"We Don't Have to Look Very Far to See Who's Being Maimed and Injured"

Interview with Susan Levine About How the Medical Humanities Are Framing Large Questions of Deep Politics

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Susan Levine's work is positioned at the intersection of medical, political, and visual anthropology. She is the convenor of the Health Humanities and the Arts interdisciplinary master's program at the University of Cape Town. Her interests span a variety of subfields in anthropology, including political economy, youth and childhood studies, ethnographic film, and medical anthropology.

We met in Ljubljana, where she was participating in an Erasmus exchange for academic staff and the conference that was part of the *Days of Cooperation with African Universities.* Like many of our colleagues from African universities, Susan Levine contributed decolonial perspectives and methodologies to our discussions, particularly in the field of medical anthropology. That's why we invited her to share more about her work with us in this interview, where we talked about how she became involved in the medical humanities, the connection between medical and visual anthropology, and why debilitation (Mohamed 2023, Puar 2017) as a concept is so important these days.

I wanted to begin this interview with your amazing story of how you became a medical anthropologist. How did that journey unfold for you?

Susan Levine (Author: Coco Van Oppens)

I think there were multiple routes to becoming a medical anthropologist. And the most striking is really my early experience. My father was a pathologist at Stanford University and was on a team of researchers who identified a cancer called Burkitt's lymphoma that has a viral component. In his early 20s, my dad contracted this virus during his research, but he didn't know that until he

was in his late 30s. He had become a leading pathologist on tumours of the thymus and a much loved teacher. He died when he was 42. But before he died, because he'd been a mountain climber and a marathon runner, he had a very, very strong heart. And the cancer affected everything except his heart. When he died, it was catastrophic for me and our family. But I think as heartbreaking as his dying was, it was his suffering and the inability to find an easy way to bring a peaceful end to his life in a more caring death. All those big existential questions (Why me? Why now?) that medical anthropologists ask – about bioethics and disease, that are bound up with thinking about bodies and embodiment, healthcare systems, and the legality of it – converged later in my life when I came upon medical anthropology, and it really made sense that some of those questions had been planted in me quite early.

A second route towards medical anthropology was the start of my career at the University of Cape Town, which coincided with catastrophic HIV/AIDS affliction and the rise of AIDS denialism in South Africa. The deadly combination of the State President Thabo Mbeki's refusal to accept HIV/AIDS science and the Minister of Health's rejection of antiretroviral treatment required urgent political and intellectual response. These historical figures desired African solutions to what they considered an African problem and very forcefully rejected Western science. Millions of people were infected and died, with international and national alarm that our state was advocating a combination of lemon juice, garlic, and the African potato to cure AIDS. Having grown up in California and witnessed the AIDS activism of the 1980s, where people were pushing back against intense homophobia and framing AIDS as GRID (gay-related immune deficiency), it was very peculiar to come to South Africa. It was almost like an echo chamber.

At that time it didn't really matter if one was a physicist or a poet. We fought for antiretrovirals and were trying to get the government to acknowledge the relationship between HIV and AIDS. In those early years, I also got involved in a documentary film project, doing the advocacy work and (peer) education, just because the government was not doing that work. It had to come out of the grassroots protest movements and NGO initiatives. This was my initiation into the field of medical anthropology, which I hadn't really known before.

And then a third thread of how I started to be involved with medical anthropology was by chance. While taking several gap years from study, I came back to Cape Town on a holiday to visit my mum, and I ended up on a camping trip in the Cederberg mountains with an anthropologist named Nancy Scheper-Hughes, who I didn't know at that time. She told me about her work in Brazil, and it sounded really fascinating. At the time she was doing research around community justice, and she asked if I wanted to be her assistant. It was only a few years later that I returned to graduate school and went to the American Anthropological Association meetings and realised what a rock star and super famous person Nancy was. But she had been so humble and so kind in a way, not trying to really let me know, like who she was fully. After that I became a big Nancy Scheper-Hughes fan, and I started teaching her work. It was through meeting her and the works of medical anthropologists such as Paul Farmer, Arthur Kleinman,

Lawrence Cohen, and Veena Das that the field of medical anthropology began to take shape for me. And then I was able to go back and reread some of Marx's own work on health, factories, and children's health.

All this developed a thread in my own research, which was invested in thinking about health at the cusp of capital, power, domination, race, gender, and class. And so somehow medical anthropology was entwined from the start with my work in political economy. Medical anthropology is a way of framing very large questions of deep politics, of war, famine, genocide, and entitlement, about who has the right to maim other people's bodies, or who has the power to wield a genocide, whether it's in Sudan, Gaza, Yugoslavia or Rwanda.

> In your previous answer, you mentioned that one of the threads through which you became involved in medical anthropology is also visual anthropology. How have medical anthropology and visual anthropology intersected through ethnography in your work?

While I remain an anthropologist, I'm pretty convinced that working across disciplines is the way to go. I like the idea of working in and out of disciplines, but never losing my anthropological training or insight, and at the same time stepping out of the discipline to regard the epistemological frameworks of other disciplines. I am very interested in medicine, but also in art production, storytelling, and filmmaking.

For my senior thesis at Bard College, I documented a play called *You Strike a Woman, You Strike a Rock,* which was an incredible piece of theatre directed by Phyllis Klotz. This play was an improvisational story, a play about three women who had moved from the Eastern Cape in South Africa to Cape Town to try to find their husbands, sons, and brothers. It was banned in South Africa, but they performed it in churches or wherever they could, and I attended it many times. At the same time, I was telling a similar story through the life histories of two women, who were the first people to set up an informal community called Crossroads in 1976.

Between 1976 and 1986, Crossroads became a vibrant township. Women activists and community leaders demanded legal status, water rights, and electricity, and the apartheid state became very concerned about their activism. In June of 1986, the state armed a group of people in the township with guns, and they effectively orchestrated what they called "black on black violence". The state was basically leveraging and creating conflict within the community. People at Crossroads were pretty much bulldozed to the ground and were resettled. After apartheid came to an "end", the story of Crossroads was a scar in South Africa's history. People were speaking about the damages, loss of family, homes, and lives. My research happened literally while this was happening.

Another thing, as said before, in 1999, I got a job at the University of Cape Town and was soon also asked by a filmmaking company called Day Zero Productions to come along with them and analyse the impact of a series of documentary films that they had produced called *Steps for the Future* about HIV/AIDS. Over a period of five years, we travelled with a mobile cinema

unit and 35 films through Lesotho, Mozambique, and South Africa. We showed films to local communities in places where there wasn't formal media reach. There was a wave in which medical anthropology around HIV/AIDS joined sides with visual anthropology in terms of advocacy, public health interventions, and peer education. In that sense I developed a course in ethnographic film and visual anthropology at the University of Cape Town. Now we've shifted the course from visual anthropology to multimodal ethnography, which is one of the core elective courses in our interdisciplinary master's program called Health Humanities and the Arts.

> Can you tell us a little bit more about how you are integrating different visual art based approaches into the medical humanities and look at them as both research methods and forms of presenting data in this student program? One of the examples is probably also body mapping?

The body mapping started in an HIV context with Jonathan Morgan's book *Long Life,* in which he worked with women who were HIV positive and used body maps as a way for them to reflect on their stories, to reflect on their bodies, to produce a kind of an archive for their own children. We use body mapping in our classes to open students' awareness of their own experiences of health. We invite professional body mappers because it can open some deep traumas. We work with Jade Gibson, who's an artist and specialises in leading workshops on body mapping. Once the students know how a body mapping workshop feels, they can use it in their own research to generate their own body maps, though we always say to do it very carefully.

There are so many different things that are pulling the medical and the visual together. For example, the hospital design should be occupied by medical anthropologists who've thought carefully about the relationship between space and wellness. That alien sense, especially in these big biomedical hospitals, is pretty awful. In this context, we had one experience that was frustrating. We were invited by the Department of Health to help them think through nine waiting rooms in the Western Cape. It was a huge opportunity for the students, and they put all their ideas forward. They had great suggestions based on ethnographic work, like building chairs with backs instead of benches, incorporating power stations so people could charge their phones while waiting, and many other structural things that would have made the waiting time more bearable. But at the end of the day, the Department of Health just put in some TVs, even if patients didn't feel the need for them.

But then there's other spaces where we have excellent relations, like the Red Cross Children's Hospital in Cape Town. This unique medical setting includes artwork for the children to enjoy, music, an in-house radio station where kids who are staying long term can make their own radio programs, and they also do regular performances around honouring the dead through music before autopsy. In South Africa, it is interesting to think about the ways in which music has always been a part of the healing, whether it's Khoisan, Hausa, or Zulu. The nurses sing to their patients, they sing in the hallway, it's a way to pass the time, and it is

part of their healing. The medical humanities in Africa have always been here.

My last question is about the concepts you work with. When you talk about the medical humanities, are there particular concepts, like debilitation, that you would like to say something about?

Debilitation (Mohamed 2023; Puar 2017) is emerging as one of the most important concepts of our time. And the reason why I think it's so important is that if you think about the genocide in Gaza and Sudan, people think about genocide in terms of death. If you think about disasters in the gold mines or the diamond mines in South Africa, the emphasis is on death. If you think about Covid, one worries about death. Within the world now, death is kind of everywhere. But in fact, for the dead, there's no experience there, right? You're dead. If one shifts from death to debilitation, you get a very different set of questions. Then you can focus on amputations, on people who live on debilitated landscapes, on dead animals, on the earth that has been scorched by bombs, on starvation and grief worlds. Debilitation is permanent maiming, permanent injury, permanent grief, permanent loss of loved ones. Similarly with gold mining, the antithesis of death is debilitation. And you live with the consequences of toxic exposures, of miner's injuries, things falling on your head, concussions, missing limbs, broken bones, and other forms of debilitation, like eating food that's been sprayed with toxic pesticides. We don't die from it, but we will eventually die of cancer from it. But while we are living, we live in forms of debilitation and injury.

And so that's why I think Jasbir Puar's book *The Right to Maim* and Kharnita Mohamed's work on disability and debilitation are so important, because it shifts our focus from death to debility. What debility does as a concept is it sits together with older models of exploitation, alienation, and Marxist social theory, but it extends it profoundly by asking us to really reckon with brokenness and power. It asks how race, class, gender, and power create debilitated bodies and lives along those axes. We're still looking at the same trajectories of privilege and underprivileged. Kharnita makes the point that a very tiny percentage of people on the planet are born with disabilities and that most disabilities are produced in very violent societies through war, rape, injury, and harm. Her basic argument is that we need to rethink what it is to be disabled from a political and historical perspective, that it's not a natural category, and that it replicates most of the political economies of the inequality in the world. And we only have to look to Uganda, Gaza, the Democratic Republic of Congo, Sudan, Ukraine, Russia. We don't have to look very far to see who's being maimed and injured.

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