

Boom and bust

Thinking through health care
resource allocation in an oil economy

Marlee McGuire

Abstract

In this think piece I argue that there is an interactive relationship between physical and symbolic landscapes, and that the interplay of the two forms a ‘therapeutic landscape’. This reformulation of Gesler’s (1992) concept of the therapeutic landscape helps to make visible the relationship between utilitarian systems of natural resource extraction and notions of deservingness for care. I show how in Alberta, Canada, there was a shift in the therapeutic landscape following the late 2014 crash in the global price of oil. Alberta is an ‘oil economy’ with an economic system that is strongly dependent on its oil and gas extractive industry; its public health care system is supported in part by royalties paid by private oil companies. When the global price of oil dropped, both health policy researchers and parents of children with rare and severe genetic diseases worried that costly treatments might be valued differently in this new terrain and that patients might be deemed undeserving of such expense. The therapeutic landscape concept applied in this way becomes a tool for understanding the linkages between economies of care and the political economy of place.

Keywords

natural resource extraction, deservingness, care, rare genetic disease, pharmaceuticals

The crash

In late 2014, the global price of oil plummeted. By January 2015 the price per barrel of oil was US\$45, down from over US\$100 just a few months earlier (United States Energy Information Administration 2016). A line from the first pages of my field notes, written while conducting fieldwork in a health technology assessment (HTA) and health policy unit based in Edmonton, Alberta, reads: ‘Gas is cheap, it’s -35 degrees Celsius, and everyone is speaking in hushed tones about the “crash”’. Edmonton is a city of about 900,000 that serves as the infrastructure and service hub for Fort McMurray, the center of the notorious Canadian ‘tar sands’ oil patch. The oil industry has a strong cultural and geographical presence: Edmonton’s hockey team is named the Edmonton Oilers (until recently, a giant artificial oil rig was lowered onto the ice during home games), and ‘Alberta Oil’ shot glasses and sweatshirts are available for purchase in the Edmonton and Calgary airport gift shops. Oil and gas pipelines run underground all across the province, an invisible presence apart from the intermittent poles erected to remind people not to dig too deep into the surrounding terrain. Most people can name at least one family member or friend involved in the oil industry in some way. Shifts in the price of oil are dinner table conversation.

This think piece looks at some of the ways that people spoke about publicly funded access to extremely expensive ‘orphan drugs’¹ after the oil price crash. I show how a drastic drop in the price of oil, in a place where the extraction of oil is so deeply situated both culturally and economically, was accompanied by a shift in the ways people talked about care and being cared for. This is because the Albertan provincial health care system² is partly financed by

¹ Drugs for rare genetic diseases are frequently called ‘orphan drugs’ as they are considered to be ‘orphans’ of the profit-driven medical market. Incentivizing legislation such as the US Food and Drug Administration’s 1983 Orphan Drug Act facilitates their development and puts no limits on the prices that can be charged for treatments with an orphan drug designation.

² Provinces and territories have jurisdictional authority to run their own separate health care systems, as provided by the Canada Health Act. Each province or territory funds its health system through a combination of federal funding, income tax revenue, industrial revenue (such as oil company royalties), and in some cases mandatory monthly premiums. Wealthier provinces have more money to invest in their health care system and other public programs. Because of its oil revenues, Alberta has long been considered prosperous relative to other provinces, particularly the prairie and maritime provinces.

royalties collected from oil and gas resource extraction companies.³ I adopt the concept of therapeutic landscapes as formulated by Gesler (1992) not only to understand ‘why certain places or situations are perceived to be therapeutic’ (735) or to understand ‘health care-seeking behavior in particular environments and places’ (744) but also to elucidate how the physical and symbolic elements of the landscape exist in interactive relationship to one another. In referring to the physical landscape, I highlight the utilitarian use of place: in this case, a system of oil extraction. In referring to the symbolic landscape, in this context of health resource allocation, I highlight feelings of deservingness for care in relation to economic conditions. Expensive drugs for rare genetic diseases illuminate this interplay during a period of budgetary scarcity because rationales for their extreme costs – between Can\$150,000 and Can\$850,000 per patient per year – strongly depend upon patients with rare diseases being seen as ‘deserving sick’ (Willen 2012; Petryna 2011) and worthy of such expenditures. The crash and its aftermath threw into relief the fact that pharmaceuticals and the systems designed to allocate them are profoundly emplaced.

I arrived in Edmonton to begin my fieldwork at a health technology assessment (HTA) and health policy unit in early January 2015, shortly after what people called ‘the crash’. The cash flow of the province of Alberta, heavily dependent on royalties and income tax revenue from oil extraction, was said to be in a state of crisis. The unit where I conducted fieldwork does research and policy work on orphan drugs in Canada’s publicly funded health care system, and also conducts HTAs to advise the provincial government on which new technologies to fund. But when I arrived to begin fieldwork, a freeze had recently been put on all HTA activities and the budget was being reorganized. I began to hear the buzz as soon as I started my fieldwork: Would the HTA and health policy unit be completely cut in the next provincial budget? Would the government start looking to cut more technologies and treatments? What would happen if any new patients with a rare genetic disease were diagnosed and needed expensive therapy in this difficult time? And for the patients already receiving publicly reimbursed treatments: would the provincial government get even stricter about the benefits it would like to see demonstrated in order for a patient to continue access treatment?

When the price of oil changes drastically, the symbolic landscape shifts drastically alongside it: this is an organizing principle of a ‘boom-and-bust’ economy based upon cycles of growth

³ Unlike in some other ‘oil-rich’ countries like Norway, the royalties taken from the private oil extraction industry operating in Alberta are low. For example, Norway charges royalties of almost 80 percent of industry revenues, while the province of Alberta charges royalties of only about 10 percent, resulting in drastically different levels of savings to draw upon in periods of scarcity (Das 2016).

and decline. The reflections of two young Alberta women named Stephanie and Ella that are presented here help illustrate this interactive relationship between the physical and symbolic landscape of care in a settler colonial⁴ capitalist context based largely upon resource extraction. Stephanie and Ella are both mothers of children with a rare and severe genetic disease called mucopolysaccharidosis type II (MPS II), whose publicly reimbursed enzyme replacement therapy, idursulfase, costs approximately Can\$350,000/year for life. The mothers both emphasized the inherent value of their children's lives, no matter what the economic conditions may be, and also reflected on a shift they sensed in the therapeutic landscape that determines access to their children's expensive treatments following the oil price crash. This think piece asserts that the political economy of health cannot be disconnected from the structural and political-economic arrangements of place.

The physical landscape and budgets for care

While I spent weekdays at the HTA and health policy unit learning the logics, tensions, and formulas of HTA and health economics, I spent many evenings and weekends traveling to spend time with families affected by rare disease. It was in this context that I met Stephanie, a young white woman in her mid-thirties. She has four children, one girl who is profoundly deaf and three boys who have MPS II. The province of Alberta did not initially fund the expensive enzyme replacement therapy when her three boys were originally diagnosed, which only happened after years of misdiagnoses. With its high cost and relatively low evidence base for benefit, the treatment wasn't seen to be cost-effective enough. But Stephanie and her family appealed to the media and put public pressure on the provincial government to fund the treatment, and eventually it was approved. Pressuring governments through the media is a common pathway towards rare disease treatment in Canada, and an entire underground advocacy network springs into action when it looks like a therapy might be denied to a newly diagnosed child.

When I met Stephanie in early February 2015 after an MPS patient advocate put us in touch, she was preparing to move to Ontario, three provinces east of Alberta. The move wasn't for a few weeks, but she had already begun packing their things, and half-full boxes lined the walls of the kitchen. 'I think the economy is different there, less dependent on the price of oil', Stephanie reflected, as we compared the differences in services for kids with disabilities between Alberta and Ontario. Stephanie knows the vagaries of the global oil economy well.

⁴ The province of Alberta is located upon Indigenous territory shared by the Cree, Saulteaux, Métis, Blackfoot, Nakota Sioux, Mohawk, and Dene nations, and a treaty-mediated relationship is maintained between the government of the province and the Indigenous people to this day.

Her husband Jacob is an oil-rig worker, and spends long periods working in different parts of the world as well as equally long periods at home without work when employment is scarce. She felt they were getting out of Alberta just in time: with the price of oil what it was, how long would the province be willing to keep paying for her children's care? The strong emphasis on cutting government spending voiced both by the progressive–conservative government in place at the time and in the local media had left Stephanie feeling a bit anxious to get to Ontario where things might feel less precarious. 'It's funny', she said, as we sat on her couch chatting while the kids watched a movie on the television, 'before I had these kids I was kind of individualistic – I thought everyone should deal with their own problems – but now I see how everyone needs to help each other, probably because I know what it feels like to worry that I won't be helped when I need it'.

In his original overview of therapeutic landscapes, Gesler (1992, 743) writes: 'Landscape formation is dynamic, a constantly evolving process, molded by the interplay, the negotiation between physical, individual, and social factors'. The social and geographic landscape of Northern Alberta is partly organized around oil and gas extraction: pipelines, paved highways, flight routes, and services lead to and from the Fort McMurray hub, and the actual physical landscape is scarred with the smoking craters, tailings ponds, clear-cut survey lines, and work camps produced by the process of oil exploration and tar sands extraction. Oil families like Stephanie's know well how resource extraction determines flows of movement and feelings of security or insecurity depending on how things go. Boom-and-bust economies affect therapeutic landscapes for both beneficiaries and providers of therapies that 'shift both the practical and moral frameworks of our existence' (Mol 2008, 90) as those shifts occur alongside the budgetary logics that shape how care becomes conceived.

The symbolic landscape and the valuation of life

Ella, also young white woman in her thirties, is the mother of two children. She was an oncology nurse before taking a leave a few years ago to spend more time with her family following her son's diagnosis. She never went back to work. Her second child, Andrew, now five, was diagnosed with MPS II as a toddler and had started enzyme replacement therapy shortly thereafter. I had arranged to meet her at her home after she responded to a call for research participants that the Canadian MPS Society had sent out to their membership base. My conversation with Ella helps to illuminate the affective relationships between health resource allocation, oil resource extraction, and place. By the time we sat together at her kitchen table on a warm April morning in 2015, the oil crash had shifted from being a crisis to the new normal. Despite small spikes and dips, the global price of oil had stagnated at around US\$40/barrel. Unlike many parents of children with rare disease, Ella didn't have to appeal to the media to convince the province to fund Andrew's treatment, as they'd

approved his doctor's request for treatment without much fanfare. Still, as she explained to me, the cost of the therapy combined with the oil crash had increased her generalized sense of unease:

We never tell anyone what the cost of our son's weekly treatment is. Because people would be horrified that their tax dollars are going to pay for that, you know? We have a life expectancy [for our son] that is hopefully now beyond the second decade of life but how do you justify that to a population? We certainly don't share that information, because you get looks of horror. . . . I do lose sleep over it. Because I think, we here in Alberta are very much a 'have' province and very much used to having great health care and things paid for, but not now, it's different now. And we would be bankrupt within a year if we had to pay for it ourselves.

By saying 'but not now, it's different now', Ella linked her feelings of insecurity to the price of oil, expressing her fear that her son's deservingness to receive an expensive therapy might shift under a new system of value and care. A Can\$350,000 therapy might not raise too many eyebrows in a boom, but Ella loses sleep over how people might perceive such costs in a period of scarcity.

As Gesler (1992, 737) writes, 'most social scientists who study health would agree that environment and culture play extremely complicated, interacting roles in health', and Ella's quiet reflections help to illustrate this interaction as it pertains to the symbolic landscape that shapes notions of deservingness for care. The exploitation of the physical environment through oil extraction is what made Alberta a 'have' province, as Ella termed it, which enabled certain forms of valuation of life to proceed. In the context of budgetary scarcity due to the falling price of oil, valuing life in high-cost, high-tech, and low-evidence ways falls under scrutiny.

A few weeks after I met with Ella, the HTA and health policy unit held the first of two 'citizens' juries'⁵ on social values for health care in the era of high-cost, low-evidence drugs. During our planning meetings for the juries, my colleagues frequently reflected on how all the talk of scarcity surrounding the low price of oil in public discourse might shift public sentiments about the rare disease drugs they'd be asked to consider in their deliberations. We spent a long time thinking about how best to frame the trade-off exercises that the jurors would partake in so that the jurors wouldn't have their views of deservingness clouded by

⁵ A citizens' jury, as described by Wakeford (2002, 1), is a form of research wherein a group of jurors believed to be representative of a wider population are asked to deliberate upon an issue of social or political significance.

the surrounding political economic context of budgetary scarcity. Ella's worries about telling people the cost of her son's therapy as well as my colleagues' worries about jurors' deliberations being shaped by the surrounding economic context show how symbolic landscapes of deservingness for care can be affected by what is happening with the actual physical landscape. The therapeutic nature of a place draws together all of these individual and collective dimensions of valuation.

Extracting the political

In Canada, health policy is frequently seen as separate from industrial and mining policy, but I have argued here that the two are linked: practically, affectively, and through flows of capital generated from underground bitumen deposits, extracted by private industry, and funneled into provincial coffers in the form of royalties and income tax revenue. The shift in the therapeutic landscape in a period of oil-related economic decline perceived by both Stephanie and Ella demonstrates how, at least on the level of subjective experience of place, a therapeutic landscape is something developed in the interactive relationship between the physical and the symbolic landscape. A keen attention to the political economy that shapes both budgets and feelings of deservingness for care is necessary to understand this complex relationship.

Both Stephanie and Ella's experiences demonstrate that affect is not only phenomenological, it is structural and political-economic as well. Their sense of the shift in the therapeutic landscape after the crash helps illuminate the complexity of systems of valuation of bodies and lives. Their reflections throw into relief the underlying affective reverberations that occur when governmental frameworks of care are shaped by the dynamic process of growth and decline in a boom-and-bust economy. The symbolic and physical landscapes become even more tightly linked conceptually when the cost of oil is low, because the pressure to increase extractive practices for economic reasons increases, making it seem like oil extraction is a necessity for collective survival rather than a situated but mutable practice that can be changed (Fisher 2009).

Implicated as they are within politics of health resource allocation, expensive rare disease drugs show how pharmaceuticals and the systems designed to allocate them are emplaced. Tim Ingold (1993, 152) critiques the 'sterile opposition between the naturalistic view of the landscape as a neutral, external backdrop to human activities, and the culturalistic view that every landscape is a particular cognitive or symbolic ordering of space'. An analysis of therapeutic landscapes that accounts for both the physical landscape and the symbolic landscape moves beyond this opposition. It demonstrates that the therapeutic qualities of a place can only be understood by understanding the interactive relationship between people

and the places that they inhabit, between economies of care and the political economy of place. Medical anthropologists can use the therapeutic landscapes analytic to more pointedly critique bureaucratic systems of care by making visible the often-obscured conceptual and material links between health resource allocation and natural resource extraction.

About the author

Marlee McGuire is a doctoral candidate in the Department of Anthropology at the University of British Columbia, and a Canadian Institutes of Health Research Douglas Kinsella doctoral researcher in bioethics. Her dissertation explores the various systems of value and valuation of bodies and lives at play in clinical, industry, and policy debates surrounding access to high-cost/low-evidence treatments for rare diseases in Canada's publicly funded health care system.

References

- Das, Satya. 2016. 'Giving Our Oil Away: Will the Royalty Review Inspire Us to Act Like Owners?' *Albertaviews: New Perspectives for Engaged Citizens* March: 28–32.
- Fisher, Mark. 2009. *Capitalist Realism: Is There No Alternative?* Washington, DC: Zero Books.
- Gesler, Wilbert M. 1992. 'Therapeutic Landscapes: Medical Issues in Light of the New Cultural Geography'. *Social Science & Medicine* 34, no. 7: 735–46.
[https://doi.org/10.1016/0277-9536\(92\)90360-3](https://doi.org/10.1016/0277-9536(92)90360-3).
- Ingold, Tim. 1993. 'The Temporality of the Landscape'. *World Archaeology* 25, no. 2: 152–74.
<https://doi.org/10.1080/00438243.1993.9980235>.
- Mol, Annemarie. 2006. *The Logic of Care: Health and the Problem of Patient Choice*. London: Routledge. <https://doi.org/10.4324/9780203927076>.
- Petryna, Adriana. 2011. 'Pharmaceuticals and the Right to Health: Reclaiming Patients and the Evidence-Base of New Drugs'. *Anthropological Quarterly* 84, no. 2: 305–29.
<https://doi.org/10.1353/anq.2011.0024>.
- United States Energy Information Administration. 2016. 'Crude Oil Prices Started 2015 Relatively Low, Ended the Year Lower'. 6 January.
<http://www.eia.gov/todayinenergy/detail.php?id=24432>.
- Wakeford, Tom. 2002. 'Citizens Juries: A Radical Alternative for Social Research'. *Social Research Update* 37: 1–5.
- Willen, Sarah S. 2012. 'How Is Health-Related "Deservingness" Reckoned? Perspectives from Unauthorized Im/migrants in Tel Aviv'. *Social Science & Medicine* 74, no. 6: 812–21. <https://doi.org/10.1016/j.socscimed.2011.06.033>.