-action through which entities, subjects and objects, come into being” (ibid). For Haraway, responding to the others we become with in our intra-actions requires learning to hold regard—the “understanding that meeting the look of the other is a condition of having face oneself” (88). Haraway’s conception of the ability to respond, this “responsibility,” is couched in her own endeavours to cultivate practices of radical companionship and becoming with animals—relations which “share suffering” (88) by acknowledging the complex cuts that have configured the uneven relation of power between humans and animals.

Pulling these points together, Astrid Schrader states that, “responsibility then entails the accounting for the practices that enact a specific cut” (2010: 286). Considered in the case of care in integrative oncology, these practitioners enact responsibility insofar as their practices respond to the cuts made between mind and body, spirit and flesh carved in the bodies of biomedicine—a view that conditions treatment protocols in oncology and the regimes of evidence that shape what gets to be legitimated as treatment. By becoming sensitive to the limitations of biomedicine and its conceptions of bodies and disease for

treating cancer—a disease that affects and is affected by more than biology—integrative oncologists are learning how to share in the suffering of their patients. They are learning how to respond to needs of their patients. They are becoming response-able by recognizing the cuts that have shaped their practice—cleaving of mind from body in biomedicine, and the double reification I wrote about in Chapter Three that teaches physicians to dislodge all emotion from their practice, and to treat their patients as objects. Integrative oncologists and the practitioners developing integrative programming for patients are becoming response-able to people living with and dying of cancer through contact with different ideas about bodies and disease derived from the complementary therapies that are used to constitute this approach—therapies that have been assembled by different cuts—different alignments of agency. Acts of care and compassion in this field—making sure patients have resources for emotional and psychological support, inviting patients to talk openly about their fears and anxieties, providing guidance on what to eat, what kinds of exercise to pursue—express emergent forms of response-ability. These are enactments of accountability for the wretchedness of conventional oncology that so many patients have experienced, and this form of caring activates different response to cancer and its treatment.

Moreover it precisely the responsibility and response-ability required of integrative approaches that provides further insight into why conventional oncologists are so reluctant to take on an integrative approach. There is a burden to the responsibility of integrative work—of sustaining regard for stories of suffering, pain, and fear as critical to

treating cancer. This requires taking responsibility for all the hurt that precipitates out of conventional treatment. Further, responsibility is burdened by the uncertainty of the pick—of choosing the right therapies, the right supplements, to right words to support the individualized needs of patients as they emerge, ensuring their mind, body, and spirit are being treated.² What an integrative oncologist recommends might not make a patient's life any better or any different from conventional therapy. I get the sense that it is the trouble of this knowing—the uncertainty of whether the output of caring for and responding to patients in their living with cancer will make a difference—that accounts for the reluctance of oncologists to engage this approach.

Politics and care

Where the care-filled and compassionate practices of integrative oncology seem to be taking responsibility for the cuts that have fashioned the seemingly careless approach to cancer treatment in biomedicine, I am nevertheless chilled by the troubling thought that not all patients will experience this quality of response.

I want to avoid romanticizing this practice, or suggesting that integrative oncology is governed by morals and ethics which are more principled than conventional oncology.

² Insight on the burden of responsibility here informed by discussions with Ken Little regarding his essay "Parca's Picks"—a section from his forthcoming ethnography on tourism at the edges of everyday life in Belize.

Where integrative oncology is currently a form of medical care that can only be accessed by people like Nissa who have the advantage of top-tier insurance, or the patients that Felix and Donald see who can afford to pay out of pocket, we see that integrative oncology is highly classed, begging the question of whether care in medical practice is something that has to be bought?

Staying with this trouble (c.f. Haraway 2010b), I'm reminded of Michelle Murphy's insistence of the "non-innocence" of care (2015: 5). The response-ability I see being cultivated in integrative oncology in relation to the consideration of the sensitivity of bodies activated by the incorporation of ideas about bodies and disease pulled from complementary modalities of medicine might also be interpreted, or problematized, as a complex response to the "therapeutic ethos" that drives the consumption of health practices in the West. This ethos, identified by T. J. Jackson Lears (2010), encourages people to consume therapeutic practices focused on "physic and physical health" as a means of self-realization (2010: 4). This "obsessive concern" with consuming health practices to better oneself is part of the shift toward the biomedicalization of medicine in the twentieth century, instantiated by the commodification of health (Clarke et al. 2003), the focus on health as a calculation of risk (Petryna 2002, Dumit 2013); management and self-surveillance (Rose 2007); technoscientific innovations (Franklin and Lock 2003, Thompson 2005); the proliferation and dissemination of medical and scientific knowledge beyond professional communities (Martin 1994); and the embodiment of these aforementioned processes in "medicalizing" phenomena previously unmanaged by

medicine. Together, these changes have subjected people to novel forms of management and self-care practices (Foucault 1988) that encourage them to “seek health information and health products” (Briggs and Hallin 2007: 44; see also Dumit 2004, 2013).

Integrative oncologists definitely recognize that their field is implicated in this change, and that their practice attracts the kind of patient who has learned that, “health [is] an individual goal” (Kleinman and Petryna 2001: 9). As David, a psychiatrist and a prominent integrative physician introduced in Chapter One explains that integrative medicine,

Tends to attract people who are health-conscious, who want to look after their health. They tend to be the kinds of patients who like to be involved in the treatment system. And, Americans spend more out of pocket for integrative care than they do for out of pocket for primary medical care. They make more visits to alternative practitioners than they do to mainstream medical practitioners. So it's huge, and a growing field especially in California.

Situating his comments further, David tells me that,

A lot of the push for integrative medicine has not come from doctors, but from patients. I think patients themselves see that high tech medicine is not the whole story, and that we've lost something in the very technological orientation of medicine. You know, doctors have become biotechnicians, or ‘providers,’ a term that makes my skin crawl, because the insurance system has hijacked healthcare. People are looking for the emotional support that they used to get from doctors, who knew how to help people cope with serious illness.

David's comments make clear that while integrative medicine, and more specifically integrative oncology, services the biopolitical care of the self that pulls on patients and pushes them through office doors, he imagines that the kind of care he enacts in his

practice resists the commodification of medicine because he cares for his patients, and provides them with the medical and emotional support they require to live with diseases such as cancer.

But all of the individuals I spoke to who pursued or were pursuing integrative oncology were white, middle class women. These are the kinds of patients who have the ability to leverage their economic resources for a different kind of care. Where does this leave those who want to be cared for differently, who want their needs, their pain, their sense of displacement within a system that is supposed to save them, responded to but are nevertheless not in a position to access the compassion and responsiveness of integrative oncology? Returning to the conversation which began this chapter and structure the next, what alternatives are these patients left with—what kinds of living and liveable ideas of dying are they afforded?

BODY

Arriving just minutes before the start of yoga class, I dart into a restroom to quickly change into clothing that allows for freer movement. As I head toward the space where the class is normally held, I notice the doors are closed. Nervously fumbling for my phone, Nissa pops her head out of an adjacent but much smaller conference room.

Motioning me toward the door, I see Anna pushing plush leather office chairs around in an effort to accommodate the positioning of seven people and their mats. With hands on her hip, the darkened collar of her light-grey t-shirt hinting at her participation in this reorganization, Holle describes this situation as a “shame.” “That room is booked special for Anna and this class.” Stopping herself at what I think is a threshold of criticism, Holle takes a breath and redirects her comments, “But she’s great. Anna just came in here, moved everything, and made it work.”

I’m struck, motionless and wordless, by the absurdity of this situation. Of the seven people who attend this class, two are in active treatment for cancer, two are in remission, and one was just diagnosed with cancer, yet again. Each has described to me how immeasurably beneficial this class is to their quality of life—that even on days when they cannot hold a single pose, they feel the sanative effects of sitting and breathing deeply with others who understand the weight of exhaustion bored into their bodies by biomedicine. And here they are, in weakened states, helping Anna, who volunteers her time and energy to instruct this course on a weekly basis, move heavy furniture in order

to improvise a space in which to practice—each implicated in a medical context that is just starting to recognize the importance of integrative interventions, but nonetheless, schedules this class in the evening, in an office building unstaffed after 6:00pm. Anna could have easily posted a sign and cancelled the class when met with the locked door, but as someone who cites yoga as integral to surviving breast cancer, she turned every handle on the floor until something gave way.

Still standing in the doorway, I hear Anna begin to invite the room to settle into their mats. I slip into a space left for me between the chairs from which Holle and Keana practice seated yoga. I am surprised to see Keana—it's been two weeks since her mastectomy. Accompanied by her husband Luis, she registers my elated incredulity with a wink.

Anna decides that after the chaotic scrimmage that preceded the class, this session will be focused on “postures of patience and balance.” Anna, who normally remains on her mat, walks the room tonight, using touch to guide each person through the postures she calls out from her tiptoes. There is something about having to make a space for this evening's class that brings a different energy to the practice. In the shadow of the mahogany conference table, careful not to get tangled in the swaths of IT cables that decorate its underside, we bend, and stretch, and breathe atop a grey carpet patterned with cream, salmon, and mint squares.

As the class ends, some find their way to standing more quickly than others. When ready, mats get tucked under arms, and car keys are fished out of pockets and purses, jiggling in hand. I notice that Keana is moving with a considerable amount of hesitation tonight, needing Luis to assist with her every move off the chair. Already living with a neurological disorder that limits the mobility of her lower body, I turn to help Keana when Anna calls to me. Anna and I had planned to meet for tea after class, but Anna is too tired. Thanking everyone for attending, she heads for the lobby. Looking back into the room, I see Nissa helping to gather Keana's cardigan and water bottle.

I met Keana about a month ago when she first started attending the yoga class. At that time she had just received a diagnosis of breast cancer and been scheduled for surgery. As a social worker, Keana was familiar with and knew to seek outreach programming. On the night that I first met her, she stood tall in her petite frame, one hand clutched on her walker, the other on a heart pendant made of striated glass that hung from a black leather cord around her neck. She spoke about her refusal to frame the treatment of her cancer as a fight—an opposition of she versus it—her reluctance to think negatively, her willful embrace of “healthy, beautiful, and energizing food” and the love she felt for her juicer. She also spoke about her cancer as an “offering” and her unwillingness to “hate it because it is a piece of me.” She refused to use militaristic metaphors to describe her treatment, or to participate in the description of her body as a machine that needed repair. She explained that her cancer is a part of her and she of it—an entanglement that cannot

be unknotted. That first night, words pushed through tears, she explained that “I want to give it love and compassion. I want to honour it.”

Her cheeks dewy and crimson, I remember the clarity with which she expressed the fear and uncertainty she felt about the surgery, and the looming probability of adjuvant chemotherapy—the way she revealed how much energy and exertion it took hold onto these very different ideas about cancer and healing.

We continue to linger in the conference room doorway. Luis and I are quiet while Nissa and Keana discuss life after surgery. I learn that Nissa has been in consistent contact with Keana. Sharing similar diagnoses, and both deeply invested in positive thinking and sharing similar spiritual outlooks, Nissa has been instrumental in keeping Keana’s healing affirmations animated.

But, Keana confesses that her positivity is weaning. “I went on the internet. I started reading medical journals, and different websites.” Turning to Luis, she tells him “You should really put the parental controls on that thing.” He chuckles, but I notice his grip on their yoga mats has tightened.

Holding back tears, she talks about how difficult it has been since the surgery to hold onto the gratitude she once described with such fervour—to hold together all those different bodies required to enact and imagine her cancer in less toxic and threatening

terms. Her eyes welling up, she begins to cry as she tells us about the loss of her breast, that part of her is missing, that she is “grieving” a part of her that is dead, that she can’t get back, that was taken from her “unceremoniously.”

I notice that Nissa, with fingers pressed to her lips, is also beginning to cry. I’ve never seen her lose her composure in the company of cancer. In the many times Nissa and I have met for coffee, or shared lunch, ran errands together through Sacramento or chatted after yoga class, I’ve only ever seen her make that face that every person seems to make when death or its shadow comes into conversation—that contortion of a folded brow and a slight frown, the wrinkling and hardening of features that only ever conveys pity—a shield against the heavy burden of shared feeling.

Keana, hand wrapped around a kleenex that Luis took from his pocket, wipes her eyes. “I don’t like that my breast is in a bin, in a freezer *somewhere*.”

With this comment, my stomach sinks. A wave of nausea floods over my body. I remember what that kind of chamber looks like.

I remember following Trennen down into the belly of the medical laboratories at Stanford. As we headed to the “mouse room” he explained his post-doctoral research was using mice to examine preventive measures for graft versus host disease (GVHD) in bone marrow transplants for blood-based cancers—a complication which arises when the

grafted tissues react to and attack the recipient—a condition that manifest many different symptoms, and puts the recipient at great risk for infections and impairments.

At work in one of the most highly regarded research labs on blood and bone marrow transplantation in the United States, he emphasized to me the “very strict, extremely expensive, and very restricted” nature of mouse protocols—that the mice that he and his colleagues work with are treated with care, and valued for how important their lives are for developing research that will benefit the health of humans.

Opening the door to a room of wheeled shelves, stacked with Plexiglas boxes, Trennen inspected the groupings of mice assigned to his experiment. Attached to the outside of one box was a small black plastic bag which Trennen explained is a mouse that had died, left for him to inspect by Rosa, the worker who cares for the mice. He opened the bag, revealing a body that was more tumor than mouse. His sadness was perceptible as he sighed and slowly fished through his pockets for a pen to record the details of this death—a dispiritedness that spoke to both the loss of the mouse, and the problem its death posed for the intervention he was testing.

We left the room, Trennan’s hand wrapped around the knot at the top of the bag, the contour of the terrifying large tumor pressing and protruding into the plastic, swinging gently in matched time to his gait.

I walked with Trennen through countless hallways and through doors that beeped and opened in response to his keycard. We passed people in lab coats pushing carts of instruments, and people in scrub-like uniforms pushing vats of linens. Turning down a corridor lined with giant teal coloured pipes, Trennen swiped his keycard once more, we entered a large room containing two trailer sized stainless steel boxes framed by security cameras and covered in warning signs, signalling the dangers of the contents. As he entered the lock code and heaved open the massive door, a cloud of odorless, frozen vapors poured out onto the floor. Overtaken by chills, I watched as the gelid fog dissipated to reveal a chamber stuffed with round Rubbermaid buckets, each lined with red plastic bags and labeled with stickers that declared biohazard and medical waste.

Trennen changed his gloves and indiscriminate in his choice, pulled the lid off one of the buckets to deposit his bag. Sealing the bin, and closing the door, he took off his gloves and logged his entry on a nearby sheet. I stood motionless, unable to muster any questions, frostbitten by the thought of what was in those buckets, all those parts, all those bodies connected to and in those bins, shocked that he did this all in shower sandals.

I don't tell Keana any of this. I just stood with her, gripped by the image of her breast wrapped in a black plastic bag, left to freeze in the cold of this containment.

Exhaling, Keana tells us that she is very tired. There's nothing to say after that. Nothing that can placate the feeling of being torn apart, torn to pieces by the very thing that is supposed to save you. There's no comment that can recuperate the unknowability of where her breast went, or what happened to those tissues once removed. Even after my time in that basement, this is an object lesson I still hesitate to undertake.

Nissa and Luis mention that they want to put the chairs back in place before leaving the room, and I suggest that Keana and I get some air. We move slowly into the hallway which overlooks the two storey atrium of this building. She remarks that the windows, now letting in what remains of the daylight, "look like prison windows" and we both comment on the mobile of abstract metal panels in unfamiliar forms that hangs from the ceiling, intensifying the already uninviting atmosphere of this building.

"I didn't notice this mobile before now." Keana smirks, "I didn't want to notice it last time."

CHAPTER FIVE: ALTERNATIVES

I remember sitting with my mum in the waiting room of her oncologist's office. She had given up on wearing wigs at that point—the heat and itch of synthetic fibres against her almost bare scalp had become intolerable. After two rounds of chemotherapy at two different hospitals, she was left with short, patchy stubble that she kept covered with cotton scarves taken from a collection I had kept in high school. Hands wrapped around the strap of the purse resting in her lap, she voiced concerns about the next phase of her treatments. The precise composition of those words have since dissolved from my memory, but the strained quality of her voice still reverberates in my body.

She was describing the treatments ahead of her as a participant enrolled in a clinical trial researching autogenic hematopoietic stem cell transplantation for non-Hodgkin lymphoma patients—the same procedure Peter counselled his patient on in the previous chapter. As if to remind herself, she listed the procedures that she would soon undergo—the neupogen injections to stimulate white blood cell production in her body, the extraction of her bone marrow, the high dose chemotherapy, and the graft of her own stem cells. I could feel her anticipating the all too familiar fallout out of these procedures—the skin rashes, the mouth sores, the intense nausea and diarrhea, the inability to eat, the exhaustion, the immobility, and the isolation of a month-long hospital stay.

As she spoke, her voice shifted from tense to sour. I felt displaced in this shift—cross that she would express such resentment for being selected to participate in a trial that might keep her alive. Side effects aside, I wanted her to hold onto the broader context, I wanted her to latch onto the possibility that she might live and that the results of her involvement in this trial might improve the probability that other people affected by lymphomas as aggressive as hers might also live. I wanted her to perform some sense of optimism.

Feeling my eyes made heavy by the weight of tears finding form, I could not muster an encouraging remark. I looked to her and asked, “Mum, what is the alternative?”

Hearing this she lowered her head, focusing in on the contents of her purse, her hands wrestling around in an effort to find something. Quietly she replied, “There isn’t one.”

She died in a hospital bed six months after I asked that question, but not before completing the trial, finding out that her tumors had grown despite the matched aggression of the transplant procedure, and then undergoing a month of daily radiotherapy in a care-filled gesture by her medical team to keep her alive through Christmas.

...

I asked my mum that rather cruel question in the middle of her treatment. My phrasing came from a place of agitation, but also from a desire to understand what it was she

wanted from and for her treatment. Did she imagine something different— did she want something different? Could her complaints be catalysts for finding a therapy that suited her better? The possibilities connected to those questions collapsed under the weight of her reply—her feeling that there was nothing for her and the masses embedded in her mesentery other than biomedicine.

How is it that a patient with cancer can arrive at the feeling that there are no alternatives to biomedicine—that other forms of treatment are unimaginable, intangible, impossible? With these questions in hand, this final chapter moves toward an ending by returning to the beginning of this dissertation to reconsider one of the more critical distinctions put forth in understanding integrative oncology—that this field is not a form of *alternative medicine*.

As explored in the previous chapters, the credibility of integrative oncology has been constructed in relation to this point—that rather than reject conventional treatment methods as implicated in the idea of alternative medicine, the integrative approach takes up medical systems and healing modalities that can be incorporated alongside the therapeutic protocols of chemotherapy, radiation, immune and hormone therapy, and surgery as a means of responding to patient needs and demands by expanding therapeutic possibilities. Of concern in this chapter is understanding the relationship between alternative medicine and integrative oncology. To this end, I examine how the category of *complementary and alternative medicine* (CAM) is unsettled by integrative efforts to

redraw the boundaries between these practices. Paying attention to where and how the category of complementary and integrative medicine or CIM is being positioned as a replacement for CAM by integrative oncologists, I ask what alternative medicine becomes in the wake of this rearrangement. Moreover, in the case of treating cancer, a disease so evasive of cure, what does it mean to suggest that there are no alternatives to biomedicine? I take up these questions as a means of intensifying my engagement with the politics of evidence in biomedicine, deepening my understanding how a sensitive configuration of bodies matters for how people live and die with cancer in biomedicine.

What's in a name?

The term alternative medicine is used to refer to a range of medical systems and therapies practiced outside of biomedicine. A nebulous and rather unwieldily category, alternative medicine is deployed in integrative oncology to designate approaches which are not considered complementary to, or compatible with, conventional cancer treatment methods—fields such as indigenous medicine, folk medicine, shamanic healing, energy medicine, and homeopathy. All of these medicines continue to be lumped together as alternatives despite diverging in their conceptions of bodies and disease. For instance, homeopathy is a healing practice developed in the eighteenth century by the German physician Samuel Hahnemann who held that *like heals like* or rather, that a disease can be treated using dilutions of substances that produce the same symptoms when taken by a healthy person. As anthropologist Christine Barry explains, homeopathic remedies are

made using a sequence of dilutions, beginning with the “mother tincture” which involves soaking the substance of the remedy in alcohol (2003: 381). The mother solution is then diluted with water, and shaken vigorously. This process repeats several times, and with each dilution, the potency of the remedy increases. Remedies range in dose from 6C to 10M, or rather six times diluted to ten thousand times diluted. Homeopathic remedies work subtly to counteract illness, and the recommended doses of each remedy are developed through careful trials called “provings.”¹ Shamanic healing, on the other hand, is sought when illness is believed to be the matter of spirit possession. Performed in many cultures, shamanism involves the transformation of the healer and the person who is ill through ritualized practices that dispel unwelcome forces and energies (Kleinman and Sung 1979, Taussig 1987, Brown 1988).

Anthropologist Anamaria Iosif Ross suggests that in the making of alternative medicine, “multitudes of unrelated and profoundly different approaches to healing are commonly lumped together by consumers, the mass media, governments, and health professionals under this generous umbrella term, including herbal treatments that are millennia old, the latest raw-food diets that challenge the hygienic imperatives of capitalist public health polices, and rigorous rituals that posit an essential role for the soul within the complex processes of health, illness, and healing” (2012: 2). For Ross, however, it is the very attempt to stabilize all these different medicines under the blanket of alternative medicine

¹ Insights here taken from personal conversation with a homeopathic professional. 209

that speaks to the challenge that therapies deemed alternative actually pose to the dominance that biomedicine has achieved in North American society:

It is significant that *alter* means ‘other’ in Latin, as in the expression *alter ego* (which can mean a second self, a trusted friend, or the opposite side of a personality) and that the notion of alternative references the idea of choice, most commonly between mutually exclusive possibilities, as well as ‘different from the usual or conventional: existing or functioning outside the established cultural, social, or economic system.’ This captures the elusive social spirit of alternative medicine: its subversive and grassroots qualities, the lack of formulaic standardization, and the fact that authorities have devoted significant energy and resources to make sure that alternatives maintain less status, power and social recognition either alongside or within the margins of dominant systems (2012: 5).

The strategies that Ross gestures to here are manifold, and intimately connected to the histories of the holistic health movement in the United States. Returning to Hans Baer’s research on integrative medicine, he identifies how the holistic health movement emerged on the West coast, localizing in Californian cities like San Francisco (2004: xii, 1). He notes that this health movement gained traction as it became “intertwined” with New Ageism—a tethering which promoted “balance in the interaction of mind, body, and spirit in its attempts to archive experiential health and well-being” in and through a connection to Eastern medicines and philosophies (ibid).

As the holistic health movement continued to grow, with institutes and training facilities being established across California, as well as the formation of the American Holistic Medical Association in 1978, Baer elucidates how many biomedical physicians “began to recognize both the limitations of their conventional approach to illness and the fact that

they were losing many of the more affluent patients” to holistic health practitioners (2004: xiii). In response to what was effectively a loss of revenue, biomedical physicians started to incorporate holistic therapies into their practice (ibid). As historian Roy Porter points out, “[biomedicine] has often assimilated a fringe practice rather than lose patients en masse to marginal medicine” (in Baer 2004: 90). Baer cites that “the importance of nutrition, low-fat diets, and vitamin substances” along with the “concept of stress as a pathogen” were once “considered by many as quackery” but have since been incorporated into biomedicine.

The term *complementary and alternative medicine* (CAM) was formed as a means of categorizing these and other incorporated holistic health practices. As a “biomedical construction” (Baer 2004: xix), this term provided a means for physicians to take up the techniques of holistic health that were so attractive to their patients without putting their own practices at risk. Classifying holistic health practices as complementary or alternative reaffirmed the authority of biomedicine to decide what constitutes medical practice. Moreover, the production of complementary and alternative medicine as a biomedical category created the conditions, or rather, pressures for holistic health practitioners to “gain legitimacy by aligning themselves with the standards of the dominant (hegemonic) system of biomedicine and professionalization of practitioners” (Ross 2012: 36). Recognizing the “biomedical hegemony” at work in complementary and alternative medicine, Baer contends that biomedicine has become “the *dominant medical system* because of the fact that it exerts dominance over other

medical or therapeutic systems” (2004: xvii). In this sense, the classification of holistic health practices as either complementary or alternative to medicine is meant to “tame” the counter-hegemonic charge of these fields (Baer 2004: iv).

This control is particularly visible in the making of the category of alternative medicine. With the inception of integrative medicine, the line between complementary and alternative medicine has been etched more sharply in order to conceive of these categories as separate. Baer contends that integrative medicine, with its emphasis on complementarity, “appears to function as a style of health care in which biomedicine treats alternative therapists as subordinate and alternative therapies as adjuncts” (Baer 2004: xix). This is marked in “efforts to control production and access to traditional and alternative medicines by adopting a public health rhetoric of ‘risk management’” (Ross 2012: 36)—forms of discipline that might also be read as redolent with the charge of colonial-like responses to alterity given that many of the practices marked as alternative have roots in cultures beyond the west (Stoler 2002).

Importantly, Baer points out that categorizing medicines as alternative is “a matter of historical circumstances and sociocultural settings” (2004: xvi)—that what counts as alternative medicine bends and shifts in relation to a landscape best understood as conditioned by evidentiary regimes in biomedicine. As prominent medical anthropologists Margaret Lock and Vinh-Kim Nguyen argue, the “the limitations of biomedicine’s objective and standardized approach” arise in the positioning of certain

practices as “alternative” particularly when those therapies are accessed by many (2010: 54). Asking the question: *alternative for whom*, these scholars take issue with the assumption that “biomedicine should be the gold standard against which the worth of all other types of medical practice must be assessed” precisely because its measurements for the efficacy of given therapy are conditional to a materialist and reductionist view of the body (ibid)—a view that does not apply to all systems of healing.

The evidentiary regimes at work in biomedicine mean that only medical systems or therapies that pass the tests of the randomized controlled clinical trial, with its emphasis on measurable changes in the biological mechanisms of bodies, receive a gilded stamp of approval. This poses significant challenges for medical practices to gain traction and legitimacy in biomedicine when they use ideas about flows of energy, ecologies of celestial and earthly rhythms, or collections of humors rather than machine analogies to make sense of bodies.

The annexing of so many medical systems as alternatives gestures to the power of biomedical and bioscientific modes of evidence production, and the myopic focus on the clinical trial as a tool for assessing pharmaceuticals (Dumit 2012; see also Cassileth 2003). Further, anthropological work on alternative medicine has produced nuanced and careful accounts of these various practices, pointing to the trouble generated when questions about the efficacy and utility of these practices are asked from a biomedical point of view (Emad 1997, Micozzi 2002, Alder 2002, Barnes 2005). That the need for

evidence in support of the efficacy of such practices is rather more indicative of political and economic interests in keeping biomedicine as the dominant system of medical care.

Magic and medicine

Where biomedicine continues to figure and be figured as a medical system grounded in evidence, alternative medicine is said to be situated on less stable ground—terrain shaped by “belief” and “magic” rather than scientific proof. This dichotomy is particularly evident in discussions about alternative cancer treatments, especially those generated by integrative oncologists. Writing together, former presidents of the Society of Integrative Oncology (SIO), Barrie R. Cassileth and Gary Deng, argue that the use of alternative medicine in treating cancer, “is especially problematic in oncology, when delayed treatment can diminish the possibility of remission and cure. Moreover, interventions sold as literal alternatives to chemotherapy, surgery, and radiation therapy tend to be biologically active, potentially harmful, and extremely costly” (2004: 81). Notwithstanding that these caveats about harm and cost might also be said of conventional oncology, Cassileth and Deng suggest that the time spent investing in the “belief” that alternative medicine can be used to treat cancer is time better spent in conventional wards (2004: xv). These physicians deem herbal tinctures and supplements, detoxification and anti-cancer diets, cures, and high-dose vitamin injections as “questionable” cancer treatments, focusing especially on the “risk is that these therapies make false promises to desperate patients—results that cannot be delivered, representing

an act of deception and betrayal” (Cassileth and Deng 2013: 656). Particular issue is taken with “miraculous cancer cures” promised by supplements such as caesium chloride (CsCl) which change the pH level of the body to high or alkaline state said to be inhospitable to cancer (Cassileth and Deng 2013: 658). Criticisms are also organized around anti-cancer teas such as Essiac, and places like the Gerson Clinic in Tijuana, Mexico—a center that provides treatment based on the idea that cancer is the result of toxins accumulating in the body, and uses detoxifying protocols such as juice cleanses, coffee enemas, and organic, vegetarian eating as treatment methods (Cassileth and Deng 2004: 83).

In her ethnographic work on the circulation of Tibetan medicine in United States, medical anthropologist Vicanne Adams (2002) homes in on the distinctions made between science and magic in the making of alternative medicine as a condition of capitalism. Adams is interested in “the ways market interests become wedded to, and in some cases undergirded by, scientific knowledge practice that, long after capitalism, continue to serve as instruments for producing globalized medical ‘truth’” (2002: 661). In speaking to the appeal of alternatives, Adams suggests that it is the very “belief in the spiritual healing qualities of Asian medicines that constitutes a large part of their attraction among consumers who suspect that the cultural differences available in Asian medicines... will give them a pharmacological advantage over existing biomedical *materia medica*” (2002: 665). This idea that non-Western medicines have some as yet untapped resource for healing perpetuates colonial imaginaries which exotify these practices, and permit the

selective consumption of their ideas and techniques. However, this “magical thinking” is also a poignant form of hope—a desire for how different substances, therapies, and knowledge about bodies will provide other means of living—a feeling that resonates with the dissatisfaction with conventional medical practices that drives patients and practitioners to pursue other methods.

The insistence that alternatives are based in belief and magic serves to separate these modalities from biomedicine—to suggest that there are irreconcilable, metaphysical differences between alternative medicines and Western medicine. But this insistence overlooks just how enmeshed alternative practitioners are in the politics and economics of biomedical practice—that their practices are also subject to the regulatory legal structures such as licensure legislation in the United States.²

Adams reminds me that it precisely the magical register of alternative medicine “that needs to be shed for medical legitimacy” (Adams 2002: 669). However, in Adam’s terms, eliminating this register in and through attempts to produce evidence for the efficacy of alternatives is a requirement that is less about proving these practices than it is about conforming alternatives to capitalist conventions. Broadening Adam’s argument, sociologists David Hess makes the point that there is “ample historical evidence that pharmaceutical and biotechnology companies have profited from patented chemotherapy

² See summary of licensure issues of complementary and alternative medicine as presented by the Policy Forum of the American Medical Association: <http://journalofethics.ama-assn.org/2011/06/pfor1-1106.html>

and immunotherapy products, as do oncologists who employ those products” (2000: 78). Adams contends that the positioning of alternative medicine as unsafe or unscientific permits “the state to protect its citizens while retaining for itself the role of arbiter of who benefits from its potential profitability” (2002: 668).

And it is this arbitration that accounts for the separation between complementary and alternative medicine—that medicines are shifted from one category to the other when their profitability and commodification is made evident, and the modality is “seen as in need of being explained – biologically, molecularly, cellularly, biochemically” (2002: 673). As Adam argues, “The public generally refuses to play by the rules of science – consuming medicines that aren’t proven, believing in things like healing images of Buddhas or in names of diseases or patterns of treatment that simply don’t make biomedical sense (and certainly can’t be tested simply). In this case, the invocation of clinical trials becomes essential to the effort to control and obtain profits” (2002: 682). Indeed, the inception of National Center for Complementary and Alternative Medicine (NCCAM) at the National Institutes of Health, located in Bethesda, Maryland, in the 1990s speaks to this—to the recognition that people were seeking medical treatment from practices other than biomedicine. This center allowed for their study and for the authority on these kinds of practices to be firmly rooted in biomedicine.

Together, these analyses of the relationship between alternative medicine and biomedicine reveals the instability of this classification—that what counts as an

alternative to and for biomedicine is constantly being contested, and is conditional and contextual such that biomedical authority is also being made and remade through the work of classifying therapies as alternative or complementary. But what happens to all this labour, the visibility of these contestations and negotiations around the hegemonic hold of biomedicine over bodies and their health in doing away with the category of alternatives in the move toward *complementary and integrative medicine* (CIM)? What is at stake with CIM?

Complementary and integrative medicine

As a health movement, integrative approaches to medicine attempt to “blend biomedical and CAM therapies” (Baer 2004: iv). The term *complementary and integrative medicine* or CIM is meant to signal this emerging collaborative effort. Hans Baer suggests that this coupling is a deliberate effort to counteract the perception of CAM therapies as “tools that are simply added to the current model” (2004: xix)—tools that, ostensibly, can be taken out when the job requirements change. Integration, in this sense, is meant to signal an effort to incorporate complementary therapies as techniques and methods that are integral to the biomedical treatment model.

Donald was the first integrative oncologist who tuned me into how integrative oncologists are attempting to redraw the topographies of the complementary and alternative medicine landscape.

The major thrust of what I do with cancer patients is really focused on nutrition and supplements. I'm more in the categories of integrative medicines. I don't like the word CAM.

Asking him to elaborate, he took a rather stern tone as if to make clear that he does not waver on this point:

I have an aversion to the word CAM because it is complementary and alternative medicine; complementary means you're using it in addition to, and alternative means you're using it instead of. How can something be both complementary and alternative? So the fact that those two got clumped together to make that easy to say as an acronym is unfortunate because it doesn't make sense. It's a bad word.

The deviance of this acronym rests for Donald in its inaccuracy:

Rarely do people come to see me looking for an alternative to conventional care. Five percent of the people I see here sneak in thinking that I have some magic cure. The majority of people are coming because they want a complementary program to integrate into their conventional therapy.

Donald's position on alternative medicine is one that he has published widely, and one that has some weight considering his prominence in the field. Editorializing his opinion for the *New England Journal of Medicine*, Donald proclaimed that, "Continuing to equate integrative and alternative medicine...is uninformed and inexcusable" precisely because "alternative therapies are used instead of conventional interventions, often without evidence of effectiveness" (2012: 2232). In a chapter he wrote for a volume on communication issues with cancer patients, a copy of which he dug out for me from a pile of supplementary materials he has photocopied for patients, Donald states of CAM that, "the whole concept is a bit of an oxymoron... *Integrative* gives a much clearer

picture that these interventions are being used in conjunction with conventional treatment options” (2013: 82). Further, in a subsection in the article on patients seeking alternative medicines, he reasons,

Patients seeking alternates have generally bought in to some degree of the ‘slash, burn, and poison’ concept of traditional cancer care and desire to avoid surgery, radiation, and chemotherapy at all costs. Try as one might, it is often difficult to dissuade such patients from their alternative paths... It is important in these situations to get as complete an understanding as possible of what has led the patient away from conventional interventions (2013: 87).

He also suggests that many patients are,

Steered to ‘alternative’ practitioners by family, friends, popular books, or Internet links. Often visits to these providers are not covered by insurance companies, and cash up front, usually large sums, is required. Despite patients, especially those who may have run out of options, are often willing to make a financial sacrifice for the hope of prolonged survival (2013: 88).

For Donald, effective communication in integrative oncology entails clarifying the difference between alternative and complementary approaches, leading patients away from what he sees as such unconventional, and unsafe pursuits. He contends that CIM will help with this process as it better expresses that integrative approaches do not use alternative medicine.

This project of clarifying the terms of complementary, alternative, and integrative medicine is one that has moved beyond the consultation rooms as point of clarification between physician and patient, to become an important argument for the professionalization of integrative oncology. American Organizations such as the

Academic Consortium for Integrative Medicine and Health (The Consortium) and the Society for Integrative Oncology (SIO) have been promoting CIM since the early 2000s as a means of situating the difference between alternative and integrative medicine, aligning the later with biomedicine and the growing evidence-base which supports the complementarity of its methods.

The circulation and promotion of this term has been effective. In December 2014, a year after I completed my fieldwork, the National Center for Complementary and Alternative Medicine (NCCAM), an office of the federally run National Institutes of Health (NIH) was renamed the National Center for Complementary and Integrative Health (NCCIH). In a press release explaining this new designation, the NCCIH clarified that, “the use of alternative medicine—unproven practices used in place of conventional medicine—is rare” and as such, priority needs to be given to “the study of complementary approaches” (2014). The bulletin also assures that, the NCCIH “will continue to focus on the study of the usefulness and safety of complementary and integrative interventions, and provide the public with research based information to guide health care decision making” (2014). Here, the jettisoning of alternative medicine from the auspices of the NIH is explained as a matter of the infrequent use of alternative medicine, and a dearth of evidence to support the safety of these practices and their continued study. The not so subtle implication in this rebranding is that there has been an increase in the consumption of integrative medicine by patients in the United States, such that this field now requires more state regulation and state-sanctioned study of such

modalities. This recategorization is resonant with the points made in the previous section concerning the way in which the permeability of the boundaries in and around biomedicine change in order to maintain the political and economic dominance of this medical system. In displacing alternatives, complementary and integrative medicine gets folded into the machinery of biomedicine, ensuring that investments in these systems of healing strengthen this hegemonic infrastructure.

Moreover, this dislocation of alternatives at the level of the state is deeply troubling as it gives the impression that there are no alternatives to biomedicine, and that the interrelation between alternatives and biomedicine isn't being actively negotiated. The inaccuracy of this could not be more visible in two legal battles regarding alternative medicine that recently unfolded in the United States and in Canada.

In September of 2014, a 17 year old girl from Windsor, Connecticut identified as Cassandra C was diagnosed with Hodgkins lymphoma—a cancer affecting white blood cells that is treatable with chemotherapy, radiation, or stem cell transplantation. Cassandra, with the support of her mother, Jackie Fortin, refused the recommended course of chemotherapy in favour of alternative treatments (Walters 2015). Shortly after, Cassandra's physicians reported Jackie to the Connecticut Department of Children and Families (DCF), claiming that Jackie had neglected Cassandra by not attending to her medical needs (Wilkinson 2015). Fortin lost legal custody, and in a dramatic display of state power, the DCF and the Windsor-Locks police force surrounded their home,

extricating Cassandra and placing her into wardship. Cassandra was then given the option to return to her mother if she agreed to undergo chemotherapy. After two sessions, Cassandra ran away from home in an attempt to avoid further treatments (Walters 2015). Worried about the legal implications of her actions for herself and her mother, Cassandra returned home. The DCF then sought custody of Cassandra, claiming that her cancer was incurable without chemotherapy, and that the state had a responsibility to ensure her treatment. The Connecticut supreme court granted temporary custody of Cassandra to the DCF, and after a failed attempt at an injunction against this ruling by Cassandra and her family, she was legally confined at the Connecticut Children's Medical Center in Hartford. In the middle of the six rounds of chemotherapy, Cassandra published an online commentary in which she wrote that,

This experience has been a continuous nightmare. I want the right to make my medical decisions. It's disgusting that I'm fighting for a right that I and anyone in my situation should already have. This is my life and my body, not DCF's and not the state's. I am a human — I should be able to decide if I do or don't want chemotherapy. Whether I live 17 years or 100 years should not be anyone's choice but mine (C 2015).

A case similar to Cassandra's went before Ontario courts in the fall of 2014 when the McMaster Children's Hospital and a team of doctors attempted to gain legal custody of J.J., an 11 year old Haudenosaunee girl from Brampton, Ontario. J.J. who was diagnosed with leukemia, and after the first week of chemotherapy, her mother decided that her cancer would be better treated with alternative medicine and indigenous medicine (Walker 2015). J.J. was taken to the Hippocrates Health Institute in West Palm Beach,

Florida—the very same private institute where Makayla Sault of the Mississaugas of the New Credit First Nation had received treatment before her death in January of 2015.³

J.J. was imbibing green juices and raw vegetables at the Hippocrates Health Institute while her case was being debated in a Brampton court. Ontario Judge Gethin Edward ruled that J.J. did not need legal protection, and that the decisions made by her family regarding her treatment “[exercised] her constitutional protected right to pursue their traditional medicine” (in Rieti 2014). With this ruling, J.J. was provided legal support by the Ontario government to develop a treatment program using a combination of Haudenosaunee medicine, alternative treatments, and conventional oncology. Unlike Cassandra’s case, the Brant Children’s Aid Society (CAS) did not get involved in the custody claims made by the McMaster Children’s Hospital out of “respect [for] First Nations Culture” (Walker 2015)—a hesitancy which speaks of a sensitivity toward the histories of violent state intervention in the displacement and management of aboriginal communities (Richardson and Stanbrook 2015). In March of 2015, J.J.’s cancer returned after a short period of remission.

Missing from many of the press articles on these stories is a nuanced concern for what motivated the pursuit of alternatives in both cases—that many people seek alternative

³ Sault was being treated for acute lymphoblastic leukemia which involves an overproduction of immature white blood cells, or lymphoblasts. This cancer is more common in children, but can be treated with chemotherapy. Sault began with alternative and indigenous medicine to treat her cancer, but later pursued chemotherapy and radiation. Chief Bryan LaForme of the New Credit First Nation, speaking on behalf of Sault’s family, claimed that she died of a stroke and the accumulated side-effects of conventional therapy (Galloway 2015).

medicines because they have already experienced the toll that conventional approaches take on their bodies, their families, and their solvency. There's also no mention of the economic conditions of each case—of whether an abundance of resources shaped the interest in accessing treatments for J.J. and Mykala at the Hippocrates Health Institute, or whether an absence of health insurance or an inability to shoulder the cost of chemotherapy, radiation, and the many prescriptions that accumulate with those treatments directed Jackie and Cassandra's attempt at seeking less expensive alternative treatments.

These stories, specific to the question of alternative medical use in the case of a minor, are nevertheless revealing of contradictory tensions around alternatives—that alternative medicine is irrelevant to the practice of biomedicine only until its use undermines the social dominance of biomedicine. To this end, writer and political analyst Will Wilkinson (2015) argues that a case like Cassandra's is significant not only for how it engages existing debates concerning medical consent, but that it also exposes the authority of biomedicine over legislative and enforcement apparatuses:

[Jackie's] standing as legal guardian with the authority to make decisions on her daughter's behalf was, in effect, *conditional* upon her agreement with the prescriptions of the doctors. That is to say, she never really had any meaningful authority in the matter. Her refusal to submit with sufficient alacrity to the will of the doctors was taken as evidence that she was unfit to be entrusted with this authority (emphasis added).

As Wilkinson makes clear, Jackie lost custody of Cassandra because of an attempt to resist the biomedical management of Cassandra's leukemia by pursuing alternative cancer treatment.

It is precisely because these cases concern minors that the knotty connections between biomedicine and the apparatuses of the law is revealed—a thicket of disciplinary power that is otherwise invisible in situations where adults refuse biomedical treatment in pursuit of alternatives. These cases offer perspective into how biomedicine and the law work together to exert control over life (Foucault 1978), making clear that contestations concerning alternative medicine are always already about making citizens— or to reiterate Wilkinson's point, that citizenship is imagined in relation to, and conditioned by, certain kinds of medicine. Because these are children, the stakes are much higher to ensure that they will become citizens who will aspire to take care of themselves in a manner that is consistent with biomedicine, and in service of the state (Pertryna 2002: 13).

Further, these contestations also reveal how important it is that patients feel a sense of agency in the decisions they make about cancer treatment—that there is a need for, and recognition needed of, spaces and practices outside of biomedicine that can be used to imagine how care could be different particularly for people who think their bodies might be treated better beyond conventional treatment. Alternatives, in this regard, are

especially important for people whose bodies are too sensitive for conventional treatments.

Alternatives matter

On a fall evening I find my office filled with the raised vowels and missing r's of Gemma's beautiful New York accent as it pours quickly and steadily out of my cell phone. Introduced in Chapter Two, Gemma is a patient advocate who runs a small nonprofit organization with a large online presence that provides information and advocacy for people with cancer interested in complementary and alternative medical treatments. From her home in Florida, Gemma and I reconnect after our truncated meeting weeks before at a Society for Integrative Oncology in Vancouver, British Columbia. We speak for hours—a duration made of our mutual interest in the topics at hand, and the many phone calls she receives during our conversation—calls from the advocates she advises, calls from people who have found her website and are seeking advice, and a call from her husband, wondering when her workday will end.

As a patient advocate, Gemma tells me that she “represents the patient's perspective and interests”—a charge she carries with her to dozens of medical conferences across the United States where she, admittedly, provokes medical professionals and oncologists to consider the patient—to take account of patient experiences, of the discomfort of navigating medical worlds as non-experts while living with and dying from cancer. Her

more day to day practices entails developing content for her social media outlets, writing articles for different patient groups, responding to emails from people requesting her insight on alternative therapies, preparing papers for publication and presentation, and mentoring other advocates.

When I ask Gemma how she became a patient advocate, she took a deep breath and replied, “yeah, good question.”

I was diagnosed with breast cancer when I was 44—that’s twenty years ago. I was suffering with multiple chemical sensitivity. At that time I couldn't go anywhere without becoming really ill. When I developed cancer, the oncologists that I was talking to had zero interest in my circumstances. Zero. He said, ‘Oh, your condition doesn’t matter.’ And I said ‘Oh, wow, my whole life is bound by the fact that I can't go into public spaces; I can't be where carpeting is.’

I left his office making the decision not to follow the mainstream because I felt like the mainstream didn’t care at all about my issues. I felt like they were looking at the cancer patient in Room 7. I’m not nobody. I just couldn't stand by it.

I went to a support group, and everyone was like ‘Oh my god, what are you going to do? You have to do something.’ I said, ‘I’m sure there's an alternative.’ And I said to myself, ‘Wait! Alternative medicine! I've heard of that!’ Amazingly, one of my really close friends had just become an acupuncturist, but I didn't really make the connection at first because how could it be alternative when it’s someone you know?

From there, I started exploring it. I ran a study group. I started writing up summaries. There was no internet back then in '93, so I [didn’t have a website]. But I was reading books. And then Cancer Care⁴ asked me if I could give them

⁴ Cancer Care is an American support service that provides nation-wide support through counselling and education to help people manage the, “emotional, practical and financial challenges of cancer” based in New York City. See <http://www.cancercare.org/about>

some information on what the patient perspective was on alternative medicine. And I just got more and more into it because I realized I had a lot of information.

Gemma attributes her attraction and ability to advocate for herself and others to her previous professional life in marketing and her family background:

I come from a family of activists. When I was six my parents, my sister, my brother and I marched with Martin Luther King for civil rights. My mother was active with me in the SANE⁵ nuclear policy organization years ago. With that background, it wasn't hard for me to get on board with this.

Of further significance in understanding the tenacity of Gemma's advocacy is the multiple chemical sensitivity that she lives with, and the forms of collective action and activism taken up by people living with this condition which inspired Gemma to politicize the impossibility of conventional treatment for her cancer.

Gemma's story evokes accounts of this "controversial illness" (17) crafted by historian and feminist technoscience studies scholar Michelle Murphy in *Sick Building Syndrome and the Problem of Uncertainty: Environmental Politics, Technoscience, and Women Workers* (2006). Murphy explains that multiple chemical sensitivity, refers to modern form of chemical injury sustained in various industrial and workplace environments, the symptoms of which, "were not only multitudinous but also varied from person to person... brain fog, shortness of breath, fainting, dizziness, nausea, rashes, fatigue, moodiness, depression, loss of memory, slowed reflexes, or other conditions" (2006: 155-6). Murphy indicates that these reactions to the outgassing of materials used in

⁵ SANE, or The Committee for SANE Nuclear Policy.

indoor environments have been deemed “unacceptable to dominant medicine” (2006: 18) —afflictions labeled “psychosomatic” so as to relieve biomedicine, with its materialist concerns, from the responsibility of treating this syndrome (175). Murphy also suggests that it is the the very unintelligibility of the MCS afflicted body that created the conditions for an activist movement in which “chemically injured people practiced experimental divestments and reinvestments in order to bring intelligibility to their bodies and create safe spaces in which to live” (ibid). Murphy notes that mundane contexts like “a newsletter, an Internet chat, a health-food store, a support group in a women’s center, an understanding church, a specialist lawyer, an environmental illness clinic, a commune” became important spaces where people with MCS congregated to share their stories, and mobilize (2006: 155).

Brought to bear on Gemma’s stories, I understand that her efforts to build an online infrastructure to provide information on complementary but especially alternative treatment options for patients are consonant with the MCS movement—that her organization builds on these broader struggles to make the sensitivities of hers and other bodies intelligible and legible to biomedicine.

When Gemma explains to me that she had surgery after learning of her diagnosis, but did not pursue chemotherapy or radiation, I ask her to tell me about the particulars of her alternative treatment course.

Well, I did a lot of things. I went to a clinic in Mexico. *I tried a bunch of things.* And as it turned out, the cancer that I had recurred less than two years later. I decided to go forward with the plan. I continued to do alternatives, but I just got a lot more serious about it. A lot of things worked to reduce the tumors, but they kept recurring. Pretty much every inch of my chest wall developed breast cancer. In subsequent conversations with oncologists who were more willing to talk to me, we kind of recognized that it wasn't really handled well from the beginning because I had what's called multi-focal cancer, but I didn't know it because the doctor didn't do a biopsy, so I didn't realize that it was, you know, everywhere, until later.

With new insight into the pathology of her disease, Gemma also learned that “all of the other stuff that I did even while it was recurring made the cancer, and subsequent cancers, grow very, very slowly.”

After this they told me ‘Oh its growing too slowly for chemotherapy, so don't do chemo.’ So I said, many times, ‘Gee this must be good, right? Because it's growing slowly, they don't want me to do chemo, it must be good?’ And everyone said to me, ‘Oh well we really can't say because you didn't do chemo so we can't tell you how you're doing.’ But you know, I was raised to be very independent, so I basically really didn't care that they were not helpful to me at all. By then I had supporters who thought that what I was doing was really cool, and there were people who were interested in what I was doing, and telling me they were going in a similar direction. And you know, I could see it—things were going my way even though medical people told me they weren't. Eventually I started working with a Chinese herbalist, and I had a very, very strong reaction to the first round of herbs I took— I had hives all over my body. Then a couple days later the hives went away, and I recognized that the cancer and the chemical sensitivity was so much better than it had been. I was so much better off.

After that, I just went with the herbs. I took them for ten months, and at one point my herbalist said to me ‘You're fine, you can stop’ and I said, ‘I might as well keep going for a while.’ So I took them for four more months, and he said to me, ‘You're really ok. You have to stop.’ That's when I stopped.

Remembering this instruction, Gemma begins to laugh. As she recoups and continues, the cadence of her voice changes, slowing and shifting in tone, conveying the gravity of living through eight years of experimenting with alternative cancer treatments:

Ironically, you know, I lived in New York City at that time. You're a Canadian so you might not know extent to what 9/11 meant to us, but it was a really big deal. I was scheduled to see my oncologist, September 12th, 2001. It was a very odd day. I basically got to the hospital [which was near the twin towers], and wasn't even sure if the doctor was going to be there. There was no public transportation running so I walked there. The doctor then told me that I was free of cancer. I walked out and I started to cry. Maybe fifty people came running up to me saying, 'Oh it's going to be ok, we're going to be fine. Don't worry.' I was crying because everything was ok, and here's this whole city, where everything is a mess, and to me, it was 'Yep. Everything is great now! I'm going to live.' So it was a very strange experience for me.

This strangeness of learning just hours after so many had died that a nearly decade-long endeavour to live had been successful renders me speechless. Gemma, probably familiar with the effect of this story, assures me that,

This was a long time ago, and the cancer never recurred. I don't get tested or anything like that. I'm not interested in that. I don't think it's necessary.

The American Cancer Society indicates that women diagnosed with stage four metastatic breast cancer have a 22% five year survival rate, meaning a very small percentage of women receiving conventional treatment for this disease live beyond their diagnosis.⁶ At the time of my conversation with Gemma, it had been ten years since her diagnosis. It strikes me that Gemma's disinterest in check-ups and the assurance that her alternative treatment protocols worked is because of the initial responses of medical professionals to

⁶ <http://www.cancer.org/cancer/%20breastcancer/detailedguide/breast-cancer-survival-by-stage>

not only her sensitive condition, but her intent to tackle cancer on different terms.

Recalling some of those early conversations, Gemma tells me with an audible smirk,

“When I started this in ’93 my first oncologist said ‘Yoga! Are you trying to kill yourself?’”

I mean, I’ve been banging my head against the wall so to speak for years. When I started out nobody thought eating mattered. Everything was so different, and I knew I was right.

One of the more potent pieces of Gemma’s story is that her pursuit of alternative treatment—therapies that are now, interestingly enough, mostly considered complementary—pushes back at the idea that the use of alternatives in treating cancer is contoured by sentiments of belief, hope, or last resort rather than an epistemology of proof.

I knew about acupuncture because of one of my close friends became an acupuncturist right before I was diagnosed. She stopped my menstrual cramps. I knew they could do something amazing, because I had menstrual cramps for thirty years, and then they were gone. But I didn’t quite believe in it. In fact when the herbalist recommended treatment, it took me four months to actually feel comfortable enough to go forward and accept the herbs.

What Gemma knew was that her multiple chemical sensitivity meant that she would not be treated well in biomedicine, and she had known a different kind of treatment through the acupuncture treatments she had received. Gemma *knew* alternative medicine could work because she had felt its effects, and also because she had conducted research, reading as many materials as she could gather, and attending conferences and meetings where she could speak with people who both praised and reviled alternative health care

practices. There was and is value in alternatives for Gemma because these are practices that “focus not on the disease, but on the person.”

With this argument in mind, I ask Gemma what she makes of the decoupling of complementary and alternative medicine in the interest of developing the term complementary and integrative medicine. Returning to our time at the Society for Integrative Oncology conference, she explains that,

I've had this conversation with the people at SIO. I had a poster last year that was criticized because I had ‘alternative’ in there and they wanted me to have ‘integrative and complementary,’ which is the term they use. I said, ‘The truth is that some people are always going to need what we still call alternatives.’ Alternatives are the things that haven’t been fully examined, and when it becomes fully examined it becomes complementary.

Even though people at SIO will criticize me for this, I will always defend peoples’ right to use alternative treatment because not everybody succeeds with conventional treatment. From an advocate’s point of view, I don't want pharma to be in control. I think that's really crazy. They don't have human interest at heart—it's a business. We have to recognize that. I often think about all the kinds of drugs that have been taken off the market and all the times information has been held back about drugs. ‘Oh wait you forgot to talk about this adverse effect, oh yeah! Well that's a problem.’ That's crazy. It's so wrong.

Referring to the tensions that exist for integrative oncologists, Gemma continues,

This comes down to the fact that they have to go with the mainstream because [integrative oncologists] are mostly hospital based, and they don't want to lose the status that they’ve gained. I don't have that. I don’t have to follow established rules, and I don't care about that at all. I care about people—people feeling better, people having more wellness, and I don't think that they can achieve that some of the time unless they have access to alternative treatment. I want to leave room for the people who need that system. It would be hypocritical for me to walk away

from it given I did Chinese herbs and I'm still here. They told me I was stage four in 1997 and I'm still here.

Gemma's story is so compelling to me for many reasons. But in particular, it strikes me as uncovering a troubling dimension in the development of integrative oncology. I recount her experiences here rather than in Chapter One alongside Berdine, David, Donald, and Felix precisely because it is only through the present dismissal of alternatives that the emergence of integrative oncology is revealed to have been conditioned by the intense forms of displacement, suffering, and uncertainty experienced decades ago by people like Gemma who were too sensitive to receive treatment in biomedicine. Gemma's story offers the important consideration that the forms of therapeutic experimentation undertaken by people like her carved the frontier that integrative oncology now populates.

Potential

Gemma's insistence on the need to keep conversations around alternative medicine and alternative paths to cancer treatment activated in integrative oncology, particularly in the defence of patients like herself who are chemically sensitive, or who need a more sensitive approach to get through cancer treatment, and for whom conventional therapies would be dire, attunes me to how ideas concerning *potentiality* and *possibility* contour the separation of these practices.

Recall moments in past chapters where the language of possibility has been used by integrative oncologists to describe complementary modalities. Felix is particularly fond of this term, using it as a means of accounting for the way in which complementary medicine provides more therapeutic *possibilities* for his practice in the form of new techniques and methods. Felix and other integrative oncologists are able to imagine the utility of complementary medicine in this sense because there is a growing evidence base for the use of such therapies with conventional oncology treatments. Alternative medicine, on the other hand, isn't charged with the same excitement, or undergirded by similar evidentiary support. Rather it is the uncertainty, the unintelligibility of alternative medicine to and within the evidentiary regimes of biomedicine that poses a *potential* for harm—for dangerous, unpredictable interactions between alternatives and oncological pharmaceuticals.

In their work on the anthropology of potentiality, Karen-Sue Taussig, Klaus Hoeyer, and Stefan Helmreich argue that “potentiality serves as an orienting concept in the life sciences, in medical practices, and in social policy related to these endeavours” (2013: S3). In the context of biomedicine, these scholars suggests that, “potentiality generally is articulated— either by explicit naming or implicit framing or both— as a hopeful idiom through which to imagine the benefits of new medical interventions. Such visions are also often premised on disrupting the negative potentials of life—for example, various types of genetic mutations, deleterious microbes, unwanted cell growth and death, and injury and aging” (2013: S4). However, these generative dimensions of potential “exist

simultaneously with those related to increasing anxiety about the negative potentials of life in the context of food safety, biosecurity, biological weapons, and armed conflict” (ibid). In this sense, potential therapies in and for biomedicine are always already coupled with the imperilments of social, political, and economic implications of such interventions.

Speaking to this tension, Taussig, Hoeyer, and Helmreich suggest that in the context of biomedicine, “potentiality indexes a gap between what is and what might, could, or even should be. Such a gap opens up an imaginative space of magic and mystery—the as-yet-known—in which future building activities relate to animating bodies and extending life in new ways looms large” and that the imagining of this gap “depends on a view of life as plastic, susceptible to forming and reforming” (2013: S5, emphasis added). As such, potentiality is inscribed into the forms of “genes, cells, organs, bodies” as “a hidden force,” that lies in waiting for the “right technological intervention in order to be realized”—discoveries often made “without recognizing the role of human action or choice” (Taussig, Hoeyer, and Helmreich 2013: See also Cooper 2008, Hayden 2003).

Critically, Taussig, Hoeyer, and Helmreich assert that, “people appear to ascribe potentiality to those things they believe can be manipulated (or they desire to manipulate) and not to those perceived as being beyond human control (or seen as not in need of change)” (ibid). Further to this point, these anthropologists assert that it is the very “promissory” qualities of potentiality hidden in biological phenomena that “creates more explicit links to capitalism and financial markets” (Taussig, Hoeyer, and Helmreich 2013:

S9), conveying the now repeating theme that what is imaginable, what is conceivable is a question of profit.

Applying these insights to the relationship of alternative medicine and integrative oncology, it seems that recognizing the therapeutic potential of many of the modalities classified as alternative medicine would mean risking biomedical legitimacy. Given that integrative oncology is endeavouring to be recognized as an evidenced-based medical practice, situated in biomedicine, leaning into the potential that alternative medicine poses for more and different modes of treating cancer would put its accumulated rigour at risk. In some senses, the potential posed by alternative medicine for integrative oncology is too costly.

However, in the consideration of practices that were once labeled alternatives, but now are considered complementary and integrative, particularly Chinese and Ayurvedic medicine, we might consider that the “imaginative gap” between potentiality and possibility, or the space that determines how a phenomena is utilized in biomedicine, identified by Taussig, Hoeyer, and Helmreich is also an affective gap—that to recognize potentiality as possibility, one must first be affected by its potential—by the incipience and intensity of that which is virtual, that which exists in moments between bodies (Deleuze 1988, 2005, Massumi 1995, 2002). In this sense, physicians must be affected by the potentiality of an alternative practice before they can begin to conceive of its possible applications, or even the routes to study its possibility. Indeed, this was the case with all

the integrative oncologists and professionals aligned with this field that I spoke with. As explored in Chapter One, each experienced forms of healing that supplemented something missing from biomedical cancer care, producing a feeling for how treatment could be different, and in that affective moment, each became motivated to materialize a different kind of practice.

Using the analytic of potential provides critical insight into the relationship between integrative oncology and alternative medicine—one in which the difference between these fields is a matter of what is possible—a question contoured by the limitations of imagination, the ranges of affect, evidentiary regimes, and the pressures of capital.

Toward an anthropology of CIM-AM

In holding close to Donald and Gemma's stories, to the tensions, frictions, complexities and necessities which continuously configure and reconfigure the relationship between integrative oncology and alternative medicine, and the attempts to realign the relations of these fields in and through the shift in acronym from CAM to CIM, I want to suggest that anthropological analytics so too consider a change of acronym. Currently CAM/IM is used both in anthropological literature, and by the Society of Medical Anthropology to designate research interests in complementary and alternative medicine and integrative medicine; however, the alignments between these fields crafted by this term are not necessarily representative of the complex cultural relations this acronym attempts to

encapsulate. If the consistent correction of my use of the term CAM throughout my fieldwork is any indication, the slash at work in CAM/IM is misaligned, and perhaps does more for anthropologists in designating the recent development and growth of integrative medicine than what is actually happening in the fields of our research.

I want to propose the use of CIM-AM in the place of CAM/IM. I contend that this acronym better expresses the kinds of negotiations that are happening in and around integrative, complementary, and alternative medicine. Resisting the smooth coating around the category of CIM, its lack of bumps and gaps which too easily service the hegemony of biomedicine and its dismissal of alternatives, I make use of a hyphen between complementary and integrative medicine and alternative medicine to get at the linking of these fields—to get at how neither can be known or enacted without the other. As a bridge between these terms and these fields, this hyphen also gestures to the passage of practices between and across this boundary, inviting the idea that the span could be increased or shortened depending on the treatment problem, and the potentiality, possibility, or affectivity of this gap. Moreover, the rejigging of this acronym also speaks to how practitioners of non-biomedical medicines are increasingly referring to and positioning their practices as complementary medicines, dropping all relation and association to alternative medicine—a strategic and political move that is evident in natural health publications, websites, and conversations with practitioners as an attempt to gain categorical legitimacy. As such, this acronym expresses a concern for how the

difference and differentiation between complementary and alternative medicine is currently being imagined and enacted.

I hope that CIM-AM, in designating the relationships between these fields as they are imagined in the context of these fields, not only cares for the stories that medical professionals and patients have told me, but also invites deeper and different forms of anthropological inquiry—work that helps to ask how the connection and separation of these fields, these practices, and these approaches contours how people live and die in biomedicine, and how those conditions might too be different.

CONCLUSION: SIGNALS

Sitting at the edge of her tiled kitchen counter, I watch as Luis, Keana's partner, plucks the tops off of strawberries before dropping them into the jug of a Vitamix blender. He pulls spinach and kale leaves from their refrigerator, washing the leaves of each before adding them along with pineapple juice, ice cubs, turmeric powder, and a few raspberries. Inspecting these components before they are spun into smoothie form, Keana tells me that this blender used to be her father's—it's motor recently refurbished free of charge after she emailed the company, telling them of his affinity for the brand, her cancer, and the desire to keep that machine going.

Between pulses, she tells me that all these ingredients have been procured from the local food cooperative. She and Luis have decided that there will be “no more junk” in their home—organic, super-foods only. As these two decide what vessel would be best to put the smoothie into for the car ride to yoga, I walk around their living room, admiring the many pieces of artwork that hang on its walls. Keana calls out the names of each artist, clarifying for me that the condensed collections of sketches, sculptures, dried flowers, and candles beside the fireplace is a kind of shrine—a reminder of all the things she wants to live for.

Deciding on a mason jar with a straw, Luis hands Keana her smoothie and reminds us of the time. Keana tosses a sweater over her walker, and we head out the door. From the

passenger seat, Keana sips her smoothie and repeatedly thanks me for being willing to drive. She feels some regret about missing the first half of Luis's baseball game for yoga, but the grip of that guilt loosens when I tell her how excited I am to watch the second half of it with her afterward.

Tonight is the second last yoga class that I will attend before my fieldwork in California comes to a close. To my surprise, and Anna's, there are three new people in attendance—an older man and a woman dressed in matching grey sweat suits, and a woman who arrives wearing a hat that seems more fitting for the Royal Ascot than a yoga class for cancer survivors.

After class I watch as Anna checks in with the newcomers. While the rest of the participants quickly make their way off the mats to talk to one another, the couple lingers half crosslegged on the floor. I hear Anna ask them about their impressions of the class, and the man mentions it was frustrating not knowing if he was coming into the poses correctly because their sequencing was confusing. Anna assures him that he did wonderfully, and that it will all get easier with practice.

Nissa joins Keana and I as we collect our things, and make our way to the parking lot. We chat briefly in the late summer breeze before departing. Keana directs me to the baseball diamond where Luis is playing. We arrive to find a mostly empty parking lot. Keenan

tells me that Luis plays in a beer league—a 50 and above team that Luis joined for fun despite being nearly a decade younger than his teammates.

From the back of her van we take camp chairs and blankets, which we position just behind the six rows of bleachers on left side of the field where about fifteen people are gathered. She introduces me to these friends and to the line of teenagers who sit restlessly in the front row. I learn that they are the little league team that Luis once coached. They now have braces and acne. They flirt unabashedly with one another and tease Luis by yelling coaching tips at him when goes up to bat, tossing peanut shells in to the air in the infectious fits of laughter that follow when he yells back.

Keana tells me that everyone gathered here is their chosen family— a group of people connected by sport, but kept close by affinity. She tells them all that we've just come from yoga class, and I can tell they want to ask how she is doing, but are reserved in their asking. I also get the sense that this is the first baseball game of Luis's that she's been to all season, but hesitate to ask for fear of any shame that might generate. Keana, perceptive as ever, tells the group that she's going start blogging about her recovery—that she's been too tired to return individual emails and voicemails, and that it would be easier to just write one, widely disseminated update. The group smiles and expresses their interest in that platform. One person even mentions they had a friend with lung cancer who did something similar.

As one of the innings ends, Luis comes over to ask Keana about yoga. He apologizes for missing the practice, and Keana promises him we'll stop talking and start watching his game. He winks, and runs back to the pitch.

Wrapped in a plaid printed fleece blanket, she asks me to tell her about the integrative oncologists that I've been meeting with. I tell her about Donald and Felix, and her interest in Donald's plant-based approach is piqued. She asks for his full name, pulling up her phone to search for it in the PubMed database. She starts reading abstracts of his papers, and delights that he is engaged in both research and clinical work, especially his work on mushrooms: "I've been eating maitake and shiitake mushrooms for breakfast since my surgery."

Finding her way to his contact information, and showing me a picture of him to confirm it's the right oncologist, she leans in and tells me "I'm going to see if I can get an appointment with him."

The sun has set, and the baseball game comes to a close. I pack the chairs and blankets into the back of the van as Keana receives gentle hugs from everyone in attendance—embraces careful of her recent surgery. They all tell her how excited they will be to receive her updates.

As we're about to buckle up, I notice Keana begin to buckle. Holding her seatbelt halfway across her chest, she tells me that tomorrow morning she has an oncology appointment to discuss her treatment plan. The surgery to remove the tumor in her breast was successful, but her oncologist is recommending adjuvant chemotherapy. She's afraid of it—of the damage it might do to all the progress she's made with her neuromuscular disorder—of all the therapy she's been through to repair nerve damage in her feet. Letting go of the strap, it snaps back and she begins to detail her worries about this treatment—of getting sick, of her hair falling out, of what it would mean if she experienced neuropathy in her hands—how difficult it would be, literally, to hold herself up—of what would happen to Luis if she died.

The stadium lights turn off, and she and I and the van are engulfed in the darkness of twilight. She begins to cry. I reach to comfort her, mentioning again that I've learned there are therapies that can help with these symptoms. She gasps for air, letting a quite response of “yeah” which breaks up her sobs.

As she's catching her breath we hear the soft whistle of a train.

“That's my Dad. He's here with me.”

She exhales. “He died suddenly a year ago.”

Her grief is audible, her voice quivers as she tells me that he used to work for Amtrak as a conductor. She remembers that in the glove compartment of his truck he kept large red and green cards on a key ring. Whenever she was out driving with him and they came across a train crossing, he would park the car, get out, and inspect the track. If it was obstructed, he'd radio in the location of the problem and wait by the side of the track, red card held high. If the track was clear, he would flip to the green card, holding it aloft instead, waiting for the whistle of the oncoming train, acknowledging his signal of safety. He kept this practice up no matter the weather, or time of day, well into his retirement.

She tells me that since her diagnosis she's heard more train whistles than ever before.

"It's him. It's him telling me I'll be alright."

We hear another whistle. Goosebumps populate my arms and legs, and I begin to cry with her. We sit, sniffing, in the orange glow of the parking lot lights as they begin to warm up.

"I'll listen for those whistles too."

Implications

In *Malignant: How Cancer Becomes Us* (2013), Jain contends that, “cancer’s deepest discomfort lies not in the obvious physical pain, or in the surgeries, or in the nausea, or in the hair loss. It lies rather in the ways that things hurt more than they need to” (217). As I have uncovered throughout my ethnographic research, some of this discomfort stems from the inability or unwillingness of oncologists to understand how their patients live with cancer. As Berdine described in Chapter One, many oncologists do not want to get into the “emotional side” of their patients, into asking and knowing about their relationships, obligations, and networks of support, because “they just want to deal with the disease.”

It’s this disposition of just dealing with the disease endemic to conventional oncology that implicates cancer patients as lone sufferers, “represented outside of the very culture that produces [cancer]” (Jain 2013: 85). It’s this displacement that makes it so easy to not get involved—to not share in the suffering of someone trying to survive cancer. It’s this dislodging that makes it difficult to think through and feel how connected each of us are to cancer.

The work of anthropologists Joseph Masco (2004), and Kim Fortun (2012) makes important contributions for understanding that cancer is a shared burden. Their stories of the permeation of carcinogens and toxins all around us further complicate what survival

means and what forms of recognition are required for beings living in environments saturated with chemicals and radioactive materials.

Examining the changes to “social and biological ecologies” brought about by the Manhattan project, Masco develops the concept of *mutation* in order to draw attention to the multi-species, multigenerational, and uncertain effects of nuclear exposure (2004: 519). Masco contends that the challenge in understanding mutation in these terms is grappling with the unknowable effects it has for future generations—of whether the fallout of nuclear technology testing will result in evolutionary gains or injury (522).

Thinking with the Bhopal disaster, Fortun’s analysis of the crumbling architectures of late industrialism gives a sense of the immeasurability of chemical released by this system (2012: 446). As Fortun states, “there are among the over 100,000 chemicals registered with governments around the world for routine use; the data hasn’t been collected, the science hasn’t been done, to understand how these chemicals affect human and ecosystem health. Thousands of new chemicals continue to be introduced each year” (ibid). The absence of information makes all the more difficult grappling with the intensities and scalar effects of toxicity in the United States.

Amplifying this point, Murphy argues that “cars, militarization, water, laws, the direction of a river, the price of oil, the properties of sand, the rise of neoliberalism, histories of colonial dispossession—are all part of a assemblage of molecular relations that extend outward in place, and into the past, as well as forward to uncertain futures” (2008: 696).

Murphy contends that we are now experiencing “the historical emergence of *chemical regimes of living*” which is, “not simply the result of new epistemological or technical innovations, but rather the accumulated result of some two hundred years of industrialized production, such as coal-based energy of the nineteenth-century, or petroleum and plastic processing of the twentieth century” (697). In this regime, “atmosphere, water, soil, nourishment, commodities and our very bodies are apprehensible as caught in possibly toxic molecular relations” (697)—bound together by the harmful effects of synthetic chemicals. With the insights of Murphy, Masco and Fortun, it becomes clear the way in which we ask individuals to experience cancer as a process of surviving is doubly problematic in that it figures cancer patients as the only people struggling with and endeavouring to survive the toxic exposure and its mutative effects.

Like Masco and Fortun, Murphy endeavours to tell stories that will incite collective action rather than collective fear. Murphy hopes that, “instead of a chain, or a focus on bodies, the notion of a chemical regime of living might better provoke questions more adequate to the history of this entangled and enfolded political economy of molecular relations” (701). This imperative resonates and deepens the call from Jain to work toward a future in which treatment for the cancers precipitating out of the toxicities of our world do not rely on disavowing the violence of biomedical treatment, or an unwitting ignorance of the perniciously chemicalized conditions of life in North America.

Provoking this point, Jain poses the question, “what would it mean to acknowledge—

really acknowledge—the sheer number of people who will literally rot from the inside out each year, with no way to stop it, while so many known causes of cancer continue to be pumped into the environment?” (2013: 69).

The grip of this question tightens when I realize that the rotting is also a result of treatments that don't work. But this isn't a question meant to provoke conversations about creating better cures or figuring out how to fix the rot. This isn't a question that asks biomedicine to ramp up its efforts. It's a question that asks how living with cancer might be less rotten—of what is required to make cancer more livable even if it's in the direction of death.

It has been my contention throughout this dissertation that the forms of sensitivity emerging in integrative oncology have consequence for these questions. By cultivating a practice which attempts to reconnect the cleaved parts of mind, body, and spirit by approaching cancer as a disease of all three dimensions, integrative oncologists reconfigure biomedical ideas about bodies and disease. In their hands, the materialist and reductionist models of biomedicine become otherwise—undone and remade with a feeling for the affectivity of bodies, and the impact of social and emotional forces on bodies. Moreover, in the challenging work of integrating conventional oncology and complementary medicines, different conditions of living with cancer are emerging—conditions that are more hospitable for learning to live with the discomfort, embarrassment, uncertainty, and ruptures generated by this disease. The forms of

sensitivity modelled in this field offer possibilities for knowing and treating bodies differently.

And I want it to be different— I want integrative oncology to make a difference. I don't want people to rot. I don't want people to sit in oncologist's offices and cancer wards feeling like they've been reduced to a part or a cluster of misbehaving cells. Left to fidget and worry and second guess everything that is happening in and to their bodies.

I don't want the possibilities of this field to be extinguished by the efforts of integrative oncology to gain legitimacy in biomedicine either. Many conventional oncologists do not take the integrative approach seriously, citing the need for more evidence of the safety and efficacy of applying complementary medicines to conventional treatment practices of chemotherapy, radiation, immune and hormone therapy, and surgery. In response to these criticisms, integrative oncology as a professional field has cut its ties to alternative medicines, using the term *complementary and integrative medicine* or CIM to designate the kinds of therapies it incorporates into conventional treatment. They have also intensified their attempts to make the treatments and remedies of Ayurveda and Chinese medicine legible and intelligible to biomedicine using the conventions of the clinical trial, despite the fact that this system of measurement and evidence production was designed for the study of pharmaceutical interventions. I want to consider more carefully how the exclusion of alternatives and the acquiescing of integrative oncology to the problematic

format of the clinical trial for proving their interventions could limit the possibilities and potentialities of this field.

I also want anthropologists to pay more attention to integrative medicine and integrative oncology. I have proposed that medical anthropologists consider the use of *complementary and integrative and alternative medicine* or *CIM-AM* rather than *complementary and alternative medicine and integrative medicine* or *CAM/IM* in better conceptualizing how the relationships between these practices are being articulated, enacted, and imagined in biomedical contexts, and how practitioners of non-western medicines are orienting their practices to better gain the attention of biomedical practitioners.

Considerations

Perhaps the most poignant point arising in this dissertation is how inaccessible the promise posed by integrative oncology is for people with cancer in the United States—that because of the political and economic structuring of oncology, medical and scientific evidence production, and insurance coverage, integrative oncology and many of the treatments it recommends can only be accessed by those with top-tier medical insurance, or by those who can afford to pay out of pocket. And given the burgeoning consideration of the connection between stress and disease, it is particularly crushing to think that people living in economically precarious conditions with cancer could, ostensibly, benefit

the most from integrative approaches. More so is the thought that the choice to pursue integrative care isn't entirely economic—that it is conditioned by the encounters with medical systems experienced by people living in precarious states—that no modality, mainstream or alternative, is accessed without complication.

The changes to insurance eligibility and availability brought about by the Patient Protection and Affordable Care Act (PPACA) could mean more choice for patients in pursuing integrative oncology. More research will be required to understand the effects of the PPACA, particularly insofar as 2015 marks the coming into effect of its mandatory mandating of basic insurance coverage for all Americans. How this will effect what treatments and therapies insurance companies will cover requires further, and detailed examination.

To better understand the differences and possibilities posed by integrative oncology, as well as the constraints around its accessibility, more research is needed. I faced limitations in accessing these spaces during my research, and was not able to participate or observe integrative treatment in clinical settings. To develop a more sustained and complex portrait of this field, anthropological research is required in both the clinics and treatment rooms of integrative practitioners and in the educational institutions where integrative oncologists are trained.

Moreover, more work is needed that focuses in on how practitioners of the medicines deemed complementary to biomedicine make sense of and participate in integrative medicine, and integrative oncology. The stories about their experiences in negotiating the remaking of categories of complementary and alternative medicine, and even their relation to the rise of integrative medicine, are absent in anthropological literature on integrative medicine.

Complications

This dissertation, while not a comprehensive study of integrative oncology, is an attempt at comprehending the significance of this field—an effort in understanding how the effects of stress, environmental toxicities, emotional intensities, and the deep cuts of mind-body dualism matter for understanding and treating cancer.

I have argued that integrative oncology is actively remodelling biomedical conceptions of bodies and disease as something far more sensitive and subtle than what can be made sense of with the mechanical analogies biomedicine has invented. The sensitivity I feel propagating in this field signals to me the possibility of different ways of living with cancer and with the idea of dying from this disease—modes that do not displace patients from what they feel in their bodies, but find ways to support those sensations, those concerns, and those ideas, however unusual. Integrative oncology is a mode of treatment

that acknowledges the agonizing and often traumatic qualities of conventional cancer care and tries to do something about it.

I end with the cautious optimism I feel for the implications of this field in biomedicine because despite the efforts of any kind of care, there is always the potential for relapse—that the intervention won't work, and the momentum will be lost. But we nevertheless, find ways to keep open the possibilities of hearing the whistle that guides us to safe passage.

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