

## CRITICAL PERSPECTIVES

On Writing About Illness: A Dialogue with S. Lochlann Jain and Jackie Stacey on Cancer, STS, and Cultural Studies

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**JS:** At the end of your book, Lochlann, you write: “*Malignant* has mapped out some of the cultural containment strategies for this crazy disease, its everywhere- and nowhere-ness.” You describe cancer as having “a grammar all its own.” “I offer this book,” you write, “in an attempt to speak to—and from within—the cancer complex,” the constituent parts of the experience of which spin a web that, “unless we are vigilant,” will entrap us (Jain, 2013, pp. 221-223). In thinking about our two books together, as we’ve been asked to do, it seems to me that the process of writing itself perhaps offered a way for both of us to try to reconfigure the imaginative landscapes of cancer cultures and to counter some of the destructive normativities of cancer’s dominant grammars. This feels important not simply in the face of particular experiences of diagnosis and treatments but also in order to index the cultural and political forces that constitute

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what you call this “cancer complex.” For, as well as feeling out of control of our bodies, we are all thrown by cancer into a place of ontological uncertainty, rewriting our histories and our futures through its shifting narrative and discursive orderings and disorderings. There is an overabundance of advice and storytelling about cancer and yet a paucity of meaningful recognitions and communications.

In looking at our two books again for this dialogue, I am struck by our respective (and very different) desires to move between different registers to process the experience of being immersed in this confusing and unwelcome world, surrounded by prescriptive imperatives and tedious clichés—some promising solutions and others just drenched in the sentimentalities of “cruel optimism” (Berlant, 2011). For an academic diagnosed with cancer while working on the social and political significance of how stories get told about injuries, as you were Lochlann, or while working on feminist readings of idealised femininities in popular culture, as I was at the time, there is just so much material to process that it’s hard not to want to write a book about it. As my characterisation of our intellectual projects just prior to our cancer diagnoses here indicates, our books speak to very different audiences at very different times, even if they do share some common ground. In the early 1990s, when I was writing my book, I don’t think I knew quite who my audience was—I think maybe I was trying to constitute one. I was keen to speak to people beyond the academy, but I also wanted to be able to mobilise theoretical debates, in order to challenge the contours of the cancer cultures I found myself inhabiting (and trapped by).

**LJ:** Jackie, thank you for starting us off in this way. Yes. Containment strategies, indeed. The way you put it here—ontological uncertainty—seems exactly right for the kind of shock that many feel on diagnosis; with a cancer diagnosis, one enters an entirely new world, and cancer is a very specific kind of world in terms of research methods, treatments, and the stories that get told around it. While I think your description of “imaginative landscapes” is deadly accurate, the tendency in cancer literature has been

to distinguish the "objective, scientific" knowledge from the "subjective, experiential" knowledge, and then to elevate the former. In our respective ways, we each analyze how these forms of knowledge have been built on that distinction in ways that have led to consequential blind spots in the understanding and treatment of the disease.

In that sense, I would not say that my goal was to reconfigure the imaginative landscape *through* writing, but rather to analyze how Americans contain *the* major medical, economic, and industrial failure that cancer relentlessly presents. The scope of the sleight of hand required to simplify the story of cancer as one of personal tragedy rather than as a complex nexus that we have reached because of fundamental blind spots in modes of everyday accounting is absolutely breath-taking. Law, science, progress, profit, environment, time, and lifespan are just a few of the domains that have worked in the service of this building, and building on, this deeply held common sense. Many of our institutions that purportedly regulate industry and practices such as medicine are simply, and structurally, unable to address the multiple, and constantly shifting, uncertainties that we consolidate with the word "cancer" presents to them.

*Malignant* (2013) hypothesizes that understanding how our society makes sense of cancer, a subject that has so carefully been segregated from the massive institutions that have constituted it in its current form (as if cancer were a separate subject that comes to these institutions and ideas fully formed), enables us to better understand not only cancer, but also the broader common sense ideas that inform our everyday lives, and the broader ways that violence (one of whose forms is cancer) underwrites our self- and national-understanding.

One way to contain the social failure of cancer is to name it as something situated outside of a united whole. This narrative goes something like: "Cancer is a terrible disease, we are doing everything we can to cure it." This of course separates out a "we" and a "cancer," and ignores the fortunes being made and lost (redistributed) through the disease. Another way is to dismiss or sentimentalize the people who have cancer. The attitude of dismissal is easily seen in the example of lung

cancer: until recently, people with lung cancer who smoked have been characterized as having asked for it, rather than as having been part of a complex situation in which cigarette companies manufactured the notion of choice. Sentimentalization appears especially around women's and children's cancers ("help a woman with cancer" rather than "get rid of BPA and other potential carcinogens"), or in the strategy of focusing on the individual's supposed depressive personality. Another way to obscure how central cancer is to the economy is to constantly separate the components of cancer so that it is nearly impossible to hold them together. The separation of cancer's causes and treatments is just one of many ways to do this (for example, focusing on early detection as a means of "prevention" offers a convenient way to divert attention from military, medical, and industrial causes). These are just a few of many concrete examples I examine in my book, of examples of the ways in which the underbelly of American progress, cancer, is carefully, disparately, and unevenly managed. In that sense, yes, the writing style I adopted was critical to my method of making evident the relays across the scales in which cancer operates—but this was one among many methods.

To come back to the point about cancer having a grammar all its own: living in the cancer complex requires learning new forms of advocacy and masochism, learning insurance language and how to negotiate social security insurance, as well as learning a whole slew of unwritten codes for how to be a sick person. All this work of learning how to negotiate one's personal and social identities that are usually learned over years—such as how to live as a white or brown person, how to live as a gendered and queer person, as a child, or an adult, and so on—all this needs to be learned quickly as one is learning how to cope with the diagnosis of a life-threatening illness. And so a large part of learning the grammar is learning how to live with the containment strategies, but these also become virtually impossible to live with. I think this is why so many people with cancer speak about how language loses meaning in this new world.

**JS:** Despite their very obviously different geopolitical and historical

groundings (about which more in a moment), these two books both seem to me to assume that culture cannot be captured by language. Both books address cancer cultures from an intellectual formation deeply influenced by poststructuralism, feminism and science and technology studies. Their reflections upon the limited and damaging ways of thinking about, and living with, cancer (in the UK in the early 1990s and in the US in the last decade or so) are acutely aware of the fractured and uneven character of social processes and yet always grappling with the institutionalised and embedded power relations that organise those processes (however chaotically or unsuccessfully). I think it's important to say that neither book seeks to capture the experience of illness through writing or aims to deliver a straightforward denunciation of the inadequacies of care through academic critique. Rather, what these two books do, in very different ways, is to grapple with this uneven and bewildering discursive terrain through shifting scales of focus in order to push back against this disorientating world.

**LJ:** Yes, exactly. Susan Sontag (1978) so elegantly traced cancer's metaphors and asked us to try to see a "pure" disease. But while her work is historically significant, I doubt that either of us would subscribe to a notion of pure disease, and certainly both of our books seek to understand how those "metaphors" go so much more deeply than the literary trope would have it, infiltrating our very notions of gender, sexuality, health, stigma, medical progress, statistics, and so on. Cancer is not a noun, but a conglomeration of interests.

The common sense notion that cancer is a name for cells that divide too quickly does not even come close to recognizing the world of cancer. Jackie's photos of herself before and after diagnosis get at this mysterious divide: Cancer is surely there in the first image, when she looks so well. It's gone (at least for the time being) in the second image, when she's recovering from chemotherapy, and yet her baldness—as a signifier of treatment, and thus of cancer—puts her squarely in the world of cancer ("in the kingdom of the sick," as Sontag [1978] put it). In other

words, there is a structural uncertainty to the disease: Is it there, are we causing it by eating fried food, will it stay gone after treatment, and so on. This medical, personal, legal, scientific uncertainty about what causes it, how to treat it, who should be treated, is encoded in different ways in different institutional and personal framings. For example, in law we most often err in favour of not seeing cancer, because legal odds often need a “more likely than not” standard. So one would have to have a more than 50% chance of developing cancer after an exposure in order to gain compensation. In essence, 49 out of 100 people exposed to a carcinogen could get cancer after a spill or other exposure, and nothing could be done to give compensation in a court of law. Thus, the uncertainty encoded in the probability statistics resulting from randomized control trials in medicine becomes something very different in law. Institutional framings seem mostly to err in favour of *not* picking up cancer. And so uncertainty has typically been resolved in favour of the interests of entities causing cancer, rather than seeing cancer as an injury. My approach was to think about the work that cancer does when it is understood as a meaningful, tidy word, rather than as a descriptor continually being shored up, and to demystify it as a way of understanding the work it does for different interests, which accrete something like a meaning.

The resulting cognitive dissonances (we know what causes cancer but we can't do anything about it, for example) have to be held together certainly at a societal level, but they condense particularly harshly in the bodies of those who are undergoing treatment (and their communities, for I want to insist that cancer is a communal event as much as an individual disease, and I think both of our books make that claim differently but clearly).

**JS:** You mentioned my use of photographs. Maybe we could pause on the selection of visual images and objects in the two books. Some of these are examples of normative models of healthy and diseased bodies, showing which kinds are used to underscore popular narratives of rescue and survivorship; others gesture towards mismatch and discrepancy, or

apparent revelation that is obfuscating and opaque, or satire that brings poignant absurdity into the frame. I use two photographs of myself to contrast the “being-sick-but-looking-well” moment of pre-diagnosis in hindsight with the “looking-ill-but-free-of-tumour” post-chemo moment. Knowing the illusory nature of the photographic promise of transparency didn’t stop me from searching back through old photos for clues of the impending medical crisis in my life. You come to know what you thought you already knew in quite a different way.

Another example is my book cover, which reproduces a portion of a work from the ongoing series *Beework* by Aganetha Dyck, a Canadian artist who places damaged found objects inside apiaries, where bees build honeycombs upon them, as if in repair. Dyck writes: “the *Beework* is about cells. Fragile cells filled with sensuous mysterious substances. Programmed cells, determined cells. Cells which are shaped, reshaped, filled, drained, cleansed, painted, prodded, invaded, monitored” (see Dyck in Stacey 1997, back cover). In her art practice, Dyck collaborates with bees, as she puts it, to produce sculptural pieces out of ordinary broken objects (which bear the mark of age and damage) left for months in specially designed apiaries; the original objects are slowly transformed through the gradual depositing of wax honeycomb. The result is a series of compelling forms that are not easily legible (Dyck, n.d.).<sup>1</sup> I loved the mixture of artistic and organic processes, the mingling of intentionality and transformation. Mutating cells are programmed, but they also have their own agency: their division and multiplication not only create new life but also threaten death. *Beework* blends wax honeycomb cell-like patterns with human technical structures, producing an exquisitely disturbing aesthetic encounter with the nature of form. Given my interest in abnormal and deformed cell growth at this time, there was a strong resonance with the ways in which these bees worked with damaged objects to produce new hybrid forms, not as a process of repair or cure, but rather as an imaginative new mode of cross-species reproduction. And the kind of cancer I had was one that transformed the meaning of the forms of human reproduction.

*Teratologies* means the study of monsters and marvel; a malignant *teratoma* is a tumour of the germ cell (in my case the egg cell), which can produce many different kinds of organs as it grows—hence the common allusions to “monstrous births,” as the cell can contain recognisable but distorted combinations of body parts such as nails, hair, eyes and bones. As I read about teratomas in the history of embryology, I realised how potent cells are when they become part of scientific imaginaries. I became interested in the weight of these associations and in the paradox of cells as signifiers of potentiality—of both potential life and potential



*Chess*, Aganetha Dyck, 2008. Beework and honeycomb on found porcelain figurine, 91/2x13x7. Photograph by Peter Dyck, 2008-9.





Close-up of *Matador*, Aganetha Dyck, 2010-11.

Lamp with porcelain figurine, beeswax, honeycomb, 23x8x6. Photograph by William Eakin, 2011.

death. To die from a teratoma would mean one's body had been taken over and destroyed by the potentiality of *life-giving* cells. I thought Dyck's *Beework* spoke beautifully to the ambiguities I had to learn to tolerate better when I had cancer. It's one thing to enjoy the play and deferral of poststructuralist celebrations of ambiguity in your academic textual practices, it's quite another to endure the non-transparency of one's own body in the face of a life-threatening disease.

**LJ:** I think the question of the book cover points to a crucial point: how does one represent a book about a subject in which the author's goal is to deconstruct the ways in which that subject is represented? The image on the cover of your book, Jackie, is also shot with a short depth of field such

that most of it is out of focus, and the image wraps around the spine to the back, so that no matter how one holds the book, a good chunk of the image of the sculpture is missing. That effect is perfect. I didn't have any choice about my cover (though my publisher did allow me to nix the first two options), but I did have twenty-five images inside the book. I distributed these among the chapters to indicate the range of ways that cancer has been represented in, for example, early detection campaigns, male breast cancer advocacy, scientific graphs, and medical advertisements.

**JS:** If the contours of this terrain were unexpected for both of us as we reluctantly travelled across them, then the kind of writing we produced in response seems to share an ambition to offer readers *both* critical purchase and affective connection.

**LJ:** Yes, beautifully put.

**JS:** In approaching the question of "how uncertainty can be reproduced as knowledge" (p. 221), as you put it, Løchlann, perhaps there was a desire to register the intensely textured and conventionalised, yet always elusive and baffling, quality of the social significance of our encounters along the way.

A mixture of first-person accounts and cultural analysis defines the shifting scales and registers of these books, their modes of address blending intimate narratives with social criticism. For me, the inspirations for this kind of "writing otherwise" (as I have come to think of it, see Stacey & Wolff, 2013) came less from feminist science studies, as this field was still relatively new terrain in my intellectual life, and more from feminist cultural studies. The inclusion of a range from digressive, poetic and anecdotal interruptions to conventional academic writing that I admired at that time came from writers such as Carolyn Steedman (1986) and Valerie Walkerdine (1990); their books seemed to me to have successfully combined stories from childhood with social and cultural criticism. More recently, feminists in science studies such as Jackie Orr (2006) have

interspersed familiar forms of critical analysis with shifts in register to signal formal and discursive interference; and the wonderful creative non-fiction writer who is also an academic, Mary Cappello (2009), has written what she calls a breast cancer anti-chronicle. And, of course, in queer studies, Eve Kosofsky Sedgwick's famous elegy 'White Glasses' (1993) triggered a more intimate style of theorising sexuality that has been continued by Jack Halberstam (1998), Ann Cvetkovitch (2003, 2012), and many others. More recently, Mary Bryson and Chase Joynt have produced a video/performance dialogue linking surgery and treatment for breast cancer with trans people's medical experiences (Bryson & Joynt, 2013) as well as Sedgwick's own writing about cancer and mortality (2010).

**LJ:** I like the way you speak of an "intimate style" of theorizing, and we both recognized the ways in which more traditional modes of academic theorizing were not going to get at the horrific and bizarre kinds of social structures we were encountering. You cite Jackie Orr and Eve Sedgwick, both of whom, along with Audre Lorde (1980), were models for me—for the sheer brilliance of their writing, the momentum of their narratives, and their commitment to understanding the deeper politics of experience. I can't help but notice that these three are also all queer identified, which has given them a certain distance from, and insight into, normative cultures. The genealogy here may be as much creative nonfiction and a commitment to exploring and communicating the insights of rigorous academic perspectives as it is a contribution specifically to a narrowly defined discipline. In that sense, I see some of my mentors, such as Adrienne Rich and James Baldwin, as writers and storytellers with strong narrative voices and political convictions. But I've also been influenced of course by a lifetime of reading novels, and Italo Calvino has recently become my favourite author. Still, the most significant academic writer of my career has been my dissertation advisor, Donna Haraway.

My method, and Jackie tell me if I'm right here in thinking that this was at least part of your method as well, was to initiate the various analyses by taking very seriously a few of the many stomach-punching

paradoxes that demonstrated significant and complex contradictions. In that sense, stories were a critical component of the narrative flow and argument, since the insights I gained from treatment would never have been accessible to me from a different observational location—one I had to consider extremely carefully and experiment with a lot.

**JS:** Yes, that describes it really well, I think.

**LJ:** As a fairly private person, I had to think long and hard about “coming out” in my writing, the role that the personal experience/voice played, what purpose it served. For one thing, let’s not forget that ten years ago discrimination and fear around cancer was, and remains, rampant and virtually impossible to identify, so in that sense I worried about coming out, particularly pre-tenure. I also found cancer was humiliating as hell, so why go there in my writing? And then, personal writing can so easily become self-indulgent, or seem to speak for itself, or come with a defensive voice—all criticisms that would horrify me even though they can equally be levelled at “academic” writing, and even though they can be launched before someone has actually read the work.

Ultimately, I decided to come out as someone who had undergone cancer treatment because I wanted to address, interrogate, and offer ways to bridge the vast chasm between modes of experience for doctors and patients and how these experiences situate knowledge claims. It was important for me to raise this issue because it really splits the literature on cancer in two and I wanted to illuminate the huge the stakes in, and costs of, this split. On the one hand we have studies in oncology and on the other we have personal memoir. But I don’t see these as complementary reports from different perspectives on similar phenomena. On the contrary, I think they are two forms of knowing that co-constitute each other, even as they dismiss and disavow one another. As a consequence of this divide, we miss an opportunity to understand how cancer science and research relies on notions of health, patienthood, sickness, economics, cause, and so on, that are worth understanding better since they underwrite not just the social life of living in cancer, but also actual

treatment options. This gap has to be bridged before we can understand the central and prevalent economic role that cancer plays in the making of American political and social life.

A funny thing happens around cancer, and I noticed this in many of my talks and write specifically about it in my introduction. Namely, people seem to gather around identities and, from that place, judge a claim. So in giving a talk, for example, if I do come out as a “survivor” I get a very different response—even with the exact same paper—than when I don’t. Thus, in either place—having, or not having had—cancer either taints or shores up one’s claims in a nearly identity politics kind of way. There is certainly something to that—something to be learned by laying one’s body on the radiation table. But to return to the main point, since one of the things I wanted to draw attention to is how knowledge on each side is incomplete, I had to work out the voice of my narrator very carefully as one that could both demonstrate the stakes in the separation and also bridge it.

I thought about how and what to write about extremely carefully, for I knew that I would have to be a trustworthy narrator, trustworthy to an audience who may not share my class, education, gender, perspective, or baseline about common sense: a modest witness, if you will. This is tremendously difficult in the cancer world because people have justifiably strong views about it and heavy stakes in believing in things such as trials, progress, and treatments (despite, or perhaps because of, the dismal success rates). On the other hand, some of the details of my story were important. Butch-ish, brown-ish, youngish for the cancer world, Canadian-ish—these details were important to the degree that their situatedness, I think, can be as expert, albeit in a different way, about cancer as a tall, cis-male oncologist, or as someone writing in an academic style that is more readily assumed to be “modest” and objective.

The narrator of the book is me but also not me. Strictly speaking, the stories are true and they are selected such that every story about my experiences serves a larger point or argument. But the character of the narrator was crafted in hundreds of rewrites and with many collaborators reading drafts. *Malignant* offers an analysis of North American cancer

cultures; it isn't an autobiography or a memoir. That separation of self and narrator, like the stories, is close to the bone simply because cancer is so humiliating. It's also terrifying and very, very boring and lonely. So no, that wasn't me. I never even had cancer.

I do think that among the risks, not the least of which is overwhelming vulnerability, one advantage of this approach, from a purely writerly perspective, is that we each gave the authorial voice a great deal of consideration and thought in ways that academic books sometimes do not.

**JS:** It's so interesting to read your account of that process. What I remembered when rereading the two books for this dialogue was how I had had to really grapple with making the more "personal narratives" an integral part of the project. I tried various methods: marking them out in a different font; beginning every chapter with a story; blending them in, as if seamlessly. Lochlann—your book seems to me to have achieved the latter. In the end, I went for the first of these options (and sometimes also the second). These different styles of writing both bring the affective dimension of illness onto the page, whilst trying to avoid the constraints and clichés of the conventional sub-genres of the classic cancer narrative. But these were undoubtedly the hardest sections of *Teratologies* to write and were also the most redrafted. Motivated by various combinations of desire and anxiety (revenge, disavowal, shame, gratitude), these stories were reshaped many times. For example, I remember that one of the dialogues I had written just didn't work; so, following the advice of a friend and colleague, I rewrote it, giving only one side of a conversation and left the other side for the readers to fill in themselves, which worked much better. When the tone of a story felt too confessional, I redrafted it with less pathos; and if the stories of my own naiveté in the face of a cancer diagnosis returned me to some of my unsophisticated pre-academic yearnings, sometimes I ironed out the embarrassment of this and sometimes I didn't.

You are right, I think, to have been cautious about the implications of using these styles of writing in relation to cancer. I am increasingly drawn to interrupting more conventional academic styles with so-called personal, anecdotal, or digressive registers, but not without ambivalence. The trouble is that as soon as you write “otherwise” as an academic who was also a patient, your writing very quickly gets folded into the genres of self-disclosure characterising cancer writing generally. Given that we’re both so sceptical about the sentimentality of those conventions, even the pairing of our books on the basis of this shared ground might cause us to hesitate. Using the language of the “confessional” or the “personal” to describe the styles we each use threatens to reiterate the generic conventions of cancer narratives that we are trying to undo. Recently I have wondered if a better way to describe those shifts in register would be to use a different language entirely; perhaps metaphors of scaling work better. For example, I could describe what I did in *Teratologies* as a scaling up and down of my focus in order to read the multiple dimensions of cancer cultures. But this doesn’t quite get at the ways in which I wanted to move readers, as well as interest them. I hoped that the unpredictable routes I followed in the writing might produce unexpected moments for the reader. My aim was affective engagement rather than directed emotional responses.

**LJ:** Yes, I like the way you put that: engagement rather than response. I think we both aim to open things up rather than offer any clear answers. *Teratologies* is unquestionably successful there; you lead with a series of explanations about how shocking and unforeseen the experience of diagnosis and treatment was, and then as the book progresses, you move into a series of brilliant insights into how work in film theory, gender, spectacle, stigma, and monstrosity reflect and illuminate cancer discourses. You begin from the horror of cancer, its monstrosity, and take that seriously—rather than domesticating it—in examining really how horrific it can be. “The tumor which these rogue cells come to form is part of the body and yet separate from it. It is produced by bodily matter but its

redundancy can kill. When it takes hold it can enlarge organs and break through the skin, bringing the inside to the outside. If only it came out immediately and could be routinely cut off like an unruly shoot, perhaps survival might stay within sight. But it hides inside instead, to protect itself until its roots prevent pragmatic amputation. It impersonates the subject long enough to establish the power of its real difference, often until it can overpower its host body” (Stacey, 1997, p. 78).

*Teratologies* is the first academic book on an illness, as far as I know, to take this interdisciplinary, intermodal approach, and I read it nearly immediately upon diagnosis. (It was recommended to me by one of my mentors, Lucy Suchman.) Because I read it so early on in my own process, far before I had any intention of writing a book on the issue, I regret to say that I did not acknowledge it nearly enough in *Malignant* for the ways that it shaped my own thinking. As I reread my copy of *Teratologies* for this dialogue, I found many highlighted sentences and exclamation points in the margins that took me right back to those early days of reading your book and that strong bond I felt with you, though I barely knew you (!). *Teratologies* was unquestionably one of the first and the best of the literature that meshed one’s own experience as part of the ethnographic material with a hard-hitting intellectual and political analysis. I can’t even imagine how hard it must have been to have come out at that point in cancer’s cultural history, let alone pioneer a new style of work in which the method really fit the questions—but the fact that you did has changed the route of gender and queer studies in initiating the long road to destigmatization.

**JS:** One of the things I most admire (or, to complicate this mutual admiration moment, maybe I also envy) about *Malignant* is the way you make these shifts in scale and register so elegantly. In Chapter Six, for example, we are introduced to your own IVF treatments through your affecting writing, and then we find ourselves in the midst of your careful and nuanced epistemological challenge to research (or its absence) in this medical field. And in the chapter on the cancer artefacts (and bodily



prosthetics) that accumulated over the course of diagnosis and treatments, Lochlann, you both detail the power of biological artifice (wigs, prosthetic breasts) in the context of the intensification of gender normativities in cancer cultures, and you show how identity knowledges are troubled by precisely the objects that promise their stabilisation. Cancer prosthetics bring sharply into view how much gender is a question of reading and being read—of legibility. As you put it: “If the wellness could not be faked, the ‘femininity’ could” (Jain, 2013, p. 209).

This made me think of what Joan Riviere (1929) and Mary Ann Doane (1991) argued (in psychoanalysis and then film theory respectively): femininity is a masquerade that performs itself for another—its achievement depends upon a having-been-read-ness. Your story of how you might be read as the “bald dyke from San Francisco” matches my own exploration of the queerness echoed between the unspeakable embodiments of the C word and the L word (in the UK in 1991 anyway). When I was rewriting these sections (the first draft was jotted down while I was still in hospital after the surgery), I was surprised not to find more written about sexual stigma and taboo; this was partly why I relied on my own affective registers as a starting point. I wrote much of the book in the early 1990s when queer theory and affect debates had yet to make their full impact. Looking back, I can see so many ways to redo this chapter now (maybe Heather Love’s new work on the stigma archive will inspire me to return to this area [see Love, 2015, forthcoming]).

**LJ:** Alas! That’s the price of being the innovator: others build on and take courage from your work. Your work on the L word and the C word prefigured and enabled the queer theory that then emerged, and deserves to be even more widely cited for both its content and its role in the development of the discipline. This is an example of the high cost of the ways in which scholarship is segregated, and in particular the segregation of work on medical issues, such that I suspect *Teratologies* is understood more as a book on cancer than on queer/gender theory, cultural studies, or political theory. This is an opportunity lost and a genealogy disavowed.

**JS:** Perhaps we should also pause further here on the differences between the books and on the hesitation we might want to express about the obviousness of their “pairing” here. It is important to say here that when we were first invited to have this dialogue, my tendency was to try and articulate the common ground between the two projects. As our dialogue has developed, it has also become important to question some of the underlying assumptions about the “shared” categories (cancer, lesbian, academic, feminist, patient, queer) that might be the grounds for the comparison.

**LJ:** I completely agree. I think this pairing can itself be seen as symptomatic of the overdetermination of narratives that come to be seen overarchingly as cancer narratives. In fact, in most ways our books are completely different in terms of method and approach, subject matter, politics, and scholarly contribution.

I would love to see other kinds of pairings that start to engage the real substance, as well as the ostensible topics of the books. I’d imagine an amazing dialogue coming from you and Doane or other film scholars who think through stigma, gender, precarity, and visibility. I’d love to be paired with folks who write explicitly on queer studies or political economy.

**JS:** Exactly. If cancer has a “grammar all of its own,” as you put it, Lochlann, then it is surely an overdetermined one, in the general sense of saturated with contradictory significance and thus not easily intelligible in any definitive way. Like multiple “dream-thoughts” condensed in a single image or potent thought displaced into an apparently trivial image, the grammar of cancer strains to contain an impossible overload. To pull at any sentence thread within this grammar is to find oneself unravelling the uneven and charged formations that constitute the cancer complex. Whether causation, treatment, prognosis or future prevention, the conflicting advice and worldviews flood into the spaces of uncertainty. Too much information of the wrong kind, too much advice and too little listening—cancer’s cultures proliferate so much knowledge they make it

hard to come up for air. The C word and the L word chapter in my book turned to the weighty experience of representing stigmatised categories that generated a visceral sense of anxiety in others, which one then had to deal with, alongside the illness and its treatments. In the context of early 1990s British culture, the affective charge around cancer was always more than the sum of its parts. I suppose the easy way of saying this is that cancer generated an especially powerful psychic force (and I think it still does, even if things have changed a lot since then).

**LJ:** Even in the last decade since I began writing my book, the landscape has completely changed. Ten years ago young adults were a completely isolated group when it came to the diagnosis, treatment, and sociality of cancer. While the stunning financial hardships, lack of treatments, and late diagnoses are still rampant, there is an incipient medical recognition of the specific needs of this demographic and recently a lot of social networking and activism has emerged, so the whole experience is perhaps equally as hopeless, but at least not so isolating.

**JS:** Yes, that change is really important I think. The general orientation of the two projects might be that they both attempt to take the pulse of cancer cultures at a particular moment in ways that speak outwards to the more generalised landscapes beyond them. In other words, they try to diagnose what articulates with what, when, how and why: a kind of history of the present (as Berlant [2008] would call it), or a study of a cultural conjuncture (as Stuart Hall [1980] would have put it). But, of course, my context was the British National Health System and the Welfare State (or what was still left of it after Thatcherism) in Birmingham in the early 1990s. Unlike your focus on drug companies, private medical insurance and lawsuits (which come both from your North American context and from your previous research interests), my social criticisms were aimed at the ways that Thatcherite policies had decimated financial support for the NHS by cutting government funding and by marketising internal structures and relations between departments and hospitals. A direct example from that time is my witnessing two nurses barter plasters for cardboard sick bowls,

when the chemo ward I was on had literally ran out of them and there was nothing for me to throw up into.

In writing the book, I was also keen to challenge the discourse around self-responsibility, which not only reinforced a pernicious individualism but was also shaming (and blaming) of people with cancer, shining the spotlight away from the government's social responsibilities and towards patients. It's not that there aren't plenty of pharmaceutical company policies of which to be rightly critical in the UK; it's just that the priority for social scientists of medicine at that time was to try and help maintain the foundational principle of the NHS which was (and continues to be) so much under threat: that is, that all treatments should be "free at the point of access."

So that's one important difference between the contexts of our books; the other, of course, is our interdisciplinary backgrounds. I see you using your anthropological eye to caution against the economic and legal underpinnings of many of the alienating medical practices organising the "cancer complex." My own interest in film theory and cultural studies provided the framework for my focus on visualisation and fantasy. The PhD project I was three weeks away from completing when I was diagnosed was about changing cultural investments in idealised female bodies on the cinema screen—as eventually explored in *Star Gazing: Hollywood Cinema and Female Spectatorship* (1994). My focus at that time on the surface perfections of female stars in 1940s and 1950s Hollywood could not have contrasted more strikingly with the images of teratomas in the medical textbooks I looked at to find out about this kind of tumour. Etymologically referring to "monstrous births," the photographs I found in those medical textbooks reminded me of the disgusting iconographies of body horror films—the complete opposite of the idealised "clean and proper bodies" (Kristeva, 1982) that I had been studying on the Hollywood screen. This led me into the exploration of a teratological imaginary, that fantasy landscape generated by the tension between fear and fascination, whose *mise-en-scène* was distinctly science fiction in tone.

In fact, it was reading science fiction criticism in film studies for *Teratologies* that first led me into feminist science and technology studies more generally (an influence that has continued rather than being a passing phase). I'd been aware of this field at the Centre for Contemporary Cultural Studies (CCCS) in Birmingham, where I was completing my PhD, but it was definitely at one remove from the psychoanalytic theories of spectatorship I was struggling to put into dialogue with ethnographic studies of audiences at that time. It's less that I developed a framework for the book after diagnosis and treatments, and more that I found myself plunged into this phantasmatic world of embryology and cell biology (of teratology) that seemed already populated by the iconographies of science fiction cinema (and vice versa). The only way I seemed able to find an orientation through this nightmarish world of excessive cell growth and monstrous births was to begin to theorise the other side of the surface perfections of femininity as the hidden horrors of the maternal body. Our repeated need to return to scenarios that enable us to ensure a clear distinction between the two seemed to be evidenced in the popularity of science fiction genres and our fascination with medical dramas generally. This was my starting point for writing a book that emerged from having cancer. The affective familiarity of being diagnosed with a stigmatised illness (especially at my age then, 31) echoed responses I had noted to living a stigmatised sexuality (which I had announced to my family and friends relatively recently—5 years or so previously). I began to write notes about this affective echo while I was still in hospital rehearsing the news with visitors and other patients (who were mostly having hysterectomies).

**LJ:** Yes, and I found it especially incredible to re-read your Chapter Three, in which you so acutely worked out the layerings of monstrosity metaphors in thinking through different kinds of stigmatized bodies and through multiple theorists coming at this question from different angles. This chapter is brilliant. Read it.

I don't see my book as an activist book *per se*. I'm less interested, for example, in figuring out who should have responsibilities to whom than in understanding the stakes of our blind spots and the logics that hold our attention away from seeing these stakes, or the implications of how we currently misunderstand this rogue-ish, noun-ish cancer. *Malignant* examines the routes by which our attention swerves from understanding the depth of cancer as an economic decision and misleads us toward pseudo-questions, such as how much we as a society should spend on treatments, or whether we are winning the war on cancer. In that sense, my approach was to try to take away the natural analytic end point that cancer presents when it is closed off as an object in itself, and to rather see it as a window on the array of phenomena that have arranged it, and closed it off, as if it were an object. The most I can hope for with my book is to provide some language for those who suffer from similar cognitive dissonances, or those who seek more accurate ways of understanding the depth of the paradoxes that construct cancer as we know it. In that sense I aimed to take a hard look at the deeply vicious cycles and human costs of the simplistic and idealistic ways we understand the economy and its health, and provide routes to a richer understanding of the values that underlie what I'm calling the political-medical-economy.

**JS:** I see what you mean. Not an activist book, unless we hope that intervening into blind spots and logics is its own modest kind of activism. Academic activism perhaps?— if that's not a contradiction in terms. But that's the subject of a whole other dialogue topic for another day I think.

**LJ:** To question the construction of "cancer" in our society is to question some very deeply held beliefs, beliefs that won't change. In my view, the best we can do is to shine a bit of flicker, which I try to do methodologically through a form of writing and attention that I call, using the concept of my friend Derek Simons, Elegiac Politics (see Simons, 2006 and Jain, 2007). I certainly don't think that an elegiac structure *needs* an autobiographical component. But there are two parts to that approach that I do think are critical. The first is an attention to the ways that logics of thought (for

example, in risk calculation) can systematically structure and at the same time obscure violence, and the second is an attention to the real human costs of those sacrifices that are contained by such ways of structuring an issue.

Elegiac Politics aims to “recognize the quiddity of both the violence and the ways we justify it, hide it, and render it logical and explainable—each time in slightly different ways. An Elegiac Politics recognizes the dangers of the narrative form, and commits to show rather than to describe, to question rather than explain, and to invite rather than inform.” This is a definition of Elegiac Politics that Simons and I have been working on together (see Simons, 2006 and Jain, 2007). Perhaps this would be a good moment to turn to the question of queering temporality in our work.

**JS:** Yes. Thinking about this issue for this dialogue reminded me of what Gunhild Hagestad, wrote about getting cancer: it is like “falling out of time” (Hagestad, 1996, p. 205)—everything around you continues to be organised through the conventional flows and routines of calendrical structures, while your own temporal structures fail to hold you anymore. In *Teratologies*, I sought to link this feeling of temporal scrambling with a critique of the kinds of heroic stories that get published about surviving cancer. I loved the extract from Miriam Engelberg’s *Cancer Made Me a Shallower Person* (2006) in your book, Løchlann, and I also enjoyed Barbara Ehrenreich’s *Smile or Die* (2010), as both of these challenge the progress narrative of stories of endurance and survival (often presented as a steady upward curve towards wisdom, thanks to the “gift” of a cancer diagnosis). This is a reductive stereotype, I know, and actually today there are many more variations on this kind of heroic narrative. But when I was diagnosed, it felt to me that this was the pervasive discourse not only in the personal narratives and self-help books I was given, but also in everyday conversations.

Looking back on *Teratologies* now, it’s obvious how much it was a book about queering temporalities. Psychoanalytically, of course, the past-present-future distinction that has organised modern ideas of time

makes little sense. If we can be returned to affective states from our childhood in ways that make the past feel like yesterday, then, in psychoanalytic terms, as Melanie Klein (1975) has argued, there is only ever present time. I have increasingly turned to psychoanalytic frameworks for understanding our attachments to the illusory (and reassuring) teleological organisation of modern notions of time. Recent theories of queer temporality have given a new psychosexual charge to the strangeness of modern time (already much written about by philosophers for decades). What I appreciate about recent debates that have become so influential in the field in the last few years (Edelman, 2004; Freeman, 2010; Halberstam, 2005; Love, 2007; Munoz, 2009; and so on) is that they make the double move of exposing the heteronormativity of teleological structures and narratives (see Valerie Traub, 2013) whilst also demonstrating the strangeness of time itself. I think what I was grappling with, in the context of what you so eloquently called “living in prognosis,” Lochlann, was how to write about the ways in which the embodiment of heteronormative temporality is articulated through conventionalised linear narratives that collapse with the onset of life-threatening illness. Cancer, as you write, adds a particular charge to this loss because of its shaming capacities and the problem of its legibility. Mary Bryson and I (2013) have written about this in relation to queer representational politics and strategies.

One way to think about “living in prognosis” is as the scrambling of time: perhaps the past becomes overly present as it is scanned for possible aetiologies; perhaps the stretched-out future most (white, middle-class) 30- to 40-year-olds take for granted shrinks to an unpredictably truncated span that makes the present feel always poignant; or perhaps all decisions feel so impossible (and absurd) that even the most trivial options become relative and contingent. Without over-stretching the articulations between queerness and temporality (see the *GLQ* roundtable, including the critique of this connection by Annamarie Jagose, in Dinshaw et al., 2007), we might argue that cancer brings to the fore a disturbance to patterns of self-narration and quotidian routines that have generally



anchored heteronormative ways of organising one's life; in this sense, cancer's chaotic impact on the capacity to live one's life through the flows of modern time will echo and deepen a sense of queer temporal disturbances already familiar to many.

**LJ:** Yes, that is beautifully put—I like this contextualization of temporal regimes within heteronormativity and your reading of the impossibility of pasts and futures, and you write of that beautifully in your introduction as well. I was particularly interested in thinking through time in two ways. First, I was interested in how capitalist structures of accumulation work to both consolidate normative ideologies of normative lifespans (that are so shattered for young adults, in a different way than for children, diagnosed with terminal or life-threatening illnesses of any kind). In thinking through these temporalities and how they become taken for granted, I looked to economic structures such as social security and retirement savings accounts, normative social expectations/structures such as marriage and children, and read-early detection campaigns against those.

Second, I became fascinated with the utter—and yet virtually impossible to bring together—difference between the constant population statistics generated in the studies around causation and treatment, and the singular individuality of a cancer diagnosis and prognosis. I call this effect “Living in Prognosis” (Jain, 2007) and trace how the statistics move through medicine, medical malpractice law, and various laws and policies that might limit carcinogenic exposures. Prognoses gain a solidity at the population level not reflected in the experience of individuals (or even for populations: institutions such as law courts and regulatory agencies have simply been unable to imagine how to deal with this paradox). Uncertainty becomes a number, which lends it a sense of credibility that simply falls apart when you scratch the surface. The overlooking of this uncertainty by courts, physicians, and policymakers of good and bad faith without fail gives the advantage to cancer rather than to defending against cancer.

Combining these two ways of understanding immortal and mortal time enables me to examine how effective the rhetorics of progress in a

war against cancer have been, even despite all the evidence to the contrary both in causation and in treatment. It can be hard for people to hear that argument, because it goes against the grain of hope, common sense, medical promise, and progress, and it forces us to recognize just how misleading it is to think about cancer as an external, rather than an internal, social, medical and economic threat.

**JS:** A good place to stop, as we've run out of time (and we are over the word count). But to be continued I hope.

## Notes

<sup>1</sup> During the mid to late 1990s, numerous art exhibitions featured works by and about women with breast cancer, following a decade of art exhibitions by and about people with HIV/AIDS. In 1995 Aganetha Dyck's work was included in the traveling exhibition "Survivors, In Search Of A Voice: The Art of Courage," curated by Barbra Amesbury and Joan Chalmers for the Royal Ontario Museum, Toronto, with the support of the Chalmers Foundation. This exhibition explored breast cancer through the work of 24 Canadian women artists in collaboration with 100 women with breast cancer and was viewed by an estimated 250,000 in Toronto and one million internationally (Gordon 1997). Two articles about the exhibition by Lynna Landstreet (1995a and 1995b) were published in *Xtra!*, the Toronto gay newspaper, now online only, founded in 1984 and published by Pink Triangle Press. Barbra Amesbury (born 1948) is a Canadian singer-songwriter, composer and filmmaker, and philanthropist who had several Top 40 hits in Canada in the 1970s as Bill Amesbury before coming out as transsexual. Chalmers (born 1928), the renowned Canadian philanthropist and supporter of the arts, is her long-time partner and collaborator on projects including the Woodlawn Arts Foundation, through the support of which works from the Survivors exhibition are in the collection of The 519 Church Street Community Centre in Toronto.

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## Bios

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