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## **Malignant: How Cancer Becomes Us by S. Lochlann Jain (review)**

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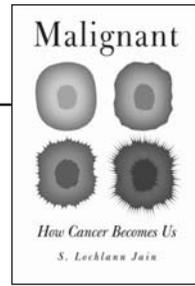
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## NEW RELEASE BOOK REVIEW

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S. Lochlann Jain, *Malignant: How Cancer Becomes Us*.  
Berkeley: University of California Press, 2013. 304 pp.

I had not intended to become a cancer anthropologist. I can say, without shame, that when I finished my first project, the intent behind my move to the National Cancer Institute (NCI) was to follow the money. Acknowledging the NCI as the 800-pound, pink ribbon-festooned, funding gorilla of the NIH, the epitome of Nixon’s *War on Cancer*, it was a move to understand one of the single, greatest public efforts to address human illness. I wanted to understand cancer disparities as an anthropological object, the dual construction of science and politics, a research agenda and grant portfolio made real by health scientist administrators who themselves would constitute my new “village” (Lee 2009a). It was also a four-year post-doctoral fellowship with full healthcare benefits. Cancer science and cancer care is truly an enormous configuration of contemporary American undertakings, and we should not overlook the (ancillary? derivative?) academic enterprise that grows alongside it, albeit dwarfed in scope and dollars.

“Cancer may start as a series of dividing cells...but it is more richly understood as a rhetorical term that can powerfully organize relationships and as a key player in the broader history of the United States and elsewhere” (233). More simply, “cancer can’t be inside so many people and remain outside society” (221). It is in this light that Jain’s new text comes together as a meditation on cancer as part of a uniquely American contemporary landscape. Three previously published essays are adapted here in a new configuration with four new chapters, building new arguments while simultaneously weaving an analysis that draws on her prior projects in injury

and malpractice law (Jain 2006). To push the metaphor, *Malignant* started as an idea evolving into something new to progress and proliferate, to take a life of its own. Jain's choice of title was not benign, which should tell you something about her thoughts on the matter.<sup>1</sup> Jain describes her book as an effort to map out cultural containment strategies (221), exposing or calling into question how the organizing of information about cancer—even with the aim of finding cures—does violence to the lived experience of the disease and its effects. *Malignant* uses cancer as a framing device to present a different take on the downstream consequences of the rise of population thinking (Porter 1995).

Scholarly writing offers an inherent challenge, none more so than anthropology. To be scholarly, the author has to immerse herself in the phenomenon, deeply, perhaps for years, such that the strangeness of the thing in question becomes familiar, thereby understandable. And then, in the moment of writing, an author must bring readers close enough to see that thing in stark relief, all the while conveying the daily-ness—the routine of what is, in truth, simply other people living their lives—such that readers are compelled to recognize how this account can only be true.<sup>2</sup>

Jain uses Maurice Blanchot to provide a philosophical vignette for “Living in Prognosis: The Firing Squad of Statistics” (Chapter 1). Her engagement with the Frenchman pivots on the juxtaposition, “I am alive. No, you are dead.” This is an interesting invitation that I take up because it helps me think about Jain's positionality across the texts that she has assembled to create *Malignant*. Blanchot, who writes poignantly elsewhere about literature and the right to death, says of Thomas Mann's fiction:

...he does not respect the rule of nonintervention: he constantly involves himself in what he is telling, sometimes through interposed persons, but also in the most direct kind of way. What about this unwarranted intrusion? It is not moralizing—a stand taken against a certain character—it does not consist of illuminating things from outside—the thrust of the creator's thumb as he shapes his figures the way he wants them. It represents the intervention of the narrator challenging the very possibility of narration—an intervention that is, consequently, an essentially critical one, but in the manner of a game, of a malicious irony. (1981:137)

The first chapter, then, is about survivorship: what that word means in the cancer context but, more importantly, what that experience means in this day and age. In this, readers would find it productive to read *Malignant* against Paul Stoller's (2009, 2004) accounts of the vicissitudes of remission that make less of an attempt to take on a larger cultural critique than Jain. Jain herself offers, perhaps, a useful synecdoche of her objectives in a footnote to this chapter: "Survivor takes the sting out of the stigma, but the rhetoric may also be understood as part of a broader cultural cancer-management technique" (236, fn 7). I was struck by her treatment of capital and kinship, time and accumulation, and the ways in which the threats of cancer (as diagnosis, as treatment options, or as early detection) play against her vision of the market and life's risks. Jain is an interlocutor, then, with anthropologists Peter Benson (2011), Karen Ho (2009), Adriana Petryna (2009), and Caitlin Zaloom (2004), some referenced in Jain's work, whose accounts on different vectors also dissect the seductions of risk and probability, particularly amidst ideologies of productivity. A key difference here, however, is the way that Jain deftly uses observations of her own experience, both as anchor and as foil, to fully realize the larger dynamics of the cancer complex. Patient-ness brings a very different warp to the weave.

Jain's contribution to a recent edited volume, "Be Prepared," distills the paradox of individuated agency against the inexorable march of survivorship statistics (Metzl and Kirkland 2010), published after Jain's initial version of "Living in Prognosis" (presented in part as Chapter 1 of *Malignant*). In "Be Prepared," Jain relates her own faux pas in greeting a former partner's bald sister as the means to understand how perceived exceptionalism is "only the flip side of my own shame" (Metzl and Kirkland 2010:170). I laughed out loud at the reproduction of Lance Armstrong's "game face" (53), also cast as the "Poker Face: Gaming a Lifespan" in Chapter 2 of *Malignant*. This is particular genius as the photo precedes the chapter on scars and gender representation, where Jain notes as an aside that, to her knowledge, "Armstrong prefers releasing images of his face to images of his cancer scars" (81). Lance Armstrong has been a complicated (anti-) hero, an archetypal figure of American exceptionalism rebounding from cancer, creating the LA Foundation that strategically became LiveStrong! just as his legacy went fully pear-shaped. However tragic, the Armstrong legacy for the cancer community, especially in Texas, is reflected not only in the excellent track record of LiveStrong!, but also in his legislative advocacy that helped create the Cancer Prevention & Research Institute

of Texas (CPRIT), a bond-supported funding agency second only in the world to the NCI but dedicated (surprise!) to funding the fight against cancer within the bounds of the Lone Star State.<sup>3</sup> In Texas, the aptly-named Cattle Barons' Ball, the single largest fundraiser for the American Cancer Society, is *the* Dallas high society season soirée held annually on the grounds of Southfork, the ranch estate known worldwide as the Ewing mansion for the epic TV series (cue soundtrack). Everything is bigger in Texas; nothing is bigger than Big D.<sup>4</sup>

Since I moved to Texas, I think about territory differently than I did as a coastal-city (read: New York progressive) anthropologist. Reading through *Malignant*, I wondered about the pseudo-cognates: territory from *terre*, terror from *terreur*. “The temporality echoes the double action of prognosis: causing and evacuating the terror of a potential future” (Jain 2007b:81). Jackie Stacey’s earlier *Teratologies* (1997), similarly, used personal experience to reach for a cultural narrative of cancer but framed across the specific terrain of monsters and marvels rather than what feels more like the means of production backdrop of *Malignant*, and Stacey does not explicitly insist on an Englishness to her thesis with the same urgency that Jain ties cancer to fundamentally American themes.

Jain’s earlier cultural treatise is on display when she connects notions of agency and responsibility for cancer and its sequellae to malpractice, torts, and less successfully to statistical thinking that undergirds cancer clinical trials. Jain tacks back and forth from local disease to the larger systems in which single tumors, indeed, whole individuals, are embedded. Her earlier book, *Injury*, similarly tracks the traces of the American contemporary to “locate lines of knowledge and make policy under conditions of extreme uncertainty” (2006:155). In *Malignant*, we see this most clearly in issues of early detection and diagnosis that result in both over- and under-treatment that is the territory of Chapter 7, “Can Sir: What Screening Doesn’t Do.” If I were to pull out a single nugget of the different themes in this book, it would be the power of the emotional response that comes in the course of learning more about cancer. Such emotion is not only at the initial moment of diagnosis, but also detectable in an intellectual’s response to the discovery that, in the face of the unknown, turning to vast reams of data (of all types) available about her new condition does not bring the comfort and succor we expect to come from greater knowledge (Woodward 2009). Her text asks us, what matters more? “[T]he interpretation of one who has much at stake by virtue of literally embodying the

disease, or the understanding of someone for whom a tightly specified set of research data offers no more than a professional tool” (17)?

Since becoming involved in a study of rural cancer services, I am very conscious of what it might feel like to live somewhere in the 14,000 square miles of North Texas, fearing a lump but having limited access (financial or geographic) to clinical care. In the rural breast cancer screening and patient navigation model that I am evaluating, the services offered are based on meeting the national screening guidelines set out by the CDC’s National Breast & Cervical Cancer Early Detection program and operationalized by the Texas Breast & Cervical Cancer Services that provides a fast-track to Medicaid for under- and uninsured women. Women using our program receive services according to eligibility, while the providers receive reimbursement when the services provided meet guidelines; that is, a screening mammography that detects an abnormality must lead to both a diagnostic mammography and a clinical breast exam conducted by a certified clinician, with appropriate biopsy, all within a certain time frame. The guidelines also create different clinical pathways for asymptomatic (routine screening) versus symptomatic women who report a reason for concern that is triaged through our oncology nurse-driven navigation process (Argenbright et al. 2013).

Although Jain is right enough that the unintended consequences of over-screening (or of treating benign disease) are serious, it matters what population such screening efforts target. For example, in the last eight months, 86 percent of the women my program screened and 97 percent of the women reporting symptoms were uninsured. On average, about a quarter of these women had never before had a mammogram or had not had one in the past ten years. National guidelines recommend that women 40 years or older receive a mammogram once every three years. The issues Jain raises are important and raise many questions from women, their advocates, and their physicians. But even with the Affordable Care Act-established health exchanges struggling to go live this winter, there are hundreds of thousands of people who have no access to even baseline screening services; these people are not at risk for over-screening in the same way.

Clinical quality is often a moving target, and the stories Jain’s informants recount are poignant. In one case, Carolyn reports a discouraging experience when her physician conducted an inadequate clinical breast exam (170). To provide a benchmark to understand Carolyn’s real dismay, I spoke to my breast health manager about what our program offers for under- and

uninsured women. My oncology-certified nurse colleagues use the vertical strip method for their clinical breast exams. It provides complete exam coverage from the axilla to the sternum and from the clavicle to the infra-mammary ridge, making it the most comprehensive type of clinical breast exam used. The amount of time varies (more tissue equals more time); we allow 30 minutes for review of history, education, and the exam itself.

In sharing these accounts, the author writes on behalf of the host of patients who find themselves understandably confused, at sea, in the midst of new, often unexpected, information about cancer, where the concrete ground of fact is often lost amidst the fog of medical nuance, or simply the inability of the medically-trained to remember to be human in the face of bewildered and vulnerable patients. The initial *Representations* essay, “Living in Prognosis” (Jain 2007b), bears the subtitle, “An Elegiac Politics,” replaced in *Malignant* by “The Firing Squad of Statistics.” This may be unfairly psychoanalytic but, if a book review can be forgiven a close reading, Coleridge tells us:

October 23, 1833...Elegy is the form of poetry natural to the reflective mind. It *may* treat of any subject, but it must treat of no subject for itself; but always and exclusively with reference to the poet himself. As he will feel regret for the past or desire for the future, so sorry and love become principal themes of elegy. Elegy presents every thing as lost and gone, or absent and future. The elegy is the exact opposite of the Homeric epic, in which all is purely external and objective, and the poet is mere voice. (1836:275)

Fortunately, Jain does not offer us a Homeric epic; her story is not about a heroic best “in a system that could be better” (106). For example, Jain engages Atul Gawande, the healthcare reform surgeon-of-the-moment, noting that he is both an interested and informed observer as well as someone speaking from the inside. Her critique of Gawande’s narrative is telling because it resonates with her own stance in relation to what we might consider the “generalizable ‘cancer experience’” (235), although Jain’s work reveals more than the commonplace elements, what I find myself thinking of as a greater oncologic-but-culturally suspect constellation. More important for the arc of her treatise, Gawande provides the clinician voice against which Jain wants to ask the real question of personal responsibility—for causing cancer, preventing cancer, finding it at

the right time, treating it the right way, living with it, surviving through it—who is the true agent, or locus of control, when even the numbers seem to conspire against one.

Jain observes that “doctors work in complicated systems, and fault for error can be distributed in many ways” (89), then explores this observation with a 2005 case involving a wrongly administered chemotherapy drug. The very week I was reading this chapter, I was given a Harvard Business School case study concerning the Dana-Farber Cancer Institute.<sup>5</sup> The case concerns the death of Betsy Lehman, who received an overdose of chemotherapy and later died. Ms. Lehman was a 39-year-old mother of two and the health reporter at *The Boston Globe*, the newspaper which not only reported the death but documented the repercussions for Dana-Farber and their efforts to remedy the processes of care that were implicated. It is a fascinating case, and very much *en vogue* across healthcare to ask somewhat anthropological questions about risk and blame, individual decision-making, and the interaction effects of a more nebulous “climate” or “system” (perhaps even “culture”) that are somehow responsible for medical errors. And yet, the Institute of Medicine itself tells us, “To Err is Human” (IOM 1999). Jain asks us to consider if this is good enough when one has been repeatedly misdiagnosed or frankly ignored when age does not fit a physician’s expectation for disease?

*Malignant* is an admirable achievement as well as an entertaining read, in part, because the author moves so skillfully in and out across a vast, often vexing, landscape. For Jain, cancer is not just a disease, but “a constitutive aspect of American social life, economics, and science” (4), and her goal, and success, is to demonstrate the ways in which “the disease” has become us/the US. This is nowhere more evident than when Jain takes on the market, the pharmaceutical industry, and necessarily, the clinical trial enterprise. Jain’s scholarship has a strong commitment to understanding regimes of production and consumption; even in the midst of describing the “perfect capitalist disease,” Jain quips: “(a dead smoker cannot buy cigarettes)” (Jain 2007a:506)! With her particular track record of calling out the American contradictions of industry built on known and expected deaths that spawn new industries to counter illness rather than root it out in the first place, Jain’s ethnographic voice flays, in turn, all the big players from the Department of Defense to domestic oil and gas fracturing (81).<sup>6</sup>

Like the good documentarian, a reader is drawn in by a narrative voice that cannot help but marvel at the audacity of a culture that can make a

business out of anything. This is, in fact, a narrative device Jain invokes in the introduction, where she likens the journey of the text to producing a documentary film where, incidentally, her physician is adroitly cast only as Dr. Sideshow. In this sense, I was not surprised to see Vito Russo invoked quite directly in “Cancer Butch: Trip Up the Fast Lane,” where Jain uses her own experience most powerfully. In the book manuscript as Chapter 3, “Cancer Butch” artfully deploys a story of driving in the pink BMW campaign to presage an analysis of cancer as a gender personifier, contrasting Audre Lorde’s *Cancer Journals* against the portraits of Deena Metzger and Lynn Kohlman. A very personal account of post-surgical self-awareness and the public-ization (sic) of the private that scars can communicate (234-235) becomes a foil for the gendered nature of politicizing illness (Jain’s term is “pinkwashing”), as breast cancer is cast as distinctly female despite the fact that more men die of it than testicular cancer (80). But her point, then, is that breast cancer is not just female, but feminine.

Do the scars render visible the cultural sacrifice of cancer, showing that, because I bore the disease, the six other women of that one in seven stat will escape (and can I please choose who they will be)? (76)

Another theme that runs through *Malignant* is the sacrificial economics (perhaps of any disease, but arguably most significantly) of cancer. As I read through “The Mortality Effect: The Future of Cancer Trials” (Chapter 5), I puzzled over the ways in which the creation of statistics attempts to create comparability (perhaps like the pain chart that stands in for a dose request), even moral equivalency, through the abstraction of numbers of very different experiences. I thought of sacrificial politics in the decisions by various administrations to refuse media coverage of US military dead being returning to the US and then, specifically, its relation to the question of women serving in “active combat” because of some idea that the American public could not stomach seeing mothers, daughters, and sisters dying in service would undermine the “war effort.” **Sectumsempra!**

Although I would stop short of calling HIV “a ‘cool’ disease” (Jain 2007a:529), I do understand her point, by which Jain supposes she “meant a queer disease, a guy disease.” Indeed, cancer does have a particular historical relationship to shame that colleagues and I encounter today, especially among lung cancer patients (Hamann et al. 2013). The ambivalence that Jain feels from the pink-washing of breast cancer

survivorship then resists the perceived membership of acknowledged community and insider-ness that a fellow queer might find in turning poz.<sup>7</sup> As Jain well knows, however, that comes from a hard-fought struggle (86); it was not always that way. She argues, though, that “a stark difference between cancer and HIV/AIDS has been vastly undertheorized by medical anthropologists. Taking cancer seriously as an ethnographic object shows the impossibly brutal underside of US productive regimes” (Jain 2007a:506). Again, the earlier essay explains:

Rather than a call to action, an elegiac politics recognizes the basic human costs of U.S.-style capitalism. The point is not simply to eradicate the shame that has for centuries accompanied the disease, but also to acknowledge the ugliness of the disease and of the suffering it causes and to let that suffering be okay, not because it is okay but because this is what we have. I draw a space in which cancer can be brought out of the closet in a way that is not about comforting ourselves and each other, and that is not about righteous anger but, rather, is a space of mourning and a space that allows for the agency and material humanity of suffering and death. (2007a:506)

So, I see her point, but the auto-ethnographies of HIV/AIDS are still few and far between (Michaels 1990).

As anyone who “works in cancer” might attest—physicians and biostatisticians aside, Jain would argue—writing about the Dread Disease requires some level of humor. Jain uses dry wit, irony, and occasional glee, the better to skewer her targets and tack back and forth between the crudity of our society and the stark, sometimes numbing horror of suffering from cancer. From my perspective, good cultural critique is hard because the temptation to take on sacred cows can easily be upended and cast as tilting at windmills by those you chastise. But such work is often at its strongest with a dose of the zany, even manic. One reviewer argues that, “elsewhere, Jain’s voice is angry and embittered...She is angry that, for all the billions poured into research, we still don’t understand what cancer is and where it comes from. She faults the National Cancer Institute for looking more at the genetics of cancer rather than environmental causes.”<sup>8</sup> This may be true, and yet it belies the work it takes to step aside and look askance at this thing that cancer has become, as a disease or diseases, as a science and as a medico-scientific-industrial

complex. Jain's own stance is more nuanced, and anthropologically stark, although in the book manuscript, her disclaimer is relegated to the last footnote of the Introduction:

Oncologists, like other experts, practice their profession for various reasons, both complementary and contradictory, with greater or lesser skill, within often difficult circumstances. I remain agnostic on questions of hope, survival, and treatment. I point no fingers at researchers, at people choosing among a sparse set of treatments, or at those raising money for more research, camps, awareness, or rides to the hospital. Many patients, caretakers, and doctors tell their stories sincerely and sympathetically, with a great deal of anger, frustration, resignation, and grief, and these emotions remain central to any possibility of understanding the cultural status of cancer. (235, fn 44)

There is much this work does not treat. By her own admission, Jain gives short-shrift here to issues of disparities (37-40), and to race and class (Jain 2003), all of which very much matter in the politics of cancer (Lee 2009b). But issues of gender and sexuality certainly figure here. That is fair enough, as the effects of this book—the work that it does—come through the very real filter of her own lived experience. As much as *Malignant* wields social theory as political commentary, it is also part memoir in which a multifaceted academic (as we all hope we can be) comes to terms with a cancer experience in the way that academics do: sublimate to productivity, create and critique, and, particularly for most anthropologists, come out the other side with a book (251:10). If the anthropology falls short, it is playing fast and loose with accounts of clinical trial methodology, where more time spent face-to-face with a trialist would have helped to better understand how rarely placebos are used in studies of active cancer treatment, rather than tossing it out there as the proverbial sugar-pill (112); explain what intent-to-treat analysis actually seeks to accomplish (117); and to not equate Phase I and II trials for mechanistic efficacy, safety, and tolerability with Phase III comparisons against standard of care or best in class medications.<sup>7</sup> This is not to deny that corporate financial viability creates so-called orphan drugs or that the reporting shenanigans of industry-sponsored studies do not retrofit data or gag scientists from reporting null results. Indeed, I would be happy to see the FDA take a much more aggressive stance regarding

when it is appropriate to conduct a non-inferiority trial and when Pharma is simply playing with market-share. But, in truth, the thrust of the arguments in *Malignant* are not really about the legitimacy of scientific methods, but the sharp contrast between the methods of the “headcounting tribe” (36) with their sterile objectivity and the messiness of lived experience. In the (non-)face of numbers and indeterminacy of clinical supposed-facts, Jain wants to know “what to say to be seen...” (218).

Delivered, I imagine, with her wry smile, Jain concludes her book: “Shameless.” And having slain her dragon, Jain shares that she and her girlfriend have an agreement that if one of them dies indecorously, the other will make up a story (221). For that is a good enough way to end. Between brunch conversations over the Sunday papers, that trigger arguments about the plague, good sex, HPV, and ass cancer, even Michael Douglas’ public “confession” of head-and-neck disease makes an appearance, my friends and I have similarly agreed to write each other’s obits on promise that someone could be counted on to write:

He did not courageously struggle in the fight with...He loathed it, he bitched, screamed, wept, and succumbed. He was, as sometime nurses and doctors say, a difficult patient. It was awful and he hated it, now he is gone.

As Jain notes: “No Good Patient designation for me this time” (208). Amen, sister. ■

#### Endnotes:

<sup>1</sup>I spent some time thinking about how the text might be different were the title *Metastatic*, but for this author that, fortunately, would have been a different story entirely.

<sup>2</sup>*Das Unheimliche*, the Uncanny. Though I prefer Hitchcock over more orthodox Freudians.

<sup>3</sup>Disclosure: CPRIT (PP120097) funds the rural cancer screening program and evaluation I lead.

<sup>4</sup>Except maybe University of Texas’s M.D. Anderson Cancer Center in Houston. Parenthetically, the Black Tie Dinner is also the largest fundraiser in the country for HRC, the LGBT political advocacy machine. And BTD is also a Dallas event. Like I said, everything is bigger here.

<sup>5</sup>Case 9-699-025, rev. July 1, 1999.

<sup>6</sup>For the record, I do not have any data to suggest that fracking causes breast cancer, but I do not study environmental carcinogenesis in the Texas Barnett Shale, or anywhere else. I study disparities in cancer care and prevention for the under- and uninsured. This has also enabled me to sidestep, like Emmerson et al. in Chapter 7, some very difficult questions when applied anthropology enables screening guidelines (158, 161). See Revkin 2012.

<sup>7</sup>That is to say, seroconverting to HIV positive status.

<sup>8</sup>See Kirkus Reviews, September 15, 2013. Accessed from <https://www.kirkusreviews.com/book-reviews/s-lochlann-jain/malignant/> on Sept 29, 2013.

<sup>7</sup>Jain is a gifted rhetorician, but I was dismayed that “Withholding a certain treatment in order to reach a certain goal, even when the treatment in question clearly extended lives” (120) goes without footnote or explanation. My disappointment here is not with the thrust of her arguments in this chapter, only that a clinical trialist would find them too easy to dismiss on the grounds that she misrepresents design and methodology.

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