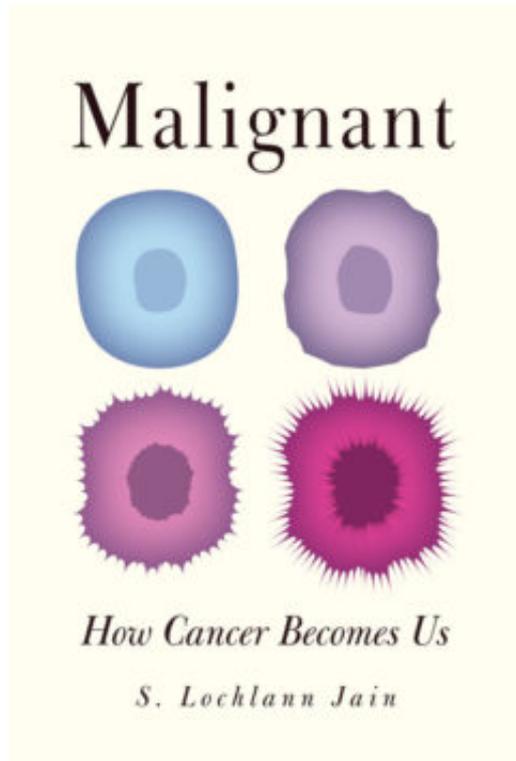


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‘Malignant: How Cancer Becomes Us’ / a conversation with Lochlann Jain

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By Tara Mahfoud



In the Stanford Hospital car park, there is a sign that reads “WARNING: This garage contains gasoline and diesel engine exhaust which is known to the State of California to cause cancer and/or reproductive toxicity.” The paradox is deadly – one runs the risk of developing cancer on their way to cancer treatment. The sign blatantly highlights the starting point of Lochlann Jain’s analysis of cancer in her 2014 award-winning book [Malignant: How Cancer Becomes Us](#), which is to understand “the ways that key aspects of the economy involve both causing and treating cancer” (p. 12). Jain showed the image of that sign, taken from her book, during her talk at the [Department of Global Health and Social Medicine’s](#) 2015 Public Lecture at King’s College London. *Malignant* is an ethnographic investigation into how cancer, despite the millions spent to cure and prevent it, remains deeply entrenched in so many aspects of American life and culture. Jain uses her own cancer experience to reflect on prognosis and treatment, time and lifespans, screening and preventative treatment, misdiagnosis and malpractice, IVF and hormones, the war-loaded history of cancer and its

treatments, and cancer objects like prostheses, wigs, and make-up. *Malignant* forces the reader to acknowledge the paradoxical, ugly, and inevitable reality of cancer today.

I am a teaching assistant on the *Introduction to Social Medicine* course at the Department of Global Health and Social Medicine at King's College London, which is taught by [Carlo Caduff](#). The course is offered as part of an interdisciplinary BA/BSc programme in [Global Health and Social Medicine](#) that combines social science and biomedical science courses. Many of the students have a background in the natural sciences, and some are study abroad students taking the course as part of their pre-medical degree. We read *Malignant* to introduce students to why and how the 'subjective' is a powerful and necessary voice in medicine, to show that illness and disease need to be understood as more than medical matters, and how studying illnesses can serve as a lens and a way to study the state and its apparatuses.

I talked with Jain about what it was like to teach *Malignant* as part of an undergraduate course, and about the implications of her arguments about the inevitability of cancer within our current political and economic landscape.

The 'Underbelly of American Culture'

TM: In the seminar discussion session following the class lecture, one of the students, said: 'I think it's unfair to single out America'. On the one hand, what is significant about this study is that it is about America – a country with a mostly privatized (and expensive) healthcare system, and a highly profitable healthcare industry that includes medical research, medical training, pharmaceutical development, and health insurance, amongst others. We discussed in class how a study of cancer in the UK would perhaps have been very different, which was a great entry point to understanding how local context affects how illnesses are dealt with and treated. The aim of your book, and you describe it this way on your webpage, is to ["better understand life through cancer"](#). So it's not just about cancer, it's about what studying cancer can tell you about life in the contemporary US.

LJ: Yes – and I think that is very much a strength of anthropology and other areas of social theory that begin from a nearly microscopic reading and work out from there. In the case of *Malignant*, the kinds of microscopic data I took extremely seriously in my "reading out," as it were, ranged from the strange feeling of reading cancer trial results and trying to fit oneself into them, to looking at an overlooked, or taken for granted term,

such as “loss of change,” in a legal trial. I reversed the usual way of looking at things. Rather than thinking (in the first example) about how the trial arranges and accounts for the individuals in it, I started from an individual response to a stack of trial reports to figure out what that had to say about the structure of randomized control trials and the culture that rendered these structures so utterly transparent. In a way it is an intuitive method, but in many cases it led to unexpected findings.

In terms of the goals and research questions of *Malignant*, yes, I could have looked at any other country because in one sense my question was: how can you see the nation’s values through the way it understands illness and health? But because I did focus on the US, and a little bit on Canada, I was able to look at some very specific struggles we have there, such as the fact that illness is, as much as anything, a means of structuring capital accumulation and dispersal. This is especially true for cancer in considering the role of industry in causing it, and then the massive profits made in treating it – and of course, losses in being treated. My goal in the book was not to pick on America by noting this fact, but rather to suggest that by analyzing many of the structures that try to address, redress, and obscure cancer, we would be able to develop richer languages with which to understand it as a cultural phenomenon that is central to so many aspects of American life.

I’m American too. I want a better system. I think we deserve better treatments and a more accurate vocabulary to understand the contradictions inherent to cancer.

TM: In the lecture you gave at KCL, in the discussion afterwards, you said that cancer is ‘the underbelly of American culture’. Maybe you could talk a little about what you mean by that?

LJ: When I say it’s the underbelly of American culture, in part I mean to indicate that Americans have been able to do so much. We’ve been able to cure, you know, malaria and polio, and an incredible range of diseases. We have been able to feed everybody, at least create enough food to feed everyone, if not feed everyone. We have the best weapons you could imagine. We have this scientific and industrial success after success, right?

And then there’s this thing we just can’t get rid of. Not only we can’t get rid of it, but we can’t really understand it. We can’t grasp it well enough to even have the conversation. Yeah, we’re creating lots of food, but we’re doing it using these awful chemicals that we haven’t mostly tested but when we do, it looks like a lot of farm workers are dying from these diseases, a lot of people who live in agricultural or nuclear regions are dying of these diseases. Cancer rates are not going down anywhere near

what we would expect by early detection. And nobody wants to link that to the increasingly profitable, increasingly brutal, increasingly expensive projects of cancer treatment where doctors are making reputations, they're making tons of money, manufacturers are making tons of money. If you want to invest in anything in the US, you invest in healthcare because that's where the returns are going to be. But noting that is not to make the story of cancer a simple one, for it is anything but.

One of the strategies, then, in the book is to understand cancer as a fluid, tentacular term that is shored up in different ways by different people with scattered and often conflicting interests. Because we don't have a good way of understanding how this term travels *as if* it were mutually comprehensible in medical, legal, regulatory and other infrastructures, we tend to think of it as a *thing* that everybody understands. And as I wrote:

"Not only does it work through the metaphors of metastasis, recurrence, and remission, but it is also at one moment a paper trail and at another an identity, at one place a statistic and at another a bankruptcy; here a scientific quandary, there, a transcendent image of a cell. One person's losses offer another a chance to leave a mark on humanity. A body image taken offers another to be found. The project of making cancer – as plural as it is singular, as vast as it is microscopic, as diffuse and discrepant as it is descriptive – resonates under one word. The simple noun *cancer* consolidates this collective achievement." (14)

Throughout the book I deconstruct the consequences closing off, rather than opening, cancers meanings.

Defining and locating cancer

TM: Something I also found really helpful in your book is your method. Throughout the book you keep showing how cancer escapes any attempts to bound it, or to be bound as an object of study. Even if you wanted the book to be about cancer it couldn't be.

LJ: Right, that's exactly right. I don't want the book to be pigeon-holed as a book about cancer, because for me cancer is simply a window onto a cultural reading of the political-economy of the US.

TM: So if you can't locate cancer, if you can't turn it into an object, then what does a study of cancer become?

LJ: My hope is that there is a lot of material in my book that will resonate differently for different readers, and one of the most rewarding comments I

get is from folks who have read the book and found it useful to think with cancer in their own lives.

By rethinking cancer as a word that was not a noun, but as a phenomenon that was a practice and constantly in motion, I wanted to bring to the fore the fundamental mystery, uncertainty, and ignorance about it and argue that we need to recognize and reckon with that, rather than pretending we know what we don't. Too often our numbers – trial results, prognosis, statistics – pose as accurate knowledge. To think of it as such is to miss the boat on nearly everything, and each of my chapters is dedicated to illustrating how that is so. In a weird way those numbers lead us to think there is clarity at exactly the moments there is least clarity: selecting a treatment plan, deciding whether to join a trial, voting on whether to allow a carcinogen to be used in food packaging.

For me this project has been a multi-decade project in the sense that I was trained by Donna Haraway at the History of Consciousness Department at the University of California, Santa Cruz. Professor Haraway was attentive to teaching us how to think and write about objects that circulate in complex and octopal ways in different contexts. She taught us a facility with theory and how to read different kinds of documents for how they were defining their terms, as it were. An EPA document is going to think about cancer differently than a medical complaint, right? So then, you can take cancer – the one thing we assumed we agreed on — in each of those documents and think about what does he mean by cancer and what does she mean by cancer. When one opens that term, that black box, of cancer, things really start to both fall apart, but also come together.

One of the chapters where I had to do this really carefully is that chapter on egg donor-ship and IVF where not only didn't we know what cancers might be caused, but there was no data on- or the kinds of data that we had were so different than any scientific study, right? And because we didn't have those kinds of specific data, it was very easy for IVF clinics to continue to say 'well there's no link, there's no proven link'. But that doesn't mean there's nothing there. So what I had to do was collect what we had and make it into an argument that made sense in the context of not only cancer being open-ended, but the ways we were studying it being not the full, nothing full there. So what do we do with that lack of fullness? Do we just give up? And I was arguing, well, no. We can do this other thing. We can look at how the answer is produced. We can look at why it is OK that these women aren't being tracked? And it's OK for these other cultural reasons that may seem completely unrelated, like the history of the American family, but they're not. They're absolutely central I think. So I don't know if that answers the question but those are a few of my strategies of how to do it.

Complicity and Blame

TM: In David Napier's review of your book, he says: ["if a direct cause cannot be identified, no one needs to be accountable"](#). This reminds me of what a student said in our class, "if everyone is complicit, then no one is to blame". With him, and with other students taking the course, complicity is perhaps the most difficult thing to come to terms with – in relation to this and other texts. There is a deep discomfort with the idea that there is no one actor to blame, one cause of something.

LJ: Complicity, of course, has levels to it. People are complicit in different ways, and this also relates to the sort of everywhere and nowhere-ness of cancer. Take for example a warning sign that lets you know that you could, in theory avoid certain cancer causing elements. In some cases, one may have some choice about how much exposure one will take on, such as, arguably, cigarettes. In other cases, the sign might appear in places that you might not have any choice about, say, asbestos in a school or home, or for folks who grew up along the nuclear testing fallout routes. Even cancer treatments risk causing other cancers.

That's exactly why cancer is the underbelly of contemporary American life: there's no easy cure, there's no easy solution, there's no easy identification of what causes it. It's a side-effect and consequence of our political-economic way of life. So in that sense, your student is absolutely right – there is no one to blame. But then there's the complicity of those of us who just want to put a certain thing on our hair that happens to have carcinogens that we may or may not be aware of, and then how might we compare that to the chemical company who knowingly uses those carcinogenic ingredients and lobbies to keep them as proprietary knowledge, and the regulatory agents who agree to do that? Personally, I think that chemical company should be forced both to disclose and to use alternative ingredients.

But what I take the student to be saying is that, if we're all complicit in some way, and there is no one to blame, then what do we do, how do we force or provoke any kind of change? And that is right – that is precisely the issue, there are no simple answers, no one to sue, which is why I am aiming to come up with an analysis that isn't just in terms of complicity and blame and choice. But I'm still interested in this kind of promise; I understand "cure" to offer a similar sort of ethereal promise. The promises of cure have been given for over a century, while the few cures that have actually materialized have served to structure cancer and cancer research in a regime of futurity that also shaped many other dimensions of how we understand it.

So in some sense, what the student is saying is exactly the kind of frustration that I'm trying to explain in this book. How did we end up at this point when we have celebratory cancer marches rather than the sorts of angry actions that pervaded AIDS activism?

TM: What does this say about the US and this 'culture' of blame? And how is this related to your previous book on injury?

LJ: It is really interesting that Americans have this reputation of suing each other both at home and abroad. I actually don't think it's true that Americans over-litigate (I'm talking here about physical injuries, not about other areas, which I haven't studied in detail), and I wrote about this in my first book, *Injury*. My first book traced the origins of this idea about a culture of blame, which as far as I can tell, came from a litigation system that grew up around people suing big companies when they'd been injured. I don't know how much you want to get into this but I'll just give you a very brief outline of my conclusions. First of all, because there's virtually no product regulation in this country, even for medical products, stuff gets on the market here that is so incredibly dangerous, and people do injure themselves. Then you have a system where there's virtually no medical care for many people. Anybody injured would have a very hard time – they wouldn't be able to work for 6 months, they may lose their job, they may not have anything to fall back on, and if they didn't have health insurance, they would really be in trouble. Even with health insurance, the expenses such as co-pays can be astronomical.

This leaves litigation as a sort of last ditch way they could help themselves and their families. Third, actually suing these companies is extremely difficult. Only 2% of people who are seriously injured in a way that could legitimately lead to a lawsuit ever sue – 2%. And of that 2%, fewer than 50% actually win because judges in this country are elected; and even then, in many states there are caps on the awards you get, making it very difficult to even find a lawyer who will take on a case. So the actual reality does not bare out the myth that there is a culture of blame in this country; this myth is the result of tort reform movements and the insurance industry.

Nikolas Rose introduced me at King's, he said something about a case that he discussed with me about a woman who burned herself with hot coffee. That case was taken up everywhere – by comedians, in advertising. She became the absolute joke of this country. It was tragic because you can really easily make a very tight little argument like, 'she had a cup of coffee, she tipped it over while she was driving, she burned herself and now she's suing and that's ridiculous'. That took me 30 seconds to say that. The other side takes a good 2 and a half minutes to say, which is that she was an old woman, she wasn't driving, she had

pulled over to have a sip of coffee. McDonalds coffee had had hundreds of complaints about burns before because they keep their coffee at 2 or 3 times the heat of normal coffee so it's scalding hot. She spilled a little bit on her groin and went to the hospital. She ended up with 3rd and 4th degree burns. She couldn't walk for weeks. So yes, she sued McDonalds, but it wasn't anything like the way that it was displayed in the news.

So when Americans and others talk about a US culture of blame, what they mean is a culture that has had its terms taken over by insurers and people who make a lot of money ensuring that there's no product regulation in this country so people who are injured are absolutely powerless. One way to make them even more powerless is to blame them for their injuries and blame them for anything they can try and do about it.

The first book and the second book are similar in terms of the basic question of how one gages a psyche, a national psyche, through sites of injury and disease.

Contingency and Inevitability

TM: At the KCL lecture someone asked you if you have an ideal world in your mind for cancer treatment, and how far away we are from it. You said 'ideally cancer doesn't exist' but you didn't think that world was possible. I want to talk about the implication of your argument – that cancer is inevitable within the kind of context that you describe. I read this insistence on the inevitability of cancer as a critique of anthropology's insistence on contingency – that things could be other than they are. Because it's that exact same realization (the counter-factual as you put it), that 'things could have been different if' that makes the experience of cancer so painful.

LJ: Yes, that's a really great point. This counterfactual paradox, set up by prognosis, for example, as well as several other painful but logical aspects surrounding our understandings of cancer does raise this more global question of both contingency and inevitability that has haunted a lot of the intellectual questions I'm drawn to.

I don't have a ready answer to whether I intentionally wrote the conclusion as a critique of anthropology, or even whether I have much of a stake in defining the discipline as such. Some of my colleagues at Stanford and elsewhere seem to be obsessed with defining it and then excluding people from it on the basis of their research questions and geographic areas. But as somebody trained in History of Consciousness and interdisciplinary humanities and social sciences, my interest is less in

anthropology as a discipline and more in how to use these incredible methods we have of incisive reading and analytic approaches to try to figure out how to understand the agonizing predicaments within which people live. I believe we have a certain responsibility to do that, and to do it as accessibly as possible.

TM: When we describe something as being everywhere, distributed, which is I think what anthropology tends to do a lot of the time, then there's also a tendency to say things could be different and there is hope in that.

LJ: Oh, you mean and I'm saying that they couldn't?

TM: Yeah.

LJ: Yes, yes, you are right, and in fact I struggled a lot with this in the writing. I suppose that ultimately I believe that in actuality, they couldn't be different. Where we *can* (and I mean we as academics) ameliorate the situation, in some way, maybe, is by having a richer vocabulary to understand and describe those paradoxes that otherwise can eat away at you. Some of the paradoxes I discuss in the book are ones that confronted the people struggling to understand their experiences in the many cancer retreats I attended. It was absolutely heart-breaking and even disgusting to see how people were left to make sense of this confusion when they are at their most vulnerable.

Americans expect ill and old people to bear the brunt of a lot of things that simply don't make sense. The most obvious example of this is the drive for cancer patients to become "survivors": to choose the best treatments (as if there were many options) or the best hospital (as if insurance didn't limit where you can go, or as if it makes much of a difference), to paste a pink ribbon on your forehead and have a cheery attitude. It's ridiculous and witnessing the depth of the torture and anguish suffered by people trying to make sense of it (over and above the usual nonsense of working out which treatments to get and battling health insurance) was what started and kept me writing. The injustice is nearly unbearable and it's virtually invisible.

That's exactly why this book is not your classic activist book. I see an activist book as saying 'here's the thing, this is messed up, we need to do it differently and here's how we could: we could regulate chemicals, we pour money into treatment, we could do this and that'. And I'm thinking, well no, we can't. If you look at the logic of the regulation or the legal system, if you look at the reasons for the dearth of research in certain areas, and so on, you start to see that the question is hugely intractable. We can't just turn that all around. If we could, it would have happened decades ago, it would have happened with the 'war on cancer'. It's not

like we don't know that 80,000 chemicals are poured into our environment need to be tested, of course we know that, but we don't do it. Why not? And not only why not, but what does that leave us with – politically, emotionally, medically. It's this last aspect that I was most interested in seeing more clearly. So you're right, it is very much a critique of that style of liberal, what I consider a liberal, anthropology.

A Conclusion

The hope that things could be other than they are is part of what makes a cancer experience painful. In Chapter 1, *Living in prognosis*, Lochlann Jain shows how patients she met throughout her treatment considered the other futures they could have had 'if' they had been diagnosed earlier (and all the other 'ifs'). "The past tends to be a preoccupation of patients and of lawyers who wonder how and when things could have gone differently" (p. 88). *Malignant* instead shows how cancer is made inevitable in the US and calls for "an elegiac politics – a stance that admits to the inevitability of these debates given the environmental and economic landscape." By acknowledging the inevitability of cancer and pointing out the problematic emotional engagement that comes with thinking about the counterfactual and pasts that could have been, *Malignant* also serves as a critique of activist arguments that insist on alternative, hopeful futures. *Malignant* is a different kind of activist book in the sense that it forces an acknowledgement of harsh realities and the political and economic landscapes that allow something like cancer to become inevitable.

Many of our students say that they have learned a different way of thinking on the *Introduction to Social Medicine* course – and it is because of readings like Jain's *Malignant*. This different way of thinking is recognition that eliminating cancer will take much more than another drug in development, a better definition of what cancer is, or another fundraiser. Students begin to understand that it will take overhauling entire economic and political systems, revising many of the assumptions underlying biomedicine, changing so many aspects of the ways we choose (or don't choose) to live our lives, and much more. Reading *Malignant* demonstrates how and why illnesses continue to exist – not despite, but precisely because of the massive investments made to eliminate them.

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