

# Understanding Care, Pain and Responsibilization - Making Sense of Policy and Practice.

## An Interview with Susanna Trnka

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Edit Szénássy

Susanna Trnka is a social and medical anthropologist of Czech-American heritage, working at The University of Auckland. Her research interests include the politics of health, the impact of violence on people's everyday lives, and perceptions of national identity. She has a long-standing interest in post-socialist societies in Eastern and Central Europe, and the Fiji Islands.

*Your previous work, based on long-term fieldwork in Fiji, is centered on the embodied experiences of political violence. You also researched how women's pain is shaped by, negotiated and accounted for in clinical settings in which social and gendered inequalities translate into health professionals' puzzlement and unequal acknowledgment of some of their patients' experiences of pain. Specifically, you explore the range of meanings that expressions of physical pain convey for Fijian women of Indian ethnic origin who live with chronic pain, and the health professionals who try to make sense of it.*

Actually, the Fiji project started out in quite a different direction. It began as a project intending to explore issues of history, memory, and the body, but soon after the research began, I realized both how much my informants talked about physical pain in the *present*, and how *gendered* this discourse was.

The people I worked with were descendants of the Indians whom the British brought over to work on Fiji's sugar cane plantations in the late 1800s, up until 1920. Part of what I came to understand is how their experiences of physical pain in the present are related to that history, and how the pain that they expressed on a day-to-day level was actually part of a larger political and historical identity, as physical pain was often used to index physical labor – the very labor that Indians were both brought to Fiji to undertake and on the basis of which they currently make claims about their ongoing right to remain there.

Much of Indo-Fijian public discourse on suffering is moreover very masculine. More often than not, story-telling and popular culture tend to highlight the figure of an Indo-Fijian *man* who is working hard and therefore economically productive, thus promoting the interests of not only himself but the entire nation of Fiji. At the same time, in clinical settings I found that a lot of the talk about suffering and physical pain was in fact voiced by Indo-Fijian women whose daily work, be it in a garment factory or household-based agricultural labor, was often not granted explicit recognition. I looked at what women say to each other, to their families and to medical personnel when they talk about pain and came to realize that often they were drawing attention to themselves and their work in one of the few fora in which they could do this.

Another aspect that contributed to this research was that we were living in a predominantly Indo-Fijian village and I found that expressions of pain were almost part of women's daily greetings; when someone asked "How are you?", not infrequently, the reply they received was "I'm in pain" or "My back is in pain". When people first said this to me, I would take it very seriously and would ask "Oh, has something happened?" or "How can I help you?". My reaction took the women by surprise. It was only by seeing how these women talk to each other, that I later realized that expressing that one is experiencing pain is connected to a moral economy of physical labor in that expressions of pain indexed the amount of physical work they had carried out. Upon further inquiry it became quite clear why these women were in pain. They would say "I'm in pain because I've been washing the laundry", i.e. working hard. I realized that this was a sort of proclamation, a way of claiming "I'm a good, industrious woman, a really active member of this community" (see also Trnka 2008). In this case, expressions of pain thus act both as 'idioms of distress', in the sense of Arthur Kleinman's (1992) analysis of pain expression, and what I like to think of as an 'idiom of pride'. One of the ways I explain this to my students is that when they meet another student during exam time and say "How are you?" and the other student answers "Ok, but I'm really stressed right now," the other student is not usually taken to be asking for *help*, rather they are seen as signaling that they are a 'good' student, i.e. a student who studies hard and takes their exams seriously.

*When you looked at pain in clinical settings, however, you analyzed how health professionals, irrespective of ethnic origin, find it difficult to acknowledge pain expressed by Indo-Fijian women, often classifying it as 'unreal'.*

Yes, this was because the medical professionals did not see the reason, the cause, for the pain as something they could readily treat. One of the arguments they made is that there is 'real' and 'unreal' pain. 'Real' pain was based on physical causes and would respond to treatment. 'Unreal' pain was pain that *seemed* to be real because the patients were visibly hurting, yet the causes, at least according to the

doctors, were work-related, social or psychological and thus not within the realm of what can be 'fixed' within the medical clinic. Indo-Fijian women would in these cases normally leave the examination room with a prescription of Panadol (paracetamol), which validated their experiences of pain. The prescription would allow them to communicate to the community that their pain was valid in the sense of having their experience legitimated by clinicians. Instead of saying "my back really hurts," women would say "I went to the doctor today and look what he gave me [i.e. the prescription] because of my back pain" (see Trnka 2007).

*How did researching embodied experiences of pain shape your own individual experience of pain or the way you look at expressions of pain around you?*

That's an interesting question. I think one of the most profound things I learnt in Fiji was the way people would *not* talk about pain. I come from a culture that encourages the expression of pain. There is a widespread understanding that if you want to deal with your pain, then you have to be open about it, you have to express it – if not publically then at least with the people with whom you are close, such as your family, friends, or members of your wider community. You should not hide things because if you conceal painful things, then they begin to fester. Such discourses draw upon on popular understandings of the Freudian concept of repression, suggesting that once pain is articulated, then it can be dealt with.

Indo-Fijians often actively engage in helping people silence very traumatic events. They do so out of the belief that by limiting conversation and *not* talking about something that is painful, one can actually help contain it. Keeping the trauma firmly within 'the past' and not bringing it into the present and not returning to it, not exploring it, helps the healing process. The pain becomes part of the past and is therefore considered to be over.

The way this influenced my life in particular is that my second child was born whilst we were in Fiji and she was very ill and had to be medically evacuated. My husband, my eldest daughter, who was three years old at the time, and I went to New Zealand with the baby. We stayed in Auckland for six weeks and then came back with her to Fiji. Once we were back in Fiji, I tried to talk about the experience with women I had seen daily for almost two years, who had supported me throughout my pregnancy and during the very difficult times of political violence and upheaval that we lived through together during the 2000 Fiji coup. What really struck me was that nobody wanted to talk about the baby's illness and when I started to speak about this experience, the women not only kept quiet, but cut me off and silenced me. I gradually understood that by being silent and making me be silent, they wanted to help me. They were trying to help me to *not* talk about it, and thus to contain the experience instead of narrating and re-living it. With their silence, they were suggesting that I do not need to bring this pain into the present, that I leave it behind and let it settle as part of my past.

*You explore sensory experience and how it collides with national identity in your recent work as a co-editor of the volume, *Senses and Citizenships: Embodying Political Life* (Routledge, 2013, co-edited with Christine Dureau and Julie Park). Can you tell us more about the book and the ideas behind it?*

The book was published in April of this year. We have twelve contributors all of whom focus on the political aspects of sensory experience, analyzing a variety of senses: not only the classical Aristotelian ‘five senses’, of smell, touch, taste, hearing, and sight, but also things like the sense of movement, disgust, and sensations of pain. Our focus is on how sensory experience gets taken as natural and thus thought to convey something objectively ‘real’ whilst it, like many aspects of bodily experience, is similarly politically, socially and culturally shaped. More importantly, from my perspective, the book goes a step further by revealing the political *significance* of sensory experience: i.e. how it is that we as a society come to say that something *is*, and indeed *must* be, a certain way because we experience it as such. To give an example, a group of people can come to be deemed as “disgusting” by others because, it is argued, their food “really does taste disgusting.” But does it? Or, as Bourdieu (1984 [1979]) has long pointed out, is taste a socially constituted category and in fact a learned response? At the end of the day, it is one thing to change people’s rational perspectives of others (or of themselves), and quite another to convince them that what they *feel* might actually also be socially and politically inflected. Our aim in this book is to show how the association between sensory experience and politically-charged categories of difference, inclusion and exclusion, come to be inter-linked, and therefore naturalized.

*Your ongoing research explores accountability, responsibility and the politics of health in relation to asthma treatment, understanding these concepts as healthcare strategies in an emerging neoliberal framework of choice, self-management and consumerism. How did you start researching these discourses through the lens of asthma treatment and why the focus on the Czech Republic and New Zealand?*

The Czech Republic and New Zealand are two excellent locations to choose if you want to compare both different modes of neoliberal health care, and more specifically asthma care. New Zealand is at the forefront of neoliberal reforms of healthcare, and is one of the leading nations in terms of instituting self-management techniques of asthma care. Most of our asthma care is set up by a general practitioner or by emergency services; usually only people with the severest asthma receive specialist care. But the key to this program is that much of the day to day management is to be carried out by the patient themselves, or in the case of young children, by their parents, to the extent that many patients, even with moderate or in some cases severe asthma, do not receive regular checkups for their asthma, but generally receive medical attention when they are experiencing a cri-

sis, or are on the verge of one. Patients are expected to keep track of the status of their asthma, and adjust their medication depending on either the symptoms they are experiencing or on their own measurements of their airflow which they carry out using portable peak flow measurers. Whilst this is often represented in terms of “empowering” patients to look after themselves, for many of the patients or parents of asthmatic children with whom we spoke, it can feel onerous, confusing and difficult, especially initially when one is struggling to learn how to cope with a potentially life-threatening condition. I have also found a number of people who turn ‘self-management’ into ‘self-blame’, assuming that there is something *morally* wrong with respect to their capacities to manage themselves if their asthma is not under control.

When I discuss this topic with top respiratory physicians in the Czech Republic, they explain that self-management is something that they are just trying to introduce, but also express a lot of reluctance over the possibility of shifting the burden of care onto patients. I think there is a much stronger sense in the Czech Republic of the necessary role of specialists and the need for ongoing medical oversight and management of pharmaceuticals. And yet, with the economic restructuring of the health services, the adoption of world-wide guidelines (GINA), and the global economic crisis, there is also pressure to devolve services onto patients. It is this tension between neoliberal logics of “responsibilized patients” and post-socialist ethics of the state’s duty of care to its citizenry that I find incredibly fascinating.

Beyond this theoretical interest, the reason for this topic and the two locations is entirely personal. I wanted to get back to doing research on medical anthropology, rather than political violence, in Fiji, but could not return there because of ongoing political issues. The situation in Fiji became increasingly unstable exactly at the time when I was granted research leave for half a year and I had to go somewhere to undertake a new round of fieldwork. I suggested to my dean that I could do a project on memory and political violence in the Czech Republic, instead of in Fiji. So in 2006 I came to Prague, on my own with two young children, to undertake fieldwork about memories of the Communist period. Within a few hours of landing in Prague, my eldest daughter had a significant asthma attack and was taken to hospital. During the first three weeks of our time, I was running from one respiratory physician to another with her. Because this was her very first attack and we did not really know much about asthma, I was learning about this condition through the help I received from Czech specialists. When we came back to New Zealand, which has one of the highest children’s asthma rates in the world, I went to see a doctor to continue her treatment and was absolutely stunned to see how distinct his approach was. The style of intervention he proposed was completely different from what we had gotten ‘used to’ in our admittedly brief time in the Czech Republic. He basically gave us a few different kinds of inhalers and that

was just about all the oversight and ‘care’ she received. When we tried to come in to see him for follow up visits, we were told that such things are only necessary if she is in distress. There followed a few years – and I do mean *years* – during which we would ring up the clinic and receive repeated prescriptions, without anyone even looking at her and assessing what was necessary and what was not.

This prompted me to think about the possibility of looking to asthma as a lens through which to see how ideas about accountability and responsibility are played out. It is a fascinating area in terms of patient-doctor relationships, relationships within the family and between family members as children grown up to ‘take responsibility’ for their own care (or not). Even ideas about relationships between citizens and the state, and citizens and corporations, get played out with respect to debates over what kinds of forms of healthcare are deemed appropriate as well as over the role of air pollution (in the Czech Republic) and damp, poor-quality housing (in New Zealand) in exacerbating this condition.

One way I’ve been trying to get a handle on this is by developing, with my colleague Catherine Trundle, the concept of ‘competing responsibilities’ as a means of trying to locate how responsibility and accountability get vested and played out across different domains. Nikolas Rose (2001; 2006) writes very compellingly about the idea of ‘responsibilization,’ in order to capture how, within neoliberal states, citizens have come to take over some of the activities and responsibilities previously vested in the state. Rose suggests that in increasingly neoliberal healthcare systems, citizens are compelled to carry much more of the burden in taking care of themselves, preventing disease, and proactively engaging in things like dieting or watching their cholesterol or sugar level. But it seems to me that there are counter-weights against these moves towards inculcating more responsabilized citizen-subjects – namely other forms of responsibility, such as the responsibility of corporations to the wider public (as represented in debates over CSR or Corporate Social Responsibility); responsibilities of states to citizens; responsibilities within and amongst members of a family, etc. So even in a highly neoliberalized state like New Zealand, you have instances when Asthma Societies advocate for shifting responsibility for administering medication from the family to a state entity like a school – when, for example, young children are simply not receiving the asthma medication that they are supposed to be given by their parents on a daily basis, and instead a school receptionist might be given the child’s asthma inhaler and asked to administer it to her or him at the beginning and end of each school day. Other non-individualizing modes of ‘care’ include healthy homes initiatives in which the state, various corporations, and charities are involved in creating better living spaces for families who live below or near the poverty line. In these respects there are some interesting parallels to groups like the citizens’ initiatives in Ostrava which hold the state and corporations to account over the environmental pollution that is seen as exacerbating or even causing asthma and other respirato-

ry conditions, though of course they are articulated in different ways and ultimately create different kinds of biosocial collectivities.

*When making sense of Czech asthma policies and practices, you are confronted with two major frames of reference: the legacies of socialist healthcare and the newly emerging effects of EU enlargement. When talking about being ‘in transition’ in terms of asthma care in the Czech Republic, where do you position this transition, what are the types of narratives that shape it?*

One thing that interests me about Czech approaches is the wide variety of different treatments for asthma. There are plenty of pharmaceutical options, but there is also a very strong and vibrant tradition of what in the West might be referred to as “alternative therapies” such as health spas, massage, physiotherapy, *míčkování* [a type of therapeutic massage that uses a foam ball], hydrotherapy, salt therapy, visits to Croatian or Greek beach resorts, etc. Many respiratory physicians are also quick to embrace and promote things like music therapy, alongside pharmaceutical interventions, on the understanding that you necessarily want to limit the amount of corticosteroids you administer and that some of these methods may help you to achieve these goals. Some of these ideas are now being brought over to the Southern Hemisphere, with the establishment of “salt rooms” for improving respiratory health in Australia. I recently did an interview with one of the founders of such an establishment in Sydney and perhaps should not have been surprised upon meeting her to discover that she is a Ukrainian living in Sydney. Not only had she ‘imported’ the idea of halotherapy or salt therapy from the Ukraine, but the very ‘salt bricks’ that lined the therapy room were brought over from Ukrainian salt mines. But such approaches are much less established in New Zealand and Australia than they are in Central and Eastern Europe.

More generally, there is a very different philosophy of what healthcare means and how it should be distributed across a society. During my most recent fieldwork visit to Prague in 2011, I conducted an interview with a representative of VZP (*Všeobecná zdravotní pojišťovna*) insurance company, the largest health insurance company. She started off the interview by explaining to me the principle of *solidárnost* or ‘solidarity’ to highlight how the Czech system, from her perspective, remains solidly rooted in Communist ideals of insuring a baseline of healthcare for all citizens, regardless of their capacity to pay for it. This led to a very impassioned defense of how a health insurance company such as VZP can justify paying for things like spa treatments or overseas trips to the seaside such as the *Mořský koník* program. Whilst these services are becoming more costly, from an outside perspective it is fascinating that they still exist, revealing just how firmly entrenched these legacies are, despite the health services being under ever-increasing financial pressure.

*What are your experiences of conducting medical anthropology research in Central and Eastern Europe as a researcher with Czech heritage, having a complicated migration background and working in a setting where medical anthropology is at best regarded with suspicion by healthcare professionals?*

I have an excellent time working in the Czech Republic. New Zealand has the highest asthma rate in the world, so most of the specialists or general practitioners I contact in the Czech Republic are curious to talk to someone from here, especially someone who has a Czech surname – especially a woman with a male surname, which strikes them as very strange! – and who speaks reasonable-enough Czech to be able to conduct interviews in their language. Coming from literally the other side of the world also enhances access, as people are more willing to make an appointment for an interview. When I am in New Zealand it is easier for people to say no, because they know I can come and see them next week or the week, or month, after. Whereas when in the Czech Republic, I say to them “I’m here for two weeks, can I see you?” and people tend to say: “Certainly, come by tomorrow”.

A lot of people here don’t know what anthropology is, so I tend to explain to my Czech informants that it is “a lot like sociology” which makes it familiar and recognizable to them. But of course one of the things that makes anthropology so exciting is its methodology, in particular the privileged role of fieldwork and participant observation as a mode of producing knowledge. My colleague Cris Shore and I have just finished editing a book (*Up Close and Personal: On Peripheral Perspectives and the Production of Anthropological Knowledge*, Berghahn Books, 2013) that engages in an examination of fieldwork and the methods that we use to produce anthropological knowledge. This project has encouraged me to reflect more deeply upon the profound significance of inter-personal relationships in our work. Whether we focus on health or some other topic, I don’t think we should lose sight of the unique role that anthropology plays in terms of taking other people’s experiences and points of view so seriously that we are willing to engage them in our analysis and re-shape the very concepts by which we understand the world we live in.

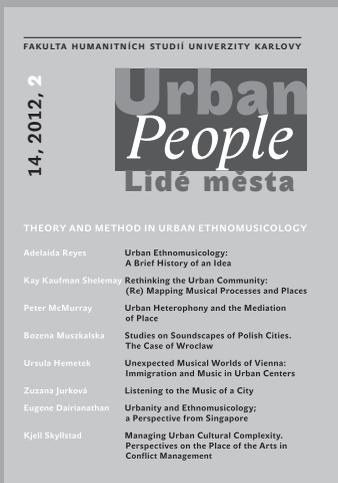
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