

**Pharmaceutical Surveillance, Medical Research,  
and Biovalue among the Urban Poor**

by

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## **ABSTRACT**

This dissertation is an exploration of the ways in which therapeutic interventions and medical research surrounding HIV/AIDS are co-constitutive in Vancouver's impoverished inner-city community. It explores the ethical implications for medical research, epidemiological surveillance, and ethnography in the late-capitalist, twenty-first-century Canadian context. I combine elements of an ethnography of clinical care – including extensive naturalistic-observation at urban medical clinics that provide HIV treatment and interviews with clinicians, health administrators, people living with HIV, and scientists - with a reading of epidemiological literature pertaining to HIV-positive people living in Vancouver's inner city.

In which ways is the production of medico-scientific knowledge related to the distribution of pharmaceuticals for HIV in Vancouver's inner city? Here, I examine (1) the state-sponsored public health programs that have been created to improve compliance through the use of directly observed therapy, (2) the epidemiological discourse on adherence, (3) the relationship between pharmaceuticals and treatment, and (4) the contestation of therapeutic guidelines in the clinic. Informed by the writings of Michel Foucault, I situate my analysis within larger debates surrounding postcolonial medicine, disparities in access to treatment, and the global politics of HIV/AIDS research. I reflect on the ways in which inner-city populations are regulated and monitored through both illicit and licit pharmaceuticals.

I suggest that citizens whose lives are characterized by poverty, suffering, and abandonment in the Canadian state, who are perceived as “valueless”, have become critical commodities in the combined therapeutic and research economies, where they are valued for their suffering, disease, and bodies. Drawing on the work of Nikolas Rose, I suggest that, in the inner city, a lack of vitality constitutes a source of biovalue. The AIDS virus itself is a productive force, and becomes valued, through creating the imperative for vaccines, pharmaceuticals, and epidemiological surveillance. For epidemiologists and other medical researchers, the virus and its effects, along with the results of interactions between the pharmaceuticals and the disease (e.g., drug-resistant viruses), are productive sources of new scientific knowledge and new subjectivities. Finally, I reflect on the implications of this for conducting ethical critical ethnographic research on biomedicine.

**Keywords:** adherence, pharmaceuticals, ethics, HIV, DOT, ethnography, Downtown Eastside

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Corinne Gurney, Arlene Sinclair, Rod RockThunder, and Grade Edge. As expert research participants, they forced me to continually rethink my own research practice. They also offered sharp, critical commentary on medical research and public health in the Downtown Eastside, thus forcing me to grapple with paradoxes, contradictions, and the madness of being poor and sick. In December 2005, Frank McAllister died, tragically and alone, on the street. While his death was only one of many this past year in the Downtown Eastside, I was particularly shaken by it. Not only was he abandoned by the state but also, perhaps, by me. His loss forced me to consider the ways in which I, and the ethnographic practice and research in which I engage, was complicit in his death.

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## **CHAPTER 1**

### **DELIVERING MEDICINES AND COLLECTING DATA: BIOVALUE AND THE COMMODIFICATION OF SUFFERING**

Petryna and Kleinman (2006, 4) explain that “the coexistence of effective life-extending technologies and lost life chances in local places where essential medications remain unavailable presents contemporary ethnography with an urgent challenge to make sense of this paradox.” But how do we account for places where people have access to free pharmaceuticals for life-threatening diseases and yet do not engage in therapy, instead falling ill, suffering, and dying from their illnesses? This is the paradox with which we are faced in Vancouver’s inner city.

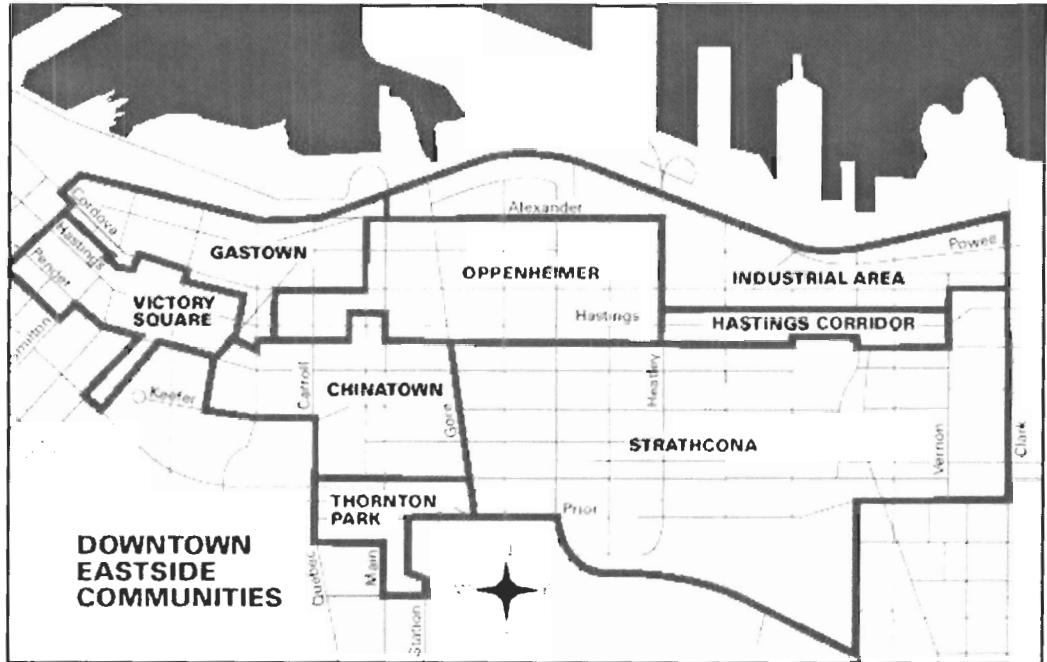
As the HIV pandemic sweeps across impoverished and politically fractured nations in Africa, which are unable to support the institutional infrastructure to deliver medicines or to mobilize the economic resources to purchase expensive antiretroviral therapies, we witness a devastating loss of life. But in the Downtown Eastside, a small inner-city community of Vancouver, British Columbia, we witness a paradoxical twist: free universal health care, free HIV medicines, and yet a lack of engagement with therapy. Dr. Julio Montaner, director of the British Columbia Centre for Excellence in HIV/AIDS,<sup>2</sup> reports that 45 percent of eligible HIV positive patients are not accessing treatment. Epidemiological surveillance suggests that a startling number of patients who have died from AIDS have never taken antiretrovirals (Wood et al. 2003). Among those patients who do take antiretroviral therapy, it is reported that many do so inconsistently, resulting in poor health outcomes and resistant viruses.

In 1997, in response to growing rates of illicit drug use and epidemics of HIV and hepatitis C in Vancouver's inner city, the Vancouver/Richmond Health Board declared a public health emergency. News reports quoted Dr. Michael O'Shaughnessy, then director of the Centre for Excellence, saying that the HIV epidemic "continues to spread at an alarming rate."<sup>2</sup> The medical health officer, Dr. John Blatherwick, for Vancouver urged the public to "wake up" and "get going." Both researchers and senior-level health administrators issued a plea to address the declining health of Downtown Eastside citizens. Immediately after the declaration, the provincial government promised \$3 million to help address the HIV epidemic. The federal minister of health then announced that his office would contribute \$1 million. Out of this crisis arose the 2000 Vancouver Agreement, whereby \$13.9 million was allocated for a range of interventions aimed at decreasing the co-epidemics.<sup>3</sup> Among other things, the agreement included increased health services, increased policing, and new housing initiatives.

### **The Downtown Eastside**

I once heard Byron Good say something to the effect that the colonial haunts these spaces that we explore.<sup>4</sup> This is particularly true in the Downtown Eastside, not just because brown bodies are visibly overrepresented but because relations between the state, biomedicine, and citizens are eerily similar to those that existed under early mid-twentieth-century colonial rule in Canada.<sup>5</sup> The Downtown Eastside is a space clearly marked by a colonial history, where contemporary colonial management takes on new and old forms simultaneously (Culhane 2003). Aboriginal peoples are still governed under the federal Indian Act; their health care is the responsibility of the federal government. Yet, Aboriginal people and the devastating history of colonial legislation is

overwhelmingly absent in epidemiological reports and biomedical research, included only as a variable in statistical analyses of risk factors.



**Figure 1. Map of the Downtown Eastside.**  
**Source: City of Vancouver, 2006.**

Like Margaret Mead’s Samoan girls, the residents of the Downtown Eastside have become infamous through research and the circulation of their images, their stories, and their demographics. The media have played an influential role in shaping the public’s imagination of this community as a place of crime, disease, and filth. In fact, the Downtown Eastside has become famous for its misery and suffering. “There is no comparison,” “there is nowhere else like it,” “it’s a place like no other” – these are epithets commonly used to describe the community. The Downtown Eastside has a long history of housing low-income populations. Today, it continues to be characterized by poverty, substandard housing, elevated rates of illicit (and perhaps licit) drug use, higher than average mental illness, and visible drug and sex industries.

The intersection of Main Street and Hastings Street is the metaphorical heart of the community – what many locals refer to as “Pain and Wasting” (see, for example, Adilman and Kliewer 2000) (See figure 1). This epithet conjures up images commonly associated with the neighbourhood, which, all too frequently, is characterized with reference to the illicit drug trafficking, the public use of injection drugs and inhalation of crack cocaine, the intense poverty, the crime, the violence, and the concentrated street-level sex industry. In their attempt to advocate for more comprehensive healthcare services, researchers direct our attention to the vices and plagues that have beset the community, emphasizing that it is “North America’s most active public injecting scene” (Kerr et al. 2003, 580), convincing us that lives here are characterized by “desperation, dispossession and despair” (Spittal and Schechter 2001, 802). It is filled with “damaged” people, the site of “an explosive and ongoing epidemic” (Spittal et al. 2002, 895), constituting “one of the poorest neighborhoods in Canada” (Gurstein and Small 2005, 717), an “urban ghetto ... home to ‘superinfections’ of Hepatitis A and C, and epidemic outbreaks of tuberculosis and syphilis” (Benoit, Carroll, and Chaudhry 2003, 823).<sup>6</sup> These descriptions are usually countered with recommendations for improved services, new interventions, or critiques of existing public health services – the descriptions often function more as rhetorical devices than as scientific evidence.

While many of these descriptions may be accurate representations of components of the Downtown Eastside, they have the effect of diverting our attention away from the reasons these conditions exist, concealing the forces that shape and form these particular contexts and lives and, thereby, further stigmatizing and pathologizing the community. These images conceal the fact that other communities also experience drug use, sex work,

and despair – that individuals in middle-class, privileged neighbourhoods engage in illicit sexual acts, use illegal drug paraphernalia, have “chaotic” lifestyles, and engage in violent, criminal behaviour. The Downtown Eastside is not unique in manifesting these behaviours, but citizens in other communities have supports and safety nets that protect them from the intense gaze of researchers, advocates, the media, bureaucrats, and politicians. In addition, the Downtown Eastside is located between two important historical sites in Vancouver – Gastown and Chinatown, which are key tourist attractions - and it is on the edge of Vancouver’s prosperous downtown core. As a result, the community has undergone a marked degree of gentrification. But none of these descriptions account for the messiness and complexities of life in the inner city.

Combined with other influences (such as the media), health and medical research overwhelmingly constructs the Downtown Eastside resident as an injection drug user (even though there appears to be evidence to suggest that crack cocaine, either inhaled or smoked, has become the prominent drug of choice).<sup>7</sup> Regardless, many residents of the Downtown Eastside and individuals who seek care in that community are *not* drug users. During a clinical observation I saw a patient who sought care at one of the Downtown Eastside clinics even though he was not a local resident. Aboriginal, living in a suburb of Vancouver, and working in the construction industry, the man, after suffering from a bout of thrush, had recently discovered that he had HIV. The clinician attending to him tried to establish how he had become infected and, early in the intake, asked whether he had been an intravenous (IV) drug user. The patient said no but that he was a recovering alcoholic. During the session, the clinician asked two more times about IV drug use, insisting: “But you *must have been* an IV drug user at some time?” The patient insisted that he had not.

This portrayal of all Downtown Eastside residents as intravenous drug users bleeds into public policy, and, as I illustrate in this dissertation, contributes to an assumption that their rationality and/or ability to adhere is compromised due to their illicit drug use. This justifies the utilization of layer upon layer of surveillance through directly observed therapy (DOT) programs.

The Downtown Eastside includes a diverse range of people. Students, lower working-class single men, new immigrants and refugees (primarily Chinese and Vietnamese), non-Aboriginal people, Aboriginal people, drug users, and women involved in the sex industry. The gentrification projects have made the neighbourhood appealing to artists, academics, and other urbanites as well. Men are overrepresented both statistically and symbolically. This dissertation, however, pertains to a very small fraction of the estimated sixteen thousand people living in the Downtown Eastside. It is difficult to find accurate estimates of HIV prevalence, but researchers at the Centre for Excellence calculate that approximately two thousand people in the neighbourhood are HIV positive. Of those two thousand, they calculate that one thousand would be eligible for treatment under current therapeutic guidelines.<sup>8</sup> In 2005, approximately 350 individuals were taking highly active antiretroviral therapy (HAART) in the community. For the most part, this dissertation addresses questions that pertain to the small minority of Downtown Eastside residents who are living with HIV.

Vancouver's inner city is a zone of intense surveillance and monitoring on the part of all kinds of state actors and bureaucracies. There is a very intense police presence (with concomitant surveillance) in the neighbourhood, and there are continual reports of



police brutality, video monitoring, epidemiological surveillance through various cohort studies, social research studies, private security observation, and more. Most health care programs require participants to register themselves so they can be counted and tracked. This is not surprising as, within a neoliberal climate, where battles for money for public health services and research are intense, statistics are the most effective capital in fund-raising strategies. One result of the intense surveillance of the community and its residents is a detailed, comprehensive monitoring of infectious diseases on the part of the British Columbia Centre for Excellence in HIV/AIDS, the British Columbia Centre for Disease Control, and the Vancouver Coastal Health Authority.

Since the declaration of the public health emergency, we have witnessed a deepening and widening of epidemiological surveillance and regulatory strategies. The Downtown Eastside most certainly has not been characterized by a systematic withdrawal of public and private services, left with “abandoned sites defined by absence” (Bourdieu 1999, 123; Wacquant 1999). The sheer volume of agencies operating in this space, offering housing, food, health care, advocacy, and Christian aid (among many other services), is uncharacteristic of many neoliberal states. Many of these programs are state-run initiatives, like the public health clinics; others are state-sponsored, with federal and provincial funds supporting programs that have been contracted out; some are grassroots organizations, which seek funds from both private and public sectors and/or creative commercial enterprises; and then there are the Christian humanitarian aid groups, which feed the hungry and impoverished. A week in the life of a Downtown Eastside resident alerts us to the maze of these organizations and their bureaucratic regulations, which,

along with increased surveillance and a loss of privacy, constrain residents' decisions and actions about housing, medical treatment, work, and sexual relations.

The actions and relationships of Downtown Eastside residents are imbricated in myriad systems of monitoring, regulation, and service provision, all of which is characteristic of the “roll-out” phase of neoliberalization (Peck and Tickell 2002). During the earlier phase of welfare reform (the “roll-back” phase), welfare states like Canada experienced an economic restructuring that often resulted in the withdrawal of services and the removal of funding from social welfare programming. Under the second phase of neoliberalization, Peck and Tickell suggest the emergence of new institutional apparatuses whose purpose is to contain and discipline those “marginalized or dispossessed by the neoliberalization of the 1980s” (389). Thus, what we witness in the Downtown Eastside is the simultaneous marginalization and centralization of the urban poor. They have been marginalized from social life and formal economic systems, and yet have been spatially centralized so that they can be counted, observed, and regulated through an assemblage of medico-administrative technologies. A whole series of neoliberal economic restructuring processes are at play here, and they work, as Allen Feldman (2001, 58) explains, to “pathologize the very populations most harmed by these economic transformations ... that fetishize their structural displacement as a form of pathologized space and pathologized embodiment.”

In British Columbia, the Ministry of Employment and Income Assistance affords a single person who is deemed eligible for employment \$510 per month for both living and shelter allowance;<sup>9</sup> a person with a disability is eligible \$531.42 per month for living

support and an additional \$325.00 for housing.<sup>10</sup> This amounts to a total monthly income of \$856.42 and an annual income of \$10,277.04, thus forcing most residents to live well below the poverty line. Most individuals living with HIV/AIDS in the Downtown Eastside have been able to qualify for the Person with Disability (PWD) rate, although recently there have been reports that HIV positive status alone does not guarantee access to this rate. Local residents turn to paid volunteer work, dumpster-diving, recycling, buying and selling, prostitution, drug dealing, and other industrious ventures – engaging in the margins of the late capitalist system – in order to supplement the meagre income assistance they receive from the province. Most of the men and women who live in the Downtown Eastside reside in single-room occupancy hotels, known as SROs, because they cannot afford to live elsewhere in Vancouver. These rooms are typically three metres by three metres, with shared bathrooms (one per floor or one every other floor). They do not contain cooking facilities. SRO units rent for between \$325 and \$400 a month (\$400 a month may include a small bathroom).

Services and programs for inner-city health, in particular, seem to be the most prolific, perhaps an indication of the depth of what Adele Clarke and colleagues (2003) refer to as the biomedicalization of social life. The intensity of health services in the Downtown Eastside is an interesting point of departure for an inquiry into the links between the welfare state, citizens' rights, and public health because the concentration and scale of health services here is a paradox. There are two reasons for this. First, in spite of hundreds of programs and millions of dollars of funding we still witness intense suffering, trauma, and loss; second, this concentration and intensity of programs occurs in an era when we are acutely aware of a *decline* in social welfare programs for the urban

poor. The Downtown Eastside is, paradoxically, a site of abandonment and a site of intense surveillance and governance.<sup>11</sup> This is one of many paradoxes that I work through in this dissertation as I analyze the intersections of public health, the welfare state, and the rights of citizens.

The number of organizations and services concentrated within such a small geographical space represents what some might call a ghettoization of health services. As Culhane (2003, 594) notes, the City of Vancouver's response to the HIV/AIDS epidemic and the escalating narco-economy has been to "contain" these dual epidemics, not necessarily to criminalize or police them. For some, the concentration of health services for the urban poor, for those living in intense poverty, and for those with addictions, mental illness, and other illnesses (such as HIV) makes sense and is understood as being important with regard to the creation of patient-centred care. Residents in the Downtown Eastside should have easy access to health services that are tailored to their specific needs, staff who understand the complex needs of "marginalized" patients, and environments within which they feel safe and at ease. Here, the epidemic has been framed geographically: it is located in the inner city (van Loon 2005; Feldman 2001). Yet, apparently, this framing does not reflect the actual spatialization of the disease. At the Forecast Seminar Series at St. Paul's Hospital, on 7 March 2007, Dr. Robert Hogg commented that the majority of current HIV infections occur among men who have sex with men (MSMs) – typically not considered the demographic residing in the Downtown Eastside.

During the same time that we witness expanded public health services and an intensification of policing we also witness a parallel intensification of research in the Downtown Eastside. There is increased interest in documenting the HIV epidemic, evaluating services that are created to curb the disease, and a demand for increased surveillance of contributing “risk factors”. In part, this is a result of the medicalization of social life, whereby addictions, homelessness, and poverty become mediated by biomedicine; however, it is also related to the emergence of evidence-based medicine and a movement towards standardization in biomedicine (Timmermans and Berg 2003; Mykhaloskiy and Weir 2004). Medical research, like that produced by the British Columbia Centre for Excellence in HIV/AIDS, provides scientific evidence to state bureaucracies that effectively shape policy and practice, not just with regard to clinical medicine but, increasingly, with regard to various parts of social life. As Mykhalovskiy and Weir (2004) have pointed out elsewhere, evidence-based medicine has transformed decision making in health care, influencing therapeutic guidelines, doctor-patient relationships, the evaluation of health services, and the delivery of standardized care. The emphasis on evidence is similarly present in the Downtown Eastside, where public health administrators are continually demanding evaluations of programs to monitor their impact on health and their cost-effectiveness, resulting in the prolific production of particular forms of scientific knowledge about disease, Downtown Eastside patients, and the space itself. This is particularly true in relation to the delivery of HIV medicines for Downtown Eastside residents.

Increased health services, attention to inner-city populations, an innovative harm reduction strategy: all of these things seem inconsistent with the twenty-first-century

neoliberal Canadian state, in which we expect to witness a withdrawal of social welfare support for the urban poor. And, indeed, we do, in some areas and some sectors of welfare provision and health care. But in the Downtown Eastside, harm reduction strategies and health research continue to be well-funded and well-supported. In fact, a colleague living in France tells me that Europe now looks to Vancouver as the model of innovative care; the Downtown Eastside is known internationally for its impressive, novel approaches to harm reduction, including needle exchanges, supervised injection sites, and the heroin replacement trials. But we are left wondering how and why, under this intense assemblage of health strategies, people still appear so sick, hungry, and impoverished? The main question I ask here is: What are the unintended consequences of this assemblage of mutually constituted research practices and therapeutic technologies in which HIV positive Downtown Eastside residents are enmeshed?

Specifically, this dissertation examines the production of medico-scientific knowledge in relation to the distribution of pharmaceuticals for HIV in Vancouver's impoverished inner-city community. I examine the relationships between epidemiological research cohorts, clinical trials for vaccines, the development of therapeutic guidelines, and the theorizing of adherence as it relates to the creation of specialized therapeutic subjects. How is power exercised through biomedical practices and categories like "compliance," "efficacy," "non-adherence," and "disease"? I examine the clinical dynamics of the distribution of pharmaceuticals, specifically through modified DOT programs at inner-city health clinics. Pharmaceuticals, in particular, HAART,<sup>12</sup> are at the centre of this analysis: Why, when, and how do individuals prescribe and consume these medicines?

Vinh-Kim Nguyen writes about the process whereby colonies are made into laboratories in which they are reorganized and new subjectivities are formed and studied.<sup>13</sup> Sunil Amrith (2004) has described how south Indian urban communities functioned as living laboratories in which tuberculosis (TB) research was carried out between the mid-1950s and mid-1960s. Vancouver's inner city, I suggest, provides multiple parallels to what these authors discuss. Indeed, Downtown Eastside residents speak to this phenomenon on a regular basis, referring to themselves as "guinea pigs," saying how tired they are of research and of medical experiments. Research in the Downtown Eastside is in no way limited to the exploration of health, disease, or illness; nor is it limited to epidemiologists or health researchers. Historians, geographers, sociologists, urban planners, filmmakers, artists, criminologists, and, of course, anthropologists all carry out research in the neighbourhood. Nor are these researchers limited to local universities like the University of British Columbia or Simon Fraser University; rather, they include people from across Canada and the United States.

On another level, this dissertation is an exploration of the interface between the Canadian state and biomedicine. In the Canadian context, health care is state-sponsored (i.e., financed by the government and conducted by state-actors or government worker) while medical research is state-funded (i.e., financed by the government but conducted by "independent" researchers). In British Columbia, health researchers are supported through grants from the Canadian Institutes of Health Research (CIHR) and the Michael Smith Foundation for Health Research (MSFHR). The MSFHR is a provincially mandated research organization dedicated to funding BC researchers. In March 2001, the Province of British Columbia made a commitment to donate \$110 million for the

establishment of the MSFHR. In 2005, the provincial government promised another \$100 million for ongoing support.<sup>14</sup> The CIHR is the federal government's health research funding agency. In the 2005-06 fiscal year, it predicted an annual budget of \$809 million.<sup>15</sup> Pharmaceutical companies also fund medical research on HIV/AIDS but usually basic and clinical medical research. Thus, in the Canadian context, the state has a central role. Medicine distribution and access are regulated not just by industry but also by the Canadian state through state-sponsored research institutes and state-sponsored health care. I do not mean to suggest that we are witnessing a centralized, powerful state that controls all facets of health care; rather, I am suggesting that the Canadian state comes to operate in insidious ways through contracting out, enabling non-state institutions to take on the role of monitoring and regulating citizens. It is not the Canadian state that counts, monitors, or regulates citizens of the Downtown Eastside but, rather, agencies and organizations that are funded through the state, specifically through public health campaigns for prevention, treatment, and *research*. The BC Centre for Excellence, through its epidemiologic surveillance, counting, and monitoring, functions to manage and regulate inner-city populations. In this way, as Michel-Rolph Trouillot (2001, 130) argues, state-like practices of governing come to work through non-governmental sites to "produce state effects as powerful as those of national governments."

Under classic liberal and Marxist definitions of power, the state was an institution, something "above," which governed those "under" it. As Michel Foucault (1980, 60) insists: "one of the first things that has to be understood is that power isn't localised in the state apparatus." Foucault (1991, 103) does not see the state as central in a theory of



power; rather, he suggests that the state is “no more than a composite reality and a mythicized abstraction, whose importance is a lot more limited than many of us think.” The power of the state is no longer situated in an institution or among a body of individuals but, rather, is shared, ubiquitous, and dispersed. Thus, some of Foucault’s critics have wrongly concluded that, for Foucault, the state was not integral to a study of power. He explains, “I don’t want to say that the State isn’t important; what I want to say is that relations of power, and hence the analysis that must be made of them, necessarily extend beyond the limits of the state” (Foucault 1980, 122). Foucault encourages us to think differently about *the ways* in which people are governed and to understand that the state is just one disciplinary power field among many. This dissertation explores this rethinking of the state by examining the relationships between state-sponsored health care and state-funded research and their effect on urban poor patients, who have become new and specialized therapeutic subjects.

### **Biovalue, research, and therapeutic economies**

In spite of the intensity of public health initiatives and medical research in the Downtown Eastside, we are witnessing an abandonment of its residents (Bichl 2005). One cannot help but notice the clearly visible signs – homelessness, hunger, and illness. Portrayed by the media as “junkies,” “criminals,” and “prostitutes,” the residents of the Downtown Eastside are blamed for their own misfortune. Nancy Fraser’s (1997) genealogy of the meaning of “dependency” in the Western welfare state illuminates how the urban poor become pathologized and stigmatized by their poverty: they are denigrated for their dependency on the state and denied the basic rights granted to other citizens.

Nowhere does abandonment seem more visible than in the body. If we can speak at all about “embodied citizenship” (Bacchi and Beasley 2002), I would argue that, in the Downtown Eastside, the body is the most obvious marker of non-citizenship. This is particularly true for those living with HIV. Their bodies are marked by dramatic weight loss, wasting, and lipodystrophy; they have gaunt faces and take medicines that give them diarrhea and induce vomiting; they are feverish; their bodies are marked by sores, by bug bites (due to sleeping in bug-infested rooms), by cervical cancer, by pneumonia, and by antibiotic drug-resistant bacterial infections like MRSA;<sup>16</sup> they are tired, exhausted from sleeping in unsafe, insecure hotel rooms or on the street, in the rain and the cold. This bodily manifestation of abandonment is a product of multiple things and is different for each individual, but it includes the deleterious physical effects of HIV or hepatitis C, side effects from toxic antiretrovirals, chronic hunger and malnutrition, chronic or acute drug use (illicit street drugs and/or alcohol), and sometimes the effect of physical violence (from others or self-inflicted). These individuals are abandoned not only by the state but also by their families, and not necessarily for any reason that the latter can control.<sup>17</sup> As one HIV specialist working on the AIDS ward in St. Paul’s Hospital said to me, they are not productive members of society, and they never will be. There is a widespread belief that these citizens are of “no value.” This is meant not only in the economic sense (as they are not seen as contributing to the formal economy) but also in a more general sense: they are not worthy of the rights guaranteed to other citizens. This is most poignantly highlighted in the state’s ineffectual response to the tragic disappearance of what some estimate to be over one hundred women from Vancouver’s Downtown Eastside. The question of value is also central to the local political economy of antiretrovirals.

But the residents of the Downtown Eastside do contribute to and engage in multiple economies – some of which are underground, informal economies like drug dealing, sex work, and boosting, but others of which include the more formal economies of social service provision, health care, and research. The nightly Global and CBC news regularly report stories about long waitlists for surgeries, the possibility of fee-for-service, the cost of new medical equipment and medicines, reminding us of the way in which health care is tied to economies. Similarly, the very language of health care, which refers to “consumers” and “clients” rather than “patients,” highlights for us the ways in which health care is increasingly becoming about cost and economics. As Kleinman (1995) points out, contemporary biomedicine seems more akin to governmental and business bureaucracies than it does to healing traditions, either those located elsewhere or those found in Canada a quarter of a century ago.

I suggest that there is also a formal research economy in the Downtown Eastside. It is difficult to accurately measure the amount of research in which Downtown Eastside residents participate, but many do so on a regular basis. In January 2007, the program director at the Vancouver Native Health Society consulted me about a request she had received from an organization conducting research on Aboriginal girls, aged sixteen to twenty-five, from reserve communities. The “researcher” told her that the work was government-sponsored and that they were seeking young women to participate in a focus group, which would pay participants sixty dollars for their time.<sup>18</sup> When we followed up, we realized that this was a marketing research project but that the marketing company could not tell us for what reason the work was being conducted or for whom. While the Vancouver Native Health Society declined to help this organization find participants for

its focus groups, this was a difficult decision as participating in a research project for money seemed to offer a considerably better way of making a living than did many of the other options available to low-income people who are barely surviving on income assistance. As an organization that provides services to hundreds of Downtown Eastside residents daily, the Vancouver Native Health Society is frequently called upon by researchers for assistance in recruiting participants in various projects. Indeed, I myself approached this organization in 2000, when working on a research project that involved interviewing low income women and then again in 2005 when I began researching DOT programs.

There are a number of factors that contribute to the difficulty of monitoring the density of research in the Downtown Eastside. First, the Province of British Columbia has no central database or list that keeps track of this. Even if one were able to get information from, for example, ethics review boards at the local universities, this would only account for local researchers. Second, during the course of my research it was clear that Downtown Eastside residents are often unaware of when they are being used as subjects of research. For example, when I interviewed participants and asked them about their experience with research projects, some would first respond by saying that they had never participated in a research project before. I would follow up by asking whether they had ever been involved in the Vancouver Injection Drug Users Study (VIDUS) project, and they would say yes. They often explained what appeared to be a contradiction in their responses by noting that VIDUS provided treatment and medical care (they were given blood tests and care from nursing staff).<sup>19</sup> These participants didn't recognize that they were participating in a research project. Nor are they aware of the ways in which the data

collected about them through epidemiological surveillance strategies or the Drug Treatment Program become part of “virtual cohorts.”<sup>20</sup>

Who are these scientists, clinicians, and researchers? Some might interpret this dissertation as a condemnation of individual men or institutions – a postmodern critique of medicine simply for the sake of critique (Latour 2004). It is neither. It speaks to novel processes occurring in the twenty-first century, to new transformations in governing, in late capitalism, and in biomedical research. It contributes to the subdisciplines of the sociology of knowledge and medical anthropology as well as to the science, technology, and medicine studies that, according to Clarke and Star (2003, 540), should function to “open up the actual contents of scientific, technical, and biomedical knowledge for inspection through social science lenses.” I explore biomedical research carried out by epidemiologists and clinicians who are trying to assist in humanitarian aid efforts within a difficult context. I am not suggesting that research that documents disparities and inequities in health and HIV should not be carried out or funded; rather, I am suggesting that we need to be aware of the unintended consequences of (1) a public health system that delivers HIV treatment that is inextricable from medical research and (2) the deep and intense surveillance (much of which stems from HIV research) of the urban poor, particularly as it manifests itself in tensions between care and control, support and surveillance.

In this dissertation, I suggest that suffering, whether it be in the form of homelessness, disease, drug addiction, or poverty, has become commodified within two powerful co-constituted economies: medical research and HIV therapy. Marginalized

within formal economies, Downtown Eastside residents sell what they can – their bodies, sex, photographs, drugs, blood, and stories. As Nikolas Rose (2003, 15) has noted elsewhere, “those aspects of life that were previously devalued as pathology, whose humane treatment and welfare was a drain upon a national economy, are now vital opportunities for the creation of private profit and national economic growth.” In the Downtown Eastside, we see how pharmaceutical corporations, pharmacies, and drug dealers clearly profit. The term “poverty pimps,” well known among Downtown Eastside residents, refers to those of us who profit from the suffering, those of us who make a living caring for, treating, or researching the urban poor. This is not to suggest that those working, advocating, and researching in the Downtown Eastside do not have good intentions. Most do, but that is beside the point. Regardless of our intentions, we do profit from the suffering and disease that we document, perhaps not necessarily financially, but undoubtedly (at least if we are researchers) through the social capital that we accrue in our curricula vitae (i.e., conference presentations, publications, grants, etc.).

While the term “poverty pimps” powerfully highlights the ongoing disparities between those who live in the Downtown Eastside and those of us who work or do research there, it cannot account for the complexities and nuances of how value is produced through suffering. To help make sense of this, I turn to Nikolas Rose (2007; 2003), who explores similar issues in his study of the “politics of life.” He adopts and reworks the concept “biovalue,” which he takes from Catherine Waldby (2002). He explains that, “more generally, we can use the term to refer to the plethora of ways in which vitality itself has become a potential source of value: biovalue as the value to be extracted from the vital properties of living processes” (Rose 2007, 32). If we understand

vitality to refer to “the ability to sustain life” (Oxford Encyclopedia) or the “capacity to live, grow and develop” (yourdictionary.com), then how do we understand life that is barely sustaining, is weakening, or is slowly deteriorating?

While Rose (2007) and Waldby (2002) emphasize the value of the vitality of life, I suggest that, in the inner city, it is precisely the lack of vitality - the suffering, the pain, the disease - that constitutes a source of biovalue. The AIDS virus itself becomes valued through creating the imperative for vaccines, pharmaceuticals, and epidemiological surveillance. For epidemiologists and other medical researchers, the virus, the effects of the virus, and the interactions of the pharmaceuticals with the disease (e.g., drug resistant viruses) are all productive sources of new scientific knowledge, new subjectivities, and actual economic value. Patients’ blood samples are collected (during some epidemiological research projects and as part of baseline assessments before beginning treatment), as are their “risk-factor” histories, their demographic information, and their life stories, in which they end up as commodities in the research economy. All the conditions that made them “value-less” now imbue them with a new type of biovalue. This is the effect of the production of a specialized medico-scientific knowledge of HIV/AIDS combined with the increased commodification of disease and suffering. The HIV positive patient in the Downtown Eastside represents impoverishment and abandonment, yet, paradoxically, within this new biopolitical assemblage of biomedicine and the state, she or he also represents a productive new source.<sup>21</sup>

This is not an entirely new process. In fact, many social theorists and anthropologists have written about the relationships between disciplinary knowledge,

especially epidemiology, and the creation of particular subjects. Many of these scholars have been influenced by the writings of Michel Foucault, to which I turn to shortly.

### **Directly/Daily Observed Therapy and Compliant Patients**

There is an intense concern with compliant patients in the Downtown Eastside, especially with regard to medical research and public health interventions for drug users and those living with HIV. Early on in the global HIV epidemic, researchers highlighted the challenges facing drug-using communities as public health officials and clinicians debated the feasibility of providing treatment to those deemed particularly non-compliant (see Sollitto et al. 2001). Concerns about drug-resistant strains of HIV and the cost of antiviral therapies fuelled the debate, which was countered by discourses advocating for the human rights of drug users. One of the effects of the declaration of the public health emergency in the Downtown Eastside has been the adoption and proliferation of directly observed therapy (DOT) programs in the treatment of HIV, addictions (e.g., methadone maintenance therapy), and other illnesses. Although developed for treating tuberculosis, this program model has been increasingly adopted with regard to the delivery of antiretrovirals in both resource-poor settings and inner-city North American settings, where, for a whole host of reasons, adherence has been reported to be less than ideal.

In 1999, the British Columbia Centre for Excellence in HIV/AIDS initiated a pilot project that involved both research and treatment of HIV and that was modelled on DOT programs for TB. Its purpose was to increase up-take and to improve adherence to the complicated pharmaceutical cocktails that were common in the late 1990s. Observing difficulties among Downtown Eastside residents in particular, this modified DOT



program, known as the Maximally Assisted Therapy (MAT) program, offered a multidisciplinary team that provided nursing, daily medication dispensing, nutritional counselling, and psycho-social support. Although it has transformed considerably since its original implementation, this program still operates as a DOT-HAART program, now under the management of the Vancouver Coastal Health Authority. Treatment for HIV in Vancouver is not considered to be part of the Health Authority's mandate. When I asked the manager for HIV/AIDS and addictions how many dollars the Health Authority spent annually on HIV treatment, he said, "Zero." He explained to me that treatment was limited to medicines and that this was the responsibility of the Centre for Excellence. In fact, the Vancouver Coastal Health Authority does provide some support, care, and treatment for HIV positive people, primarily through DOT programs. The large majority of the Authority's health care, especially in the inner city and for HIV, is prevention-oriented.

Since 1999, then, through supportive housing programs, NGO clinics that provide HIV care, and private pharmacies, there has been a proliferation of programs developed to address the question of medication compliance in the Downtown Eastside. Not only are antiretrovirals prescribed for DOT but, depending on the clinician providing care, the clinic, and the patient, DOT may be required for methadone maintenance, other narcotics, sleeping pills, and even Tylenol 3s. DOT is being adopted not just by the state-sponsored health clinics but also by a host of agencies, including non-governmental health organizations, supportive housing facilities, and privately owned pharmacies.

In the Downtown Eastside, if you are taking antiretrovirals, then you are most likely somehow connected to one of the many DOT programs.<sup>22</sup> As a result DOT clinics are ideal ethnographic sites in which to document and explore the everyday politics of medicine delivery. They provide an opportunity for the ethnographer to observe interactions between patients, doctors, nurses, pharmaceuticals, and other interventions. In the clinic, we witness the ways in which scientific knowledge about HIV, treatment, and theories of adherence affect everyday medical decisions and practices. We witness the awkward ways in which medicine operates in public health settings, which, in some ways, seem to be set up to deal only with the most immediate and pressing health needs. In this context, we are able to see how the practice of medicine extends beyond the virus, the disease, and the body into the multiple arenas of social life. DOT programs are sites where patients and doctors negotiate power relations; they are, distinctly, spaces of governmentality (Ferguson and Gupta 2002), and they bear clear traces of a postcolonial state. Aboriginal people constitute almost half of the participants in these programs – 45 percent in 2006 and 54 percent in 2000 – raising urgent questions regarding postcolonial medicine and neo-colonial science (Tyndall et al. 2006; O’Shaughnessy et al. N.d.).

In this dissertation, by examining the politics of the delivery of pharmaceuticals through DOT programs, I trace the impact on the Downtown Eastside of the focus on adherence and on compliant patients. I suggest that DOT takes on new meaning in this community, where the observation of prescribed pharmaceuticals is paralleled by the witnessing of illicit street drugs in public health interventions, the latter being constructed as progressive harm reduction strategies (including the supervised injection site and the heroin maintenance trials).

In this dissertation, I document the ways in which HIV positive patients have responded to pharmaceutical surveillance and regulation. If the intended consequences of programs like DOT are to increase adherence, support patients, monitor compliance, and improve the health of those living with HIV, then what are their unintended consequences? This is a question of power, of the ways in which power is negotiated between doctors, nurses, patients, and medicines. I suggest that, in some situations, the depth of surveillance and regulation is experienced as coercive, paternalistic, and controlling and that patients resist this in many different ways. And sometimes their resistance strategies may appear to be contradictory. For example, one of the “everyday forms of resistance” is to simply not take medicines as prescribed (or at all) (Scott 1985). People may refuse treatment, refuse to pick up their medicines, refuse to take particular pills on particular days, or refuse blood tests. Unfortunately, this manifests itself as a form of iatrogenic violence,<sup>23</sup> whereby the reappropriation of one’s body by refusing treatment contributes to one’s illness or death. The patient resists by refusing treatment and then becomes more ill because he is not in treatment. I contend that, since the Health Board declared the public health emergency in 1997, this is one of the paradoxical consequences of the intense delivery of public health interventions. As I work my way through the development of therapeutic guidelines and their application and contestation in the clinic, the politics of preventive AIDS vaccine clinical trials, and theories of rationality and cognitive impairment among drug users with HIV, I show that, at the interface between medical research and therapy, there is both discord and acquiescence (Clarke and Star 2003).

## **Foucault and Medicine**

This dissertation began as an exploration of the spaces, or gaps, between government, research institutions, non-profit organizations, and citizens, and its purpose was to attempt to further understand the ways in which, in the twenty-first century, marginal populations are regulated and shaped through biomedicine. It contributes to a rich scholarship that explores the relationship between medicine and control. Directly observed therapy as a form of twenty-first-century pharmaceutical surveillance fits well within a Foucauldian framework for understanding biomedicine, and my project is inherently shaped by his writings on medicine, governmentality, biopower, and the body. I draw not only on the work of Foucauldian scholars who have adopted his framework but also on the work of those who have expanded and pushed his analysis farther and deeper. I am particularly influenced by the writings of those who have undertaken a Marxist reading of Foucault, including Kaushik Sunder Rajan, Timothy Mitchell, and Nikolas Rose.

Foucault's most influential writings are those that focus on the notion of power (Foucault 1979, 1980, 1989, 1990). Much of his writing is concerned with the nature of power as it has emerged during the modern era. His empirical work focuses on a newly emerging form of power - disciplinary power. This is situated in the late sixteenth century, and some have characterized it as being a "distinctively modern" form of power (Fraser 1989, 22). Foucault rejects classical Marxist and liberalist definitions of power, which define it as centralized, as negative, as something one possesses and holds over others. For Foucault, power is understood as something that intersects networks of relations; it is "positive," in the sense that it produces effects. Modern power is not

something one can hold, it is not an entity in and of itself; rather, it is multiple and omnipresent, exercised not at the state but through clinics and schools, through doctors and teachers (i.e., “experts”), in everyday practice; it is fragmentary and indeterminate. He argues that power is exercised *through* individual bodies, not *upon* them (as in the corporal beatings of past sovereign regimes). Disciplinary power is capillary in nature in that it is “co-extensive with the social body; there are no spaces of primal liberty between the meshes of its network” (Foucault 1980, 142; 1979). Power is embodied in the local, in the minute practices of the everyday, and, as a result, it runs deep and is insidious. This form of power “proliferates outside the realm of institutional politics, saturating such things as aesthetics and ethics, built form and bodily representation, medical knowledge and mundane usage” (Comaroff and Comaroff in Lock and Kaufert 1998, 6).

Foucault maintains that the traditional view of power as repressive and negative reflects a misunderstanding regarding the ways in which it operates. He asks: “If power were never anything but repressive, if it never did anything but to say no, do you really think one would be brought to obey it?” (Foucault 1980, 119). Instead, power is “a productive network which runs through the whole social body” (ibid.). It is productive in that it creates subjects (e.g., “the prostitute,” “the homosexual,” “the injection drug user,” “the non-compliant patient”), fields of expertise (sexology, criminology, medicine, etc.), and discourse (Foucault 1989). Our own subjectivity - the self, the individual - is a productive effect of power (Foucault 1980).

In the *History of Sexuality* Foucault (1990, 140) develops his notion of “bio-power” - a term he coins to describe the techniques used to subdue bodies and to control

populations. He reveals that, in the beginning of the seventeenth century, a new power emerged - a “power over life” – a “bio-power” that maintained, enhanced, and nourished “life.” Sovereign power was, in part, based on the right to take life away, whereas bio-power managed and optimized life. This shift to governing “life” is key to understanding how disciplinary power came to suffuse everything. This new, modern form of power became ubiquitous because it governs not only through norms but also through self-management. Sovereign power, which existed in legal apparatuses like the law and policing, co-existed with this new emergent form of power.

Bio-power develops along two intersecting axes and constitutes what Foucault (1990, 139) calls “two poles”: (1) the individual body (the “anatomy-politics” of the human body) and (2) the regulation of the body politic (the population). The latter is the axis of power that is focused on the human species, “imbued with the mechanics of life and serving as the basis of the biological processes: propagation, births and mortality” (139), and it is regulated through “a bio-politics of the population” (ibid.). This new bio-politic is represented by the emergence “of the problems of birthrate, longevity, public health, housing and migration” (140) and includes new fields concerned with counting and classifying populations – most noticeably, demography.

It is along the first axis that most assume the process of medicalization runs, although, Lock and Kaufert (1998) perceptively argue that the division between the two is too marked, suggesting that each bleeds into the other. According to Foucault’s theory of power, the body is perceived as machine-like, as something that can be reworked, disciplined, instructed, and improved in order to increase its utility. Optimization is the

goal: How do we get the most productive body? How do we realize its full potential? This displays a clear shift from the notion of sovereign power, which focuses on the productivity of the land or the earth (Fraser 1989). The body is now targeted by experts from many fields, including medicine and psychiatry, with disciplinary micro-techniques (Lock and Kaufert 1998). For example, in medicine, “Bodily states are labelled by experts as diseases: certain behaviours are defined as deviant, unnatural, immoral, opening up the way for systematic and legitimized attempts at medicalization of both the body and behaviour” (7). Medicine is just one of many apparatuses of normalization that regulate and discipline individual bodies.

According to Foucault, the second axis of bio-power, which is concerned with the management and regulation of human life as a whole, evolved later than the first. This strategy of power took many shapes but, most noticeably, developed as a regulatory force that controlled and maximized population. It entailed an increased interest in birth rates, mortality, health, and life expectancy. The discipline of medicine, and its concern with health, became particularly prominent as a technology (as did fields that focused on classifying and counting). There was a growing concern within the state to improve the health of the population as a means of perpetuating empire. Bio-power was exercised as a concern for a healthy population. Matters that were once considered private and familial — sexuality, reproduction, and fertility — became political, linked to concerns of government.

Disciplinary power manifests itself in *micro-practices*, techniques and tactics of “disciplinary institutions” such as schools, the penitentiary, and the hospital. This is one

of the ways in which Foucault departs from traditional Marxist approaches to power. For Marx, Gramsci, and Althusser, ideology played a central role in understanding control and domination (Waitzkin 1989). Ideology was the subtle yet pervasive technology through which a population came to consent to governance, through which society was structured and order was established. Where these other “grand” theorists gave ideology a central place their analyses (and, hence, perceived power to be centralized among capitalists or within the state), Foucault (1980, 118) dismissed it, or, rather, suggested that it could not “be used without circumspection.”<sup>24</sup> Foucault was less concerned with beliefs and/or the shaping of beliefs – or a form of consciousness. He explains that part of his concern about using the notion of ideology has to do with the fact that “it always stands in virtual opposition to something else which is supposed to count as truth” (Foucault 1980, 118). Instead, he sees disciplinary power as working through the *body* in the form of everyday local practices. As Fraser (1989, 25) explains, this has important consequences for theorizing domination because it means “that practices are more fundamental than belief systems when it comes to understanding the hold that power has on us.” It also implies that, for Foucault, there is no basic human rationale or innate human consciousness that becomes distorted through hegemonic ideologies (whatever they might be). This is because the subject is constituted by and constitutive of power/knowledge.<sup>25</sup>

In his empirical work, Foucault (1979, 1989) examines a number of disciplinary micro-practices, including the medical gaze, surveillance, and normalization. The gaze was one of the central techniques used in the disciplining of bodies. In biomedicine, surveillance is one aspect of the “medical gaze that is disciplining bodies” (Clarke et al.



2003, 172). Armstrong (1995, 395) explains that a “new medicine” emerged in the early twentieth century, one established on the “surveillance of normal populations.” This new medicine was distinctive because it targeted everyone. The workings and effects of bio-power may be most obvious with regard to those who do not fit into the “normal” category; however, bio-power functions by bringing “everyone within its network of visibility” (ibid.). Foucault also asserts that bio-power, “in creating a domain of expertise, constitutes its own subjects of analysis to which it then responds” (Lock and Kaufert 1998, 7). New technologies of surveillance create “subjects” (e.g., historically, the “nymphomaniac,” the “prostitute”; currently, the “intravenous drug user,” the “homeless”). The depth of Foucault’s disciplinary power becomes salient when we realize that these modern subjects are not passive: they are participants in the very discourses that construct them. As Vaughan (1991, 9) explains, the modern subject “is not only enumerated, and written about, by the scientific experts of the modern state, but, critically, she and he also talks about her or himself, and thus participates directly in the disciplinary regime.”

One of the ways in which medical anthropologists have documented how disciplinary power operates in the contemporary world is through examining the use of statistics, numbers, and the process of counting as micro-techniques. As Ian Hacking (1991, 181) notes, statistics are not simply a means of compiling data and providing information, they are also “part of the technology of power in a modern state”; they operate as normalizing and surveillance instruments. Although not as explicit as Hacking, Foucault alerts us to the roles that counting and classifying play in the regulation and management of populations. How this happens within the field of medicine is taken up by

Armstrong (1983), who describes the role of “measuring” and medico-social surveys in extending control over bodies. Armstrong delineates how the emergence of a “new clinical science” in the early twentieth century, which compared diseased bodies to “normal” bodies, facilitated the concurrent development of a statistical methodology for “comparing experimental and control groups” and a means to communicate findings (46). This was important for two reasons. First, it placed the “patient and his disease, treatment and prognosis, in a social and conceptual space which encompassed the social body” (47). According to Armstrong, this meant that there was a measurable space between the normal and diseased body (or between the “ill and the community”). Second, in order to accurately measure the gap, the body politic needed to become more “visible” and, thus, was increasingly disposed to the “clinical gaze.”<sup>26</sup> The latter, of course, required the development of refined survey technologies. Armstrong details how, over time, especially as the First World War progressed, the social spaces between individuals became more intensely monitored through record keeping. This meant that both disease and health could be monitored more closely. And this was key in the construction of health and disease: “whereas disease could be observed in separate individuals, health was a concept that could only be constructed from populations” (48). While the existing techniques were fruitful with regard to their surveillance of individual disease, they were weak with regard to monitoring widespread disease and/or population trends. The “medico-social survey” was the answer to their dilemma: it was a technology of surveillance that could not only monitor disease but also function as “an apparatus of normalisation” (51). It could measure health, illness, and relationships; it could order bodies into spaces; it could open up new spaces for seeing. The survey also facilitated the

extension of medical power into the community. Armstrong notes that the survey (emerging alongside the dispensary), “a mechanism for ‘measuring’ reality, could be transformed into a technology for the ‘creation’ of reality; the tactics of the survey could make the operation of disciplinary power throughout a society more effective and more efficient” (43).

Not only was this new normalizing-disciplinary power efficacious but it was also cost-effective. It is no accident that this newly formed modern power emerged during the peak of mercantile capitalism and industrialization in Western Europe. Compared to the exercise of sovereign power, the exercise of modern power involves little expense. Speaking specifically about the use of the gaze in the deployment of power, Foucault (1980, 155) writes: “There is no need for arms, physical violence, material constraints. Just a gaze ... which each individual under its weight will end by interiorising to the point that he is his own overseer, each individual thus exercising this surveillance over, and against, himself. A superb formula: power exercised continuously and for what turns out to be a minimal cost.” Disciplinary power was ideal.

More recently, anthropologists such as Charles Briggs (2003) and Leslie Butt have illuminated the ways in which statistics insidiously support coercive health policies and programs. Butt (1999) illustrates how statistics representing child mortality rates are used to justify increased governance of the local indigenous population of Irian Jaya. Here, she argues, numbers are used to create particular realities; they define the “standard,” or the “normal,” in health statistics. The search for “normal” birth weights and “normal” infant mortality rates, the concern for the healthy infant, is the rationale

used by international health experts to increase the surveillance and regulation of those who are marginal to the state. Yet, there is little reflection on what constitutes the “normal” or the “standard.” Infant mortality rates are used internationally as a universal, standard measure, without questioning what those “normal measures” represent. As Butt explains, “constructs of the normal are inseparable from political power” (83). Rarely do we consider that “scientific measures” are in fact social constructs with distinct histories.<sup>27</sup>

For his part, Briggs (2003) examines how statistics were deployed as a disciplining technique in the governance of indigenous populations during a 1992 cholera outbreak in the Orinoco River delta of eastern Venezuela. He critically reflects on how the modern state produces statistics in a manner that makes them appear neutral and truthful. His work on medical statistics during this health crisis stands as a prime example of how disciplinary power works: “New numbers created new political technologies for classifying and enumerating people, a new ‘style of reasoning,’ and a statistical and probabilistic view of society that identified ‘normal’ and ‘deviant’ characteristics and populations” (265). Modern power works through the everyday micro-practices of counting and record keeping, where it is deployed in the management of populations — in the domains of both life and death (Foucault 1990). In the Downtown Eastside, we witness a similar use of statistics, surveys, and demographic information in the making of the “vulnerable” subject.

## **Research and the BC Centre for Excellence in HIV/AIDS**

*Our influence stretches from the molecule to the community.*

-- Dr. Julio Montaner, BC Centre for Excellence in HIV/AIDS

I once commented to a researcher at the Centre for Excellence that, from the outside looking in, I had come to the conclusion that the Centre was a bit like the television series *Survivor*.<sup>28</sup> It seemed to be characterized by constant negotiations of alliances, with new ones being formed, broken, and reformed as everyone competed for the million-dollar prize. Except, with the Centre, we already knew that Julio Montaner was the \$1 million winner (literally and figuratively). He would *not* be voted off. Laughing, the researcher responded, "It's exactly like that."

A good proportion of this dissertation focuses on the Centre. As a national leader in HIV/AIDS research and as the director of the Drug Treatment Program, not to mention the provincial service whose task is to deliver antiretroviral therapy to people with HIV, it only makes sense that it would be central in any discussion about HIV treatment in Vancouver. The Centre opened in 1992, under the directorship of Dr. Michael O'Shaughnessy. It is marketed as "Canada's largest HIV/AIDS research, treatment and educational facility."<sup>29</sup> St. Paul's Hospital, which is part of Providence Health Care, is the physical site of the Centre for Excellence. It is the primary site for the care and treatment of patients with advanced AIDS, and it houses the ambulatory pharmacy – the pharmacy responsible for the provincial distribution of all antiretroviral medicines.<sup>30</sup> The Centre for Excellence positions itself as a leader in the field of HIV treatment, even more so since Julio Montaner became president-elect of the International AIDS Society in 2006. Although not trained as an infectious disease specialist (his specialty is respiratory

health), he has come to be seen as a leader in the field of HIV treatment. His list of awards and accolades is impressive. As newly appointed director of the Centre for Excellence in 2005, it is clear that he has grand visions and aggressive plans for the Centre and its researchers. New research programs are planned, as are new alliances and a more visible presence in the international HIV arena.

The Centre also participates in clinical and laboratory research, and its researchers participate in various international research projects, primarily focusing on HIV, “marginalized populations,” and injection drug users. For the purpose of this dissertation, I focus on the Centre’s epidemiological research and Drug Treatment Program. While the large majority of its research focuses on specific cohorts drawn from the Downtown Eastside community, the implications of their research extend well beyond the neighbourhood, the city, and the province.<sup>31</sup>

There are other non-Centre affiliated researchers and clinicians doing research on HIV and AIDS prevention, care, and treatment in Vancouver. Dr. Brian Conway, a researcher at the University of British Columbia in the Department of Pharmacology and Therapeutics and coordinator of the Downtown Infectious Diseases Clinic, is an internationally recognized researcher in the field of HIV/AIDS. Although he once worked there, he currently has no relationship with the Centre for Excellence since he left in 1998. Similarly, there are a number of other researchers, many social scientists, who skirt around the HIV field but who maintain a fairly quiet profile. Researchers exploring HIV and related health issues in the Downtown Eastside include colleagues (faculty and graduate students) in my own department (e.g., Dr. Cindy Patton), researchers who have

no current formal affiliation with the Centre but have appointments at the University of British Columbia (including Dr. Martin Schechter, Dr. Patricia Spittal, Dr. Anita Palepu, and Dr. Aslam Anis), and those working for the Vancouver Coastal Health Authority in associated disciplines such as addictions (e.g., Dr. David Marsh and Dr. Stan De Vlaming). The North American Opiate Medication Initiative (NAOMI), while not an HIV/AIDS treatment intervention, is both a research project and a therapeutic pilot initiative. Officially a clinical trial, it delivers prescribed injectable heroin doses to research participants who have been unsuccessful in recovery programs and/or methadone maintenance (Schechter 2002). While I focus primarily on the research and treatment offered by the Centre for Excellence, clearly my work pertains to, and is informed by, all of the research and researchers in the Downtown Eastside, including my own ethnographic research.

The distance between Vancouver's Downtown Eastside and the Centre for Excellence and St. Paul's Hospital is three kilometres. In some ways, it is a tightly bundled geographic zone neatly laid out for the anthropologist. Yet, as one moves back and forth between these two spaces, one can't help but feel that they are two very different and separate worlds. The difference between those who live with HIV in the inner city and those who research and treat it is vast.

### **Mapping It Out: Chapter Overview**

In Chapter 2, I begin by examining the ethics of conducting critical research on much needed therapeutic practices during an era plagued by neoliberal cuts and the restructuring of health and welfare programming. I also situate myself in the world of

HIV research and reflect on how I make sense of this project, which, I realize, is yet another layer of surveillance in the research economy that I critique. Is it possible to do ethical, socially responsible research in a community plagued by layers of research and surveillance?

Chapter 3 begins with an examination of the ways in which medical research constructs Downtown Eastside residents as non-compliant, hard-to-reach, and untreatable. The problem of adherence and the non-compliant patient is, in many ways, at the heart of this project and of health research in the inner city. I begin by examining the ways in which both epidemiology and anthropology have made sense of non-compliant patients. Through an analysis of therapeutic programs, I also explore the meaning of compliance and the construction of the “non-compliant patient” within the context of HIV treatment among the urban poor. Although anthropologists have pondered questions of compliance,<sup>32</sup> we have not carefully scrutinized the ways in which understandings of this phenomenon are political, economic, and social.<sup>33</sup> Nor have we considered carefully the impact that such constructions have on the everyday lives of the suffering. Through research and clinical trials, researchers contribute to the formation of particular types of subjects, engaging in what Ian Hacking (1999) calls “making up people.” In epidemiology, the use of bio-statistical modelling and scientific facts becomes a powerful form of capital, which is used to “prove” scientific authoritative knowledge (Berg and Mol 1998).<sup>34</sup>

Chapter 4 examines the international and local debates surrounding the adoption of directly observed therapy for the management of antiretroviral therapy among



inner-city populations. Here, I map out the multiple ways in which DOT has been adopted in the inner city and how it is justified by public health discourses. I illustrate how divergent DOT programs are, even though they are all based on the same model of care. The development and implementation of the Maximally Assisted Therapy Program provides a case study through which I explore how social constructions of categories like “compliant” and “non-compliant” work to transform subjects into particular types of citizens. Public health officials and epidemiology – the discipline that bridges clinical research and public health - play a central role in determining how we understand such categories.

Chapter 5 traces the way in which scientific debates about cognitive impairment, nature, and the brain in relation to HIV trickle down into the everyday practice of the clinic, particularly into medical discourse, and how they affect therapeutic interventions in the inner city. I examine two emergent themes in clinical and epidemiological discourse surrounding HIV and adherence in the inner city: (1) the link between the brain, visual biomedical technologies, and ability and (2) the emergence of a discourse of the “chaotic” and its relation to rationality. Drawing on ethnographic vignettes from different clinic and DOT settings, I highlight the similarities between these and colonial medicine.

Chapter 6 examines pharmaceuticals and prescribing practice. Specifically, I examine the contested development and use of two sets of therapeutic guidelines for HIV: (1) the International AIDS Society guidelines and (2) the localized BC Centre for Excellence in HIV/AIDS guidelines. Here I examine the contested nature of these

guidelines and the ways in which particular types of scientific evidence are contested, negotiated and peripheralized in the development and deployment of these guidelines. In which ways does industry's role in clinical trials influence these therapeutic guidelines? How do clinicians account for experience and personal knowledge in the deployment of these scientific guidelines in everyday practice? I examine ethnographically how international guidelines based on 'objective' scientific criteria may be unevenly deployed across local settings.

Chapter 7 documents the cultural politics of clinical trials for preventive AIDS vaccine and other experimental HIV medicines in the BC context. I consider the multiple ways that experimental clinical trials are framed and received within the Downtown Eastside community. I suggest that the controversy and debate that the vaccine trials evoked in the community need to be read within the specific socio-historical context of the Downtown Eastside - the particular requirements of vaccine clinical trials, the history of medical research in the community (and with similarly oppressed groups in Canada), and a growing suspicion of industry-sponsored clinical trials globally. I ask a number of questions, including: What is the value of medicines? What is the value of life in the inner city? The Downtown Eastside has become the site of intense surveillance because of its "drug problem," but what role do "ethical pharmaceuticals" play in this drug economy?

Chapter 8 concludes the dissertation with a reflection on how power operates in the Downtown Eastside space through medicine, clinics, and discourses about non-compliant patients. I suggest that power operates in ways that cannot be accounted for

through a strictly Foucauldian analysis. I turn to Peter Redfield to consider whether there is a “motivated truth” in the medico-scientific knowledge being produced in and about Vancouver’s inner city. I end with a reflection on the possible unintended consequences of my own research and the implications it has for future ethical critical ethnographic practice.

## **CHAPTER 2 STUDYING UP AND UNDER IN ETHNOGRAPHY: METHODOLOGICAL AND ETHICAL CONSIDERATIONS WHEN “SOFT” SCIENTISTS STUDY “HARD” SCIENTISTS**

As anthropologists we are acutely aware of the difficulties in doing research that is not only ethical by institutional research ethics committee standards but also morally responsible to the individuals and communities with which we work so closely. Our tainted anthropological history, in which our academic ancestors aligned themselves with imperialists, colonialists, and the CIA, or were simply unethical on their own, means that our research and its product is particularly closely scrutinized – as they should be. Our representations of those we write about is criticized for being too romantic, too critical, unfair, or downright incorrect. To make matters more complicated, our methods of research, specifically “participant-observation,” seem illusory, confusing institutional review boards and complicating their mandatory informed consent process. And, as I highlight in this project, research “subjects” are increasingly savvy, more practised; and yet, for those of us doing research among economically and politically disadvantaged and impoverished communities, they are also poorer, sicker, and more peripheralized from the centres of power.

Post-welfare inner cities pose unique challenges to ethnographers as they are communities that are often characterized by poverty, illness, and dispossession. In this chapter, I discuss just a few key ethical issues that I negotiated during fieldwork. In part, I do this by outlining the methods that I engaged as an ethnographer exploring the relationship between medical research, treatment for HIV, and the state. This chapter is

an attempt to highlight the challenges that I faced, struggled with, and attempted to address in a manner that was sensitive and respectful to those individuals who gave graciously of their time. I came to think of my ethnographic research as “schizophrenic” in nature: I was continually forced to negotiate complicated fieldsites with complicated actors, simultaneously researching “up” and “under.” I moved back and forth between Vancouver’s inner city community, the British Columbia Centre for Excellence in HIV/AIDS, St. Paul’s Hospital, Vancouver Coastal Health Authority offices, and other disparate sites relating to HIV treatment and research – a constant negotiation between privilege and poverty.

While the Downtown Eastside community is perhaps best known for its informal sex and drug trade, research is a growing industry there due to its much contested practice of providing honoraria. Research is part of an informal economy in the Downtown Eastside, where residents carefully negotiate the exchange of knowledge, narratives, and blood for monetary incentives, cultural capital, and the opportunity to have their voices heard. The urban poor are video-taped, photographed, and audio-taped. Researchers collect their blood and test it for diseases and infections; map their networks, their routines, where they work; test the efficacy of new pharmaceuticals on them. And, as reported in the local media last year, archaeologists map their human waste patterns in the alleys.<sup>2</sup>

## **Methods**

Researching and analyzing a “therapeutic practice” requires a combination of field and analytical techniques. The research methodology for this project is primarily qualitative

and ethnographic. In selecting a biomedical technology, what Rayna Rapp (1999) calls a “complex cultural object,” as my unit of analysis, I turn to ethnographic methods. The strength of ethnography lies in its ability to illuminate the effects of biomedical knowledges and practices on the everyday; it allows us to see how the quotidian practices of public health and biomedicine affect the daily lives of the urban poor both inside and outside the clinic, hospital, and/or doctor’s office. For example, epidemiological research on adherence in the Downtown Eastside relies on data provided by clinical staff who dispense medicines. But what epidemiological methods do not account for is the way in which clinical staff measure and track adherence. Often under-staffed, exhausted, and overworked, nurses lose track of patients, forget to closely track daily attendance, and, on occasion, realize that records have not been adequately kept and must rely on memory or guess work to update them. These idiosyncratic record-keeping practices are not accounted for in traditional health research methods. An ethnographic account of adherence forces us to recognize the inconsistencies in everyday clinical practice and record keeping.

Ethnography also allows us to see those we research as part of larger social, political, and economic contexts (Reinharz 1992). “Multi-sited” ethnography (Marcus 1995) describes anthropologists’ shift away from traditionally bounded categories of analysis to expanding fields that are “open-ended and unbounded” (Rapp 1999, 12; Heath 1998).<sup>2</sup> This model has aided anthropologists in developing new methodological frameworks that account for the messiness of new objects of inquiry or those subjects that are particularly slippery. Building on Marcus’s work, Kim Fortun (2001) has developed the notion of an “enunciatory community.” In her study of advocacy in the aftermath of

the Union Carbide disaster in Bhopal, Fortun, out of frustration with the stakeholder model – which could not account for the diversity or complexity of what she witnessed in Bhopal - developed “enunciatory communities” as a new model. She explains that enunciatory communities are sometimes tied to one locale and that at other times they are more scattered; they may share certain interests but do not necessarily understand them in the same way nor attach the same meanings to them. A shared interest may not even be the tie that binds an enunciatory community together; rather, Fortun suggests that what binds it is a response to a double bind, or what she also calls a “temporally specific paradox” (11). According to her, enunciatory communities do not exist without double binds. This notion of the enunciatory community proved useful for my own project, which explored double binds produced by an HIV/AIDS epidemic in a nation in which HIV is quite easily treatable. This notion allows us, as researchers, to account for the movement of biomedical technologies and knowledge in a way that “multi-sited” ethnography does not.

In a similar vein, conceptualizing my object of study - pharmaceuticals for HIV (usually antiretrovirals but, on occasion, biologics) - as a “travelling work object” meant that I was forced to follow “it” as it moved from research lab to inner-city health clinic to conference to hospital to the body (Clarke and Star 2003; Heath 1998). I followed HIV therapies as they moved through multiple social spaces: the site of development, deployment, and lived experience. As a means of laying out a coherent methodological map for this project, I conceptualized my fieldsite as being composed of these three spaces that, respectively, corresponded to the sites of development, deployment, and the lived experience of HIV treatment.

The first site of research for this project is the British Columbia Centre for Excellence in HIV/AIDS. As part of a series of interviews with experts in the field of HIV treatment I interviewed nine researchers and/or administrators from the Centre for Excellence. All of these interviews but one were audio-taped and transcribed. I observed two of the Centre's HIV specialists, who are also clinicians, during clinic. I also attended seminars (c.g., Works in Progress at St. Paul's Hospital, HIV/AIDS semi-annual updates), rounds (AIDS rounds at St. Paul's Hospital), and conferences where the Centre's researchers presented their findings on therapeutic delivery (Canadian Association of HIV Researchers Conference, International AIDS Society Conference, and the International Harm Reduction Conference). Many of these presentations are taped and are available for viewing on the Centre for Excellence's website, which provided easy access to presentations that I missed attending in person due to conflicting commitments. A large part of my analysis of the Centre's work stems from a close reading of its prolific publications list. My understanding of the Centre and its research practice is also indirectly informed by two years of informal discussions with researchers, clinicians, graduate students, and medical students who have positions or affiliations with it.

Directly connected to the Centre is the John Ruedy Immunodeficiency Clinic in St. Paul's Hospital, where staff and clinicians graciously allowed me to conduct naturalistic observation in the clinic. The Drug Treatment Program delivers antiretrovirals through the Ambulatory Pharmacy at St. Paul's Hospital. I spent time in this pharmacy conducting naturalistic observations and talking at length with the pharmacists about the delivery of antiretroviral therapy. As part of my research on the



Centre I interviewed four pharmacists that were attached to it. As the fieldwork progressed, I became increasingly aware of what an important source of information pharmaceutical sales representatives could be. They, perhaps better than anyone, know the prescribing trends among physicians. As potential sources of funding for research, these people also have an interesting view into research projects and practice. I talked at length with a number of them, often over lunch; they represented companies like Pfizer, Roche, GlaxoSmithKline, and BMS.

The second site of research is the “state” – that is, public health organizations responsible for funding HIV care and/or providing the actual delivery of HIV care. These include the Vancouver Coastal Health Authority, the provincial Ministry of Health, Health Canada, and Providence Health Care (specifically, St. Paul’s Hospital). A field placement with the Vancouver Coastal Health Authority’s Division of HIV/AIDS, Addictions, and Aboriginal Health provided me with ideal opportunities to observe the inner workings of public health administration. As part of this component, I formally interviewed ten health administrators and/or clinicians from the Vancouver Coastal Health Authority (specifically in HIV/AIDS and/or Addictions) and St. Paul’s Hospital, and I also attended meetings related to HIV, addictions, and the delivery of services to Downtown Eastside residents. Two of the clinicians also provide HIV treatment in the Downtown Eastside at the Pender Health Clinic. At St. Paul’s Hospital, I conducted participant observation on the 10C ward, known locally as the “AIDS ward,” where one of the main attending physicians is also a researcher with the Centre for Excellence. On the AIDS ward I shadowed nurses, attended staff meetings and morning rounds, and talked with clinicians about providing treatment to those deemed “hard-to-reach.”

The third site of research is the Downtown Eastside. Between February 2005 and July 2006 I interviewed forty-five HIV positive residents of the Downtown Eastside at least once (but up to four times). Twenty-three of those were men, and twenty-five self-identified as Aboriginal. These audio-taped interviews were semi-structured, open-ended, and usually lasted between forty-five minutes and two hours. During the interviews I collected basic demographics, brief life histories, health status information, treatment regimens, and histories of involvement with research projects. The participants included those enrolled in DOT programs, those who had chosen not to participate in DOT, those who were refusing (or had been refused) any HIV treatment, and those who were seeking alternative treatments. Many participants asked to do follow-up interviews and/or invited me to participate in health-related appointments, where they introduced me to their health care providers. This enabled me to observe participants as they negotiated their daily therapeutic regimens. I attended doctor's appointments, diagnostic tests at the clinic, and advocacy meetings with these people, who included drug users, sex workers, and people living with AIDS. I also often spent time walking around the neighbourhood with them, relaxed at clinics with them, went to their homes/rooms, and had casual conversations with them over lunch and dinners at the Ovaltine Café.

I also interviewed nine front-line health care providers who work directly with people who have HIV. These included social workers, nutritionists, nurses, and clinicians working with both clinics and non-governmental organizations in the community. I spent a considerable amount of time conducting naturalistic observation at two inner-city clinics providing HIV treatment (specifically, directly observed therapy) – the Vancouver Native Health Society's Positive Outlook Program and the Downtown Community

Health Clinic's Maximally Assisted Therapy (MAT) Program. At these two clinic sites I attended staff meetings, read through minutes from past meetings, and observed health care provider-patient interactions. I also conducted participant observation at the Portland Hotel Society's front desk (one of the places responsible for observed medicine delivery) and the Dr. Peter Centre. While the latter is not located in the Downtown Eastside, it does offer a modified DOT program. There, I spent many days conducting naturalistic observation at the Day Program's nursing station, where I talked informally with patients picking up their medicines, observed patient-health care provider interactions, and talked at length with nursing staff.

In the Downtown Eastside, I also observed a handful of clinicians who specialize in inner-city health and HIV care during a day in their clinics. One of the physicians invited me to spend a day with him in his Surrey practice for purposes of comparison. During the day in Surrey, I observed the clinician and a visiting HIV consultant who happened to be there for the day. During my visits to the various clinics, I was continually involved in informal discussions with staff and patients. Following ethnographic practice, I kept detailed field notes on all conversations, observations, and interactions in the field.

A number of health administrators and clinicians requested that our interviews be done "off the record," and they asked not to be taped or identified as having contributed to my research. Sometimes participants paused the audio-recorder when they wanted to speak frankly about an issue. At other times, HIV researchers and administrators were pleased to talk on the record and asked that their comments be directly attributed to them.

In such a small fieldsite, it is difficult to guarantee anonymity to all participants, particularly senior-level administrators and specialized health care providers. When possible, I use information and direct quotes obtained from publicly available sources such as publications, conference presentations, online video, and transcripts from news-radio interviews. I have followed traditional ethnographic practice in using pseudonyms and, where possible, otherwise rendering participants anonymous, whether they be clinicians, health care providers, or HIV positive residents. In cases where administrators or researchers have requested that their comments be attributed to them, I have done so.

### **Practised interviews and Informed Consent**

Conducting research in the Downtown Eastside means that many of the research participants will consist of people who struggle with addictions and untreated mental illnesses; who have histories of violence and abuse; and who are often emotionally distraught. This results in extremely exhausting and emotional interactions for both researchers and participants. It is important to be particularly cognizant of power imbalances, while, at the same time, recognizing the agency of participants to negotiate research – especially among those who are well-practised as research subjects. In Vancouver's Downtown Eastside, research has become a lucrative industry for local residents. They may participate in many different research projects, including those involving interviews, focus groups, surveys, and life histories as well as those that, through social insurance numbers and/or the provincial health insurance records system, track health service access, prescription trends, and other health performance indicators. Some are quite used to answering probing questions about their sexual practices (research about sexually transmitted infections, sexuality, sex work), illicit drug use (what kind of

drugs they use, how often they use them, where they use them), violence, and criminal activities (dealing drugs, selling sex, assaults, and so on). Many research participants have also participated in research projects as community-based researchers or research assistants, where they are trained in research methods so that they can facilitate focus groups, give surveys, and/or conduct interviews. This is part of a growing trend towards capacity building within the community, and it satisfies funding agencies that require researchers to “meaningfully engage the community in the research process.” As a result, many participants in the Downtown Eastside have become particularly savvy when it comes to negotiating the research encounter.

Practiced research participants remind us to question the role of performance in the interview, especially among vulnerable individuals who are embedded within a web of state surveillance and who are regularly required to tell their stories of trauma, suffering, and abuse – to police officers, social workers, doctors, mental health workers, and judges. They tell the stories they think we *want* to hear – stories of violence, rape, childhood abuse - often playing down times of happiness, health, and love. Recently, I was working on an unrelated community-based research project where community-based research assistants were developing their own interview schedule in order to explore questions around HIV and Aboriginality. These research assistants decided to ask questions about drug use history and sexual practices. When asked why they wanted to include such seemingly unrelated questions, they said: “*We* always have to answer those types of questions.” And, indeed, personal questions have become normalized not just by research but also by multiple layers of medico-juridico surveillance.

One result of this normalization is that many of them have become “bored” by the informed consent process. When we are dealing with people who have learning challenges and addictions, the informed consent process becomes fraught with ethical tensions, requiring delicate negotiations between researcher and participant. In Chapter 7, I reflect on the challenges involved in offering intensely impoverished women a monetary incentive to provide meaningful voluntary and informed consent in AIDS vaccine trials. I face a similar ethical challenge in my own work: how do we reconcile value and values while conducting ethnographic research in impoverished communities?

### **Value (\$) and Values in ethical research: Honoraria**

In November 2006, at the American Anthropology Association Annual Conference in San Jose, California, Nancy Scheper-Hughes, speaking about her research among traffickers in the illegal organ trade, commented that her research participants were starting to ask for large sums of money, as much as \$500, as payment for their stories. She commented that they had nothing left to sell once they had sold their kidneys - nothing but their stories. This reminds us – or should remind us - of our complicity in the commodification of their lives, their suffering, and their bodies. Scheper-Hughes (1992, 28) advocates for “good enough” ethnography: “where we struggle to do the best we can with the limited resources we have at hand – our ability to listen and observe carefully, empathically, and compassionately.” This is increasingly difficult in this intensely commodified world, where research resources seem abundant compared to those of the people we study.

One of the most significant challenges I encountered in the Downtown Eastside involved trying to negotiate the research encounter as an economic exchange (honoraria are provided to all research participants). During the informed consent process, participants are notified that they will receive a twenty-dollar honorarium for each interview, as is standard research practice in this community.<sup>3</sup>

Before I continue, I want to state explicitly that, for me, as a researcher, it is very important to provide honoraria to the impoverished men and women with whom I work in the Downtown Eastside. I do, however, want to problematize the practice of providing honoraria in the inner city, which seems, in most cases, to be adopted without reflection or debate. The practice of providing honoraria, or a financial incentive, to research participants has become a firmly entrenched practice in the Downtown Eastside. Some researchers also provide food, cigarettes, and transit for participants. The honoraria rate depends on the research project, the type of participation (e.g., survey, interview, or focus group), and the amount of time required. Twenty dollars for a short interview would be considered fair; but it is not uncommon for projects to pay as much as fifty dollars plus food and bus tickets. Providing honoraria is said to ensure, or at least to encourage, participation: how else to bring forth the peripheralized voices of the urban poor? Honoraria are also meant to provide compensation for a participant's time, knowledge, and patience - not to mention the inconvenience of having researchers delve into her/his life. Finally, honoraria are thought to be a way of directing tangible resources to disadvantaged communities.

Providing a set payment for an interview, a focus group, or a survey, while still contentious, is a much easier task than trying to negotiate payment for participant observation. My fieldwork often took place in clinics specializing in HIV treatment, which meant that, on any given day, I would have multiple informal conversations with local residents, observe multiple interactions between patients and health care providers, and be told dozens of stories in passing. On occasion, as I sat there chatting to someone in a clinic hallway, he or she would ask: "Is this an interview? Can I get paid?" I tried to fairly compensate individuals for their time and knowledge, if not with a formal honorarium, then by driving them to appointments, providing them with lunch or dinner, or some other form of assistance.

In some places, such as New Zealand, research findings that have derived from having paid informants is considered biased. Yet, as anthropologists, we have a long history of exchanging goods and services with our research communities, either directly or indirectly, as payment for the patience, time, and support of those with whom we work. However, as we work in a world that is defined more and more by disparities in wealth and by mass consumerism, with everything being for sale, the question of our financial responsibility to those we study becomes central to our ability to negotiate ethical research practice. This was poignantly illustrated by Ruth Behar when she tried to reconcile her responsibility to Esperanza, a poor Mexican peddler. Behar purchased televisions, school uniforms, and birthday presents for Esperanza, painfully aware of her own privilege as she watched her son go to school in fresh clean clothes that had been washed in the city so as to avoid the sewage-contaminated local water. Research participants share their lives, their stories, and their time with us. We are, as Behar



explains, “literary wetbacks,” taking stories across borders, visible and invisible, where the poor and marginalized cannot traverse. As she says, “the question will be whether I can act as her [Esperanza’s] literary broker without becoming the worst kind of coyote, getting her across, but only by exploiting her lack of power to make it to el otro lado any other way” (1993:234).

In the Downtown Eastside, research is a formalized transaction, an economic exchange. But how do we measure and evaluate the debt we owe to those we research – both during fieldwork and after fieldwork? What is the value of knowledge today? What is the value of their suffering, disease, and stories of trauma? How can we ever know how to fairly compensate the poor for their knowledge? While the research industry in the Downtown Eastside has provided a source of new income to local residents, in addition to some community capacity building and training, we must reflect on the capital being produced by their ongoing suffering and disease – not just economic capital but the cultural capital we reap through conference presentations, publications, and research grants. We should also ask ourselves how our payment for blood, histories, and narratives contributes to the commodification of their bodies and their lives. Paradoxically, inner-city residents are seen by many as having “no value” as citizens, yet they are embedded in multiple and powerful overlapping global economies – prostitution, welfare, drugs, and research. Marginalized from formal economies, they sell what they can – their bodies, sex, photographs, drugs, blood, and stories. As researchers, we, too, engage in the commodification of their bodies as we barter with them, asking them to recount stories of bodily violence and disease for cigarettes, coffee, or twenty dollars. The practice of

paying for knowledge makes it difficult to extrapolate what Tomaselli (2003) refers to as the stories they have to tell from the stories they have to sell.

Their state of impoverishment, combined at times with powerful addictions, forces us to consider the relationship between providing honoraria, encouraging participation, and coercion. These situations are very difficult to negotiate. There are no hard rules; we are forced to find individual solutions along the way, to continually rethink our positions as researchers and our relationships to the communities in which we spend our time. I have watched women and men sit through interviews because they needed the money, even when it was clear that they did not want to answer my personal questions about their health. I have been approached by women who, crying and dope sick, beg to participate in interviews. And in the field I was asked almost daily for spare change, an advance on the next honorarium, or the chance to do an interview. Local residents whom I had never met would approach me and ask if they could do the “survey.” They did not know who I was, what I was asking, or what I would do with the information: they simply needed the money. After a few months in the field, I started avoiding the inner-city DOT clinics the few days before the monthly income assistance pay day because I could no longer handle the mass of people that would approach me asking to do a survey, interview, or focus group. There was such urgency in their pleas, and, burdened as I was with a “privileged” guilt, I simply avoided the situation, using those days to attend meetings at the Health Authority or St. Paul’s.

As a single graduate student living on a limited budget, I felt sick not giving money to those with whom I worked when they asked for it. HIV positive, living in

substandard housing or homeless, often Aboriginal: I felt an intense guilt for having a home to go to, a hot shower to take in the morning, a bed to sleep in. Daily I struggled to figure out how to combine the practice of offering honoraria with conducting research in communities of intense suffering.

As anthropologists we are acutely aware of the imbalances in power between research institutes, researchers, and those who participate in our research; however, I do not mean to suggest that the individuals or communities with which we work are unable to negotiate or resist our research practices. Research participants are agential – especially in communities like the Downtown Eastside, where they have been involved in many projects and have become practised research informants. We know that participants may accept, ignore, resist, or protest our probing questions. Local residents who have become accustomed to the research industry and who have been forced to develop creative survival strategies are talented negotiators in the research encounter, demanding larger honoraria sums or other incentives. And they control the interview process, setting time lengths, refusing to answer certain questions, telling you the stories *they* want to “sell and tell.” Participants are not powerless in the research process; they choose to reveal and conceal personal information from the researcher. Indeed, some of those interviews in which women and men stayed to participate were often characterized by one-word answers or a simple shrug of the shoulders. At times frustrated, I would tell participants that if they didn’t feel like doing the interview that day we could reschedule and they could still keep the honorarium. Even then, they would often stay for at least forty-five minutes, perhaps afraid that, if they didn’t, they would not be invited back for another interview.

Research does offer many economically and politically disadvantaged individuals a means to voice their concerns, a way to tell their stories, a way to be heard in a world that has given them little space or opportunity. Many participants, including high-level administrators, clinicians, and HIV positive residents of the inner city, told me that they found the interview process to be therapeutic. They were glad of the opportunity to voice concerns and frustrations about public health care, local politics, and personal relations. More often than not, I was surprised by the amount of information people shared, the amount of time they gave me from their busy, hectic schedules.

### **Doing critical research on public health**

Bruno Latour (2004) has recently suggested that critical research has taken us farther away from, rather than brought us closer to, the place we hoped to be. He suggests that the critical researcher's obsession with uncovering the myth of scientific authority and certainty has led us astray. This dissertation takes up the challenge posed by Latour, which suggests that we spend less time deconstructing and more time *constructing*. The purpose of this dissertation is not to "criticize" good-intentioned individuals or institutions that are delivering much needed care but, rather, to reflect on the way in which individuals and institutions may be coerced and restricted by larger social, economic, and political forces. In other words, I attempt to explore the unintended consequences of medical research and therapeutic technologies.

This dissertation looks at an important dilemma – one that is invariably encountered when doing critical research on health services for the urban poor in a neoliberal setting: while such services offer relief from suffering, major social

restructuring ensures that it will never be sufficient as the withdrawal of support for the poor becomes state policy (Fine and Weis 1998). As a researcher who interrogates public health strategies for the urban poor, I must reflect critically on the ethics, or unintended consequences, of critical research that explores healing practices and HIV research. This is particularly important when conducting research with populations that, in an increasingly neoliberal climate, are often considered “untreatable.” It is difficult to challenge or critically reflect on treatment because of its “caring” objective - to heal (Kaufert 2000). In the Downtown Eastside, where many continue to die of AIDS and to succumb to HIV-related deaths, where the budgets of health services are more and more constrained, a “critique” of existing public health practices is a particularly delicate task, requiring a great deal of sensitivity; otherwise, we run the risk of creating unintended bedfellows – ones with whom we might not feel too comfortable.

This is a very real practical dilemma in the field. Many organizations in the Downtown Eastside have either had their funding reduced, cut altogether, or have been unable to lobby for new funds to cover growing program costs and patient needs. There is a very real concern that to critique a program being offered in the Downtown Eastside is to give funders or administrators a justification for cancelling programs or withdraw funding. This is particularly the case for programs that are considered experimental or for those that seem to push the limits of public support. The supervised injection site is a good example. Prime Minister Stephen Harper and his Conservative members have been particularly unsupportive of this facility. In September 2006, after announcing they were extending the exemption that allows the site to legally stay open only until 31 December 2007, they said they were cutting the funding for the evaluation (to the Centre for

Excellence) but, at the same time, were requesting more research from other sources. Perhaps concerned that the ongoing evaluation (from 2003 to 2006) of Insite provided by the Centre for Excellence, which has been generally glowing, was biased or “ideologically driven,” the Harper government is keen to see other research on the site. In May 2006, Julio Montaner, the Centre’s director and, thus, the person responsible for the evaluation of the supervised injection site, was reported to have said that Insite was “the single most successful project he had studied.”<sup>4</sup>

But, as anyone who works in the Downtown Eastside knows, putting forth even the slightest critique of Insite is met with serious resistance. On occasion, during discussions about the facility, I expressed concerns about it. In response, graduate students or researchers from the Centre of Excellence told me that I would be called the “nutty anthropologist” if I expressed these thoughts. At other times, I was called a “Conservative” and accused of not supporting innovative urban health initiatives. Health researchers reprimanded me for voicing any concern at all about Insite, even though my general comments were never critical of the actual site, and I was told that my not supporting it would be “politically disastrous.” While I do support a safer injection facility as part of a holistic, comprehensive harm reduction framework, my concern is that Insite has been fetishized and that as a result the public can no longer engage in constructive dialogue about it.<sup>5</sup> The fervour around both the site and the *evaluation* of the site forces us to consider the consequences of transforming a public health intervention into a “political object.”

There is no "space" to suggest that the supervised injection site sight might not be perfect, or ideal, for all community members.<sup>6</sup> And, in part, this comes from the immense cultural (and economic) capital that is invested in such a facility - health research centres, federal and provincial governments, immense amounts of funding, research grants, NGOs, individual political and research careers. Other researchers or clinicians who suggested that the supervised injection site had a *detrimental* impact (e.g., increasing bacterial infections) are publicly ridiculed,<sup>7</sup> labelled as insane or nutty, and scientifically discredited. This speaks to the ways in which particular forms of scientific knowledge are peripheralized from scientific and public debates (a topic explored in Chapter 6), but what I want to highlight here is the ethical challenge that this creates for researchers who may diverge from mainstream or "popular" opinions. Advocates and researchers working with the supervised injection site construct the debate around the site as an "either/or" argument. *Either* we have a supervised injection facility *or* people die on the street. This rhetorical strategy forces us to position ourselves as either "for" or "against." There is no in-between in the contentious world of public health.<sup>8</sup>

But it is also very clear that, in this neoliberal era, with the Conservative party in power in Ottawa, critical discussions on progressive harm reduction strategies *are* dangerous. Critiques that suggest that certain components of DOT programs or HIV treatment more generally may have unpredicted negative consequences could be the very arsenal that neoliberal politicians are seeking in their battle against the urban poor. But to reflect critically on progressive harm reduction strategies does not mean that one is "Conservative" (big C *or* little c). The purpose of critical research is to push the boundaries, to demand better harm reduction services, more critical and rigorous

research, and to contribute to dialogues in which solutions are imagined and implemented.<sup>9</sup>

Many of the public health interventions and biomedical initiatives discussed here (and their adjoining research projects) have been similarly charged with debate and controversy. Debates surrounding the use of DOT in the application of highly active antiretroviral therapy (HAART) are waged among international health researchers and medical anthropologists; controversy surrounding AIDS vaccine research is unrelenting; and the ethics of industry research and industry-funded health research continues to be debated in major medical journals. Ethnographic research on any of these issues positions one in a research field stippled with landmines.

But while we ask about the unintended consequences of medical research in the Downtown Eastside, we must also ask about the unintended consequences of ethnographic research on medicine and medical research. Anthropologists have typically been quick to raise concerns about the ethics of biomedical practices, yet there is little reflection on the ethics, or unintended consequences, of our own critical research on healing practices. As anthropologists, we are acutely aware of the ways in which our research can be appropriated and used in ways that we might not imagine – for example, as technologies of surveillance in the management of the poor and the “unruly.” I take this up in my final chapter, in which I reflect upon the ramifications of this dissertation for ethical ethnographic research.



## **Gender**

A woman who transcribed interviews for me (mostly on projects other than this dissertation) commented on my interview style. She was surprised by the “lecture” quality of my interviews, by which she meant that the male scientists whom I interviewed appeared to be lecturing me, expounding their knowledge to me. Laughing, she said that one of my interviewees had broken all previous records for the world’s longest uninterrupted monologue. She observed that, once they started talking, there was no stopping them.

While I was reflecting on this over dinner in Montreal, my dear friend and colleague, Dr. Russell Westhaver, said: “It’s because you’re girly.” “Girly,” I queried? He said, “Your handbag always coordinates with your shoes.” What Russell was pointing out was that my gender, age, class, and disciplinary background put me in a certain position vis-à-vis powerful, privileged, older male scientists. Similarly, at a conference on human rights, I bumped into one of the research prospectus examiners, a feminist sociologist, a few months after my defence. At my defence, concerns were raised that I would not be able to get access to any of the fieldsites due to the politically charged nature of my research. She asked whether I had been given access to the proposed sites? When I replied that things were moving along glowingly, she made a similar comment to that of Russell. A younger, female graduate student sincerely interested in the knowledge, the work, and the ideas of a senior, established male researcher does create a particularly productive dynamic for the sharing of knowledge.

However, just as our age and gender might enhance our access to people, places, and information it also limits it. Particular kinds of information were shared with me. I think people's willingness to talk with me was less about my "feminine" characteristics (as Russell might have it) and more about my disciplinary training. As an anthropologist, I had the distinct feeling that my work was perceived as harmless, not serious, "soft." Perhaps this, combined with being perceived as "girly" (of course, it's impossible to know whether anyone aside from Russell thinks I'm "girly"), made me the ideal researcher with whom to share stories and knowledge, but it also meant that my work was not taken seriously.

I first became acutely aware of the shift in gender from the world of Anthropology to HIV research when I attended the 2006 Canadian Association of HIV Researchers Conference in Vancouver. After a day at the conference, I was invited to join a few local researchers for a beer in the pub before the evening events started up. As I walked in and sat down at the table, I realized I was the only woman among seven HIV researchers. Indeed, the Centre for Excellence itself is a particularly gendered space, with the vast majority of senior administrators and researchers being male and the majority of graduate students being female. I was continually reminded of the gendered character of this landscape at meetings and conferences in which men were overrepresented. While my research questions do not directly address gender, I was ever-cognizant of the ways in which gender operated in my own research practice and in medical research more generally as well as the ways in which it played out in the Downtown Eastside and, indeed, in the global world of HIV/AIDS.

## **Concluding Thoughts**

The terrain of HIV research, public health interventions for the urban poor, and ethnographic research is complicated and difficult to navigate. In my own ethnographic research practice I faced many of the same ethical quagmires that medical researchers exploring HIV face in the community. More important, and to be discussed in Chapter 8, is whether or not ethnographic projects like this contribute to the very layers of surveillance upon which I reflect so critically here. What particular forms of ethnographic-scientific knowledge do we produce and what are the implications for this in such communities?

In the field I had to reconcile my inner conflict as I tried to make sense of doing research in a community already over-researched, where local residents voice frustration with the endless research projects and researchers parading around, complaining they no longer want to be “guinea pigs” as we test out new hypotheses, evaluate new drugs, and collect more stories. All of this is particularly depressing when we face the fact that all of this research has not alleviated the hunger, homelessness, or suffering of local residents.

My unease reminded me that, within anthropology, some of us are still unsettled by the practices of ethnography; we are not entirely sure we feel comfortable probing and prodding the lives of others. Nancy Scheper-Hughes (1992, 27), who has, on more than one occasion, been the centre of ethnographic debate, commented that “many young anthropologists today... have come to think of ethnography and fieldwork as unwarranted intrusions in the lives of vulnerable, threatened people.”<sup>10</sup> Foucault’s critical insight that the gaze is part of the disciplinary apparatus of governance makes us question

the force and intensity of our own gaze. We wonder how the ethnographic gaze might be part of the disciplinary power that so constrains the lives of those we study. In spite of our concerns and misgivings, many of us march forward, having reframed the ethnographic inquiry in a way that has made ethical, engaged research possible – or so we hope. This dissertation raises yet more questions about the possibilities of future ethical ethnographic research.

### **CHAPTER 3 RESISTANT BUGS, NON-COMPLIANT SUBJECTS, AND THE ROLE OF EPIDEMIOLOGY IN GOVERNING BODIES**

*Already in 1996, we had the answer to the problem. When patients took 100% of their medication, the treatment was 100% effective. The concept of adherence was born.*

-- Dr. Julio Montaner, *Forecast*, 2005

In 2005, after completing an interview with a researcher at the BC Centre for Excellence in HIV/AIDS, I was running late to get to my own doctor's appointment, which happened to be just across the street. I called to let the office know I would be about fifteen minutes late, but once I arrived and my physician entered the examining room she exclaimed, "I thought you weren't coming! You are my most non-compliant patient!" I couldn't help but smile to myself since I had just come from an interview that focused on the notion of adherence. I thought to myself, "What is it about my behaviour that has made her think that I am non-compliant?" More important, it reminded me that there is a long history of doctors' thinking about, demanding, and negotiating compliance with their patients. By no means was the concern for compliant patients limited to the Downtown Eastside, people with HIV, or the urban poor. In fact, the concept of adherence was born long before 1996, and some suggest that the concern for compliant patients dates back to 400 BCE and the Hippocratic writings.

At the core of this dissertation, and at the heart of a majority of HIV research, is the question of adherence. Both globally and locally, the biomedical discourse surrounding antiretroviral therapy and HIV focuses on patient adherence. As with tuberculosis treatment so with HIV treatment: there is an ongoing concern that poor therapy adherence will result in drug-resistant mutant strains. With HIV treatment, the

issue of adherence is considerably more complicated. Until very recently, the treatment regimen for HIV often included a handful of relatively toxic medicines that was to be taken daily – for a lifetime. Treatment for TB requires between six and twelve months of therapy, and, with the advancement of pharmaceutical science, medicines currently only need to be taken every other day. HIV clinicians are faced with a particularly difficult dilemma – demanding compliance with regard to taking medicines that often have adverse side effects and that require a lifetime commitment. This, combined with the fact that, as one HIV researcher at the BC Centre for Excellence pointed out, compliance is a challenge for anyone taking medicines – even if this merely consists of taking a two-week course of antibiotics.

The question of adherence and the compliant patient traverses many areas of HIV/AIDS: therapeutic guidelines, clinical practice, pharmaceutical science, therapeutic interventions, and epidemiological surveillance. And it has resulted in a conference that focuses specifically on adherence and HIV: the International Conference on Treatment Adherence.<sup>2</sup> It imbues every relationship the patient - or “client,” as they are now called in this consumer health care culture - has with a health care provider. Social workers, nurses, clinicians, psychologists, and epidemiologists are all concerned about whether patients are taking their medicines as prescribed. In this chapter, I examine the biomedical discourse on clinical adherence, and I specifically ask why HIV researchers are so concerned with adherence. What is the clinical basis for the emphasis on adherence with regard to antiretroviral therapy? How is illicit drug use related to adherence, if at all? I am particularly interested in what research coming out of the BC Centre for Excellence in HIV/AIDS has to say about adherence, resistance, and drug users. As leaders in the

field of HIV research and treatment, these researchers influence clinicians, policy makers, and the public. What role does epidemiology have in shaping the contemporary public health landscape of Vancouver's inner city? I examine how epidemiologic discourse constructs the Downtown Eastside resident as unable to adhere to antiretroviral therapy and the implications this might have for the delivery of care (Lupton 2000). What is the implication of the Centre for Excellence's research on adherence in drug-using communities?

### **The British Columbia Centre for Excellence in HIV/AIDS**

*1996 BC becomes the first Canadian province to adopt a triple drug therapy for all eligible patients in a publicly funded plan.*

-- *Milestones*, <http://cfenet.ubc.ca>, accessed 6 April 2006

*Since 1992, the HIV/AIDS Drug Treatment Program ... of the British Columbia Centre for Excellence in HIV/AIDS ... has distributed drugs at no cost to patients in the province.*

-- David Moore (2005, 289)

The BC Centre for Excellence for HIV/AIDS is a division of St. Paul's Hospital, and it operates relatively independently. The Centre is both a research institute (including clinical, epidemiological, and social research on HIV/AIDS) and a clinical centre (providing treatment through the Drug Treatment Program and affiliated departments like the John Reudy Immunodeficiency Clinic). Its director is Dr. Julio Montaner. He appears on the cover of *Promise* magazine -- a very close headshot shows a man about fifty years old, with salt-and-pepper hair, a greying, closely shorn beard, and a penetrating gaze. The by-line boldly reads: "MISSION POSSIBLE: Dr. Julio Montaner breaks new ground in the war on AIDS."<sup>3</sup> Montaner is an outspoken researcher who demands that HIV care and treatment be improved and delivered globally. Commenting on the global failure to deliver antiretroviral therapies to resource-poor settings, he was reported in the *Globe*

*and Mail* as saying, “It’s not ignorance. It’s not mere negligence. It’s more than a crime against humanity. It can only be characterized as genocide.”<sup>4</sup> He advocates for access to treatment for all, both locally for inner-city populations and globally for those in resource-poor settings.

Montaner is also co-director of the Canadian HIV Trials Network, which also operates out of St. Paul’s Hospital and is funded by the Canadian Institutes of Health Research, an agency that facilitates clinical trials for HIV drugs across Canada. He works as a clinician in the John Ruedy Immunodeficiency Clinic, specializing in “salvage” treatment, which focuses on treating patients who have developed drug-resistant strains and are failing treatment regimens (usually individuals started treatment before the development of triple-therapy combination regimens).

Other senior administrative and research positions at the Centre for Excellence in 2005/2006 include Dr. Richard Harrigan (director, research laboratory), Dr. Martin Schechter (director, epidemiology), Dr. Robert Hogg (director, Drug Treatment Program), Irene Goldstone (director, professional education), and Dr. Mark Tyndall (program director, epidemiology). Other researchers at the Centre include Thomas Kerr, Evan Wood, David Moore, and, more recently, the return part-time of Stephanie Strathdee. There are a number of clinicians who are directly associated with the Centre, including Val Montessori, Marianne Harris, and Rolando Barrios; however, as practising clinicians in the John Ruedy Immunodeficiency Clinic (known as the IDC), their institutional affiliations with the Centre are slightly ambiguous. The Centre’s web page



advertises that their team of researchers includes “individuals with expertise in epidemiology, ethnography, anthropology, biomedical statistics and population health.”<sup>5</sup>

Since Julio Montaner was appointed director in 2005, the Centre has been undergoing some changes to its infrastructure, and, as a result, the positions of many researchers and clinicians are a bit ambiguous. Many, if not all, of the researchers at the Centre hold multiple concurrent positions. For instance, in 2006 Mark Tyndall was not only the program director of epidemiology at the Centre but also associate professor in the Faculty of Medicine at the University of British Columbia, an attending physician on 10C (the HIV ward) at St. Paul’s Hospital, and infectious disease consultant for a number of community clinics. All of the researchers have a significant role in national debates surrounding HIV prevention, care, and treatment - specifically in relation to drug-using communities – as is illustrated by their dominant presence at national and international conferences, their prolific publications record in prominent international medical journals, and the frequency with which they are referred to in the media. Many of them participate in international meetings and act as consultants for the World Health Organization and the United Nations. They are recognized for their contributions to scientific knowledge in the field of community-based research, HIV/AIDS, and infectious diseases as well as their work with drug-using communities. All this is reflected by an impressive list of research grants from the Canadian Institutes of Health Research (CIHR), the Michael Smith Foundation for Health Research (MSFHR), the former National Health Research and Development Program (NHRDP), and various awards from pharmaceutical companies.

In the City of Vancouver, as one moves between the various HIV communities -- the Downtown Eastside, the AIDS ward at St. Paul's Hospital, the clinics, the pharmacies, the Vancouver Coastal Health Authority, the pharmaceutical industry -- one can't help but sense the powerful presence of the Centre of Excellence. Although their scientific authority is frequently contested locally by non-affiliated researchers and public-health administrators, the Centre's researchers maintain a dominant presence in national and international debates, particularly in relation to HIV and injection drug users. Their research reflects the emergence of the drug user as a particular subject requiring expert knowledge in the world of HIV/AIDS.

In 2006, as director, Julio Montaner reports to Linda Revell, who is vice-president responsible for Strategic Transformation and Tertiary Programs at St. Paul's Hospital and who reports to Dianna Doyle (who recently took over from Carl Roy), the president and chief executive officer of Providence Health Care.<sup>6</sup> In the past, researchers held positions with both the Centre for Excellence in HIV/AIDS and the Centre for Health Evaluation and Outcome Sciences (CHEOS), but recently these research centres have been more clearly differentiated.



In 1996, at the International AIDS Society annual conference held in Vancouver, BC Centre for Excellence researchers announced that providing a combination of three antiretroviral medicines was particularly effective in the treatment of HIV.<sup>7</sup> This is considered a milestone in HIV science, something that revolutionized treatment. Predictably, a brief history of the Centre's epidemiological research trajectory parallels the infection pattern within the Canadian context. Its first major epidemiological research

project was the Vanguard Project (1995), a study of HIV incidence and high-risk behaviours among young gay and bisexual men. In 1996, it launched the Vancouver Injection Drug Users Study (VIDUS). This project has followed 1,475 injection drug users for over ten years and has involved semi-annual questionnaires administered by researchers as well as HIV/HCV testing. Both the Vanguard Project and VIDUS are large, comprehensive epidemiological cohorts that have tracked research participants over many years.

In 2002, Vancouver Coastal Health Authority contracted the Centre for Excellence to evaluate changes being made in the Downtown Eastside's health services. The Health Authority funded the Community Health and Safety Evaluation Project (CHASE) for three years, from March 2002 to June 2005. Local residents were trained and hired as "peer" researchers and authorized to give surveys. With a \$600,000 contract over three years (the Centre contributed an additional \$30,000), the study surveyed four thousand residents, resulting in a comprehensive report of drug use patterns, health service access, and basic demographic information (CHASE Project Team 2005). It also links up to various health databases, thus providing researchers with endless data on prescriptions, referrals, and primary care access. The evaluation of Vancouver's Supervised Injection Site (known as Insite) is the most recent and perhaps politically contentious of the Centre's epidemiological research projects. In 2003, Health Canada announced that it was providing \$1.5 million dollars over a four-year span to the Centre to evaluate Insite, the safe injection site. The site itself and the evaluation were co-developed. Insite is a "pilot supervised injection research project," in which the delivery of health services is meshed with, in fact is contingent upon, a research agenda.<sup>8</sup> In 2006,

the federal government announced that, while it was granting a one-year extension to the site itself, it was cancelling funding for the evaluation.

The Drug Treatment Program was established in 1992 as the centralized source to distribute antiretroviral therapy in the province of British Columbia. It also provides data that become part of various “virtual” cohorts, such as the highly active antiretroviral therapy (HAART) Observational Medical Evaluation and Research Study (HOMER), the Behavioral Observational Cohort, REACH, and international collaborative cohort studies like ART-Cohort Collaboration, ART-LINC and NA-ACCORD. Robert Hogg explains how data is collected as part of the drug treatment program: “All HIV positive men and women in the current study were entered into the center’s HIV/AIDS drug treatment program when they were first prescribed antiretroviral agents by any physician practicing within the province of British Columbia. Physicians enrolling an HIV-positive individual are required to complete a drug request enrollment form. The form acts as a legal prescription and is used to compile baseline information including past HIV-specific drug history, CD4 cell counts, plasma HIV RNA levels, current drug requests, and enrolling-physician data” (Hogg et al 2001: 2569). (See figure 2). As an electronic database, the Drug Treatment Program monitors the impact of highly active antiretroviral therapy in terms of clinical outcomes. HOMER was the first of the virtual cohorts to be pulled from the Drug Treatment Program database. It includes only those individuals who were first treated with triple therapy (as opposed to mono or dual therapy regimes). The cohort expands every year and currently includes 2800 participants.

 <b>British Columbia Centre for Excellence in HIV/AIDS</b> <b>HIV/AIDS DRUG REQUEST PRESCRIPTION FORM</b> 608-1051 Burrard Street Vancouver, B.C. V6Z 1Y6 Phone: (604) 806-8515 Fax: (604) 806-9044		
This form is to be completed by the physician at the time of the initial drug request. Additional assistance can be requested by calling the toll-free number 1-800-665-7877		
		CFE: _____ <small>For further use only Patient Email J</small>
<b>I. PATIENT AND PHYSICIAN INFORMATION</b>		
Patient: (First or Given Names)		(Family Name)
Patient's Address:	Phone #:	Gender: Male: _____ Female: _____ Due Date if Pregnant (aaw)
Postal Code:	Province:	DIAND #:
Personal Health Care Number:		Date of birth: DD / MM / YY
Which hospital pharmacy/site would the patient prefer to go to pick up his or her prescription(s)? St. Paul's Hospital: _____ Other approved site (specify): _____		
Enrolling Physician (Please print): Name: _____ MSC number: _____ Address: _____ Postal code: _____ Telephone number: _____		
Follow-up physician to receive further Refill Forms (if different from the physician noted above). Please print. Name: _____ MSC#: _____ Address: _____ Tel: _____		
<b>II. LABORATORY DATA</b>		
Please record serology date. Also record latest CD4 count & viral load; attach a full copy of latest lab report of each.		
HIV serology / antigen date: _____ <small>(antigen date if aged 13 months or less)</small>	CD4 Abs: _____ <small>(DD/MM/YY)</small>	CD4 Test Date: _____ <small>(DD/MM/YY)</small>
	Viral Load: _____ <small>(SPL, VGL, metro lab, etc.)</small>	Lab Site: _____ <small>(SPL, VGL, metro lab, etc.)</small>
<b>III. MEDICATION REGIMEN</b>		
Complete information including medications from Compassionate Release/Expanded Access Programs or research protocols is required for the request to be processed.		
(a) New Medications:	Dosage:	(d) Primary reason for changes to regimen. Select one (most important):
_____	_____	<input type="checkbox"/> Side effects (specify reason below):
_____	_____	<input type="checkbox"/> Patient requested change due to side effects
_____	_____	<input type="checkbox"/> Physician decision- side effects clinically necessitated change
_____	_____	<input type="checkbox"/> Consensus (physician and patient equally)
(b) Medication(s) to be Discontinued:	(c) Medication(s) to be Continued:	<input type="checkbox"/> Treatment failure (pVL rebound / CD4 decline)
_____	_____	<input type="checkbox"/> Drug interactions (eg. methadone use)
_____	_____	<input type="checkbox"/> Inability to retain medication due to persistent vomiting and/or diarrhea
_____	_____	<input type="checkbox"/> Other (please specify): _____
Approval, if granted, is valid only for the medication regimen as listed above. To avoid wastage, please finish current prescription.		
<b>IV. OTHER PERTINENT INFORMATION:</b>		
Applicable information must be provided for request to be processed.		
History of injection drug use	Yes	No
Hepatitis C positive	_____	_____
Medication Allergy:	_____	_____
Other HIV/AIDS-related or unrelated treatments, diagnosis, or other pertinent information: _____		
Continuing treatment from outside BC? _____		
Enrolling Physician's signature: _____	MSC# _____	Date: _____
Authorizing signature: _____		Authorize Date: _____
PHARMACY COPY		V20/06/2005

**Figure 2 Prescription form**  
**Source: BC Centre for Excellence in HIV/AIDS.**

In addition, the Centre of Excellence has directed a number of smaller research projects. Comparing young Aboriginal injection drug users across two sites, CEDAR is a qualitative community-partnered project under the direction of Dr. Patricia Spittal. Maka, under the direction of Dr. Mark Tyndall and funded by the Canadian Institutes for Health Research, is a community-partnered research project that emphasizes the creation and implementation of a grassroots “peer” model of care for women involved in sex work who are currently not able to access care.<sup>9</sup> Although there is an emphasis on delivering

care (the program has hired both a social worker and a nurse), to date the project has primarily served research purposes. The Centre is also currently supervising a number of students who are doing collaborative work in epidemiology and medical anthropology.<sup>10</sup>

The Centre for Excellence conducts leading laboratory research on resistance, adherence, and drug monitoring (i.e., measuring toxicities). Under the direction of Richard Harrigan, the lab explores the influence of genetic factors on HIV, patterns of drug resistance, factors influencing viral mutations, and “improving drug adherence through the development and application of laboratory-based tools that accurately detect and report non-adherence.”<sup>11</sup> The “problem of adherence” is central to many of the Centre’s research projects and is a dominant theme in conference papers, publications, and clinical interactions. In March 2007, as part of the *Forecast* lecture series at St. Paul’s Hospital, Robert Hogg delivered a paper entitled “Adherence, Survival and Missed Opportunities among People Living with HIV/AIDS,” in which he reminded the audience that, in 2003, the Centre had reported that there was a “33 fold increase in mortality with poor adherence.” He concluded that this paper was the most important one that the Centre had produced (Wood, Montaner, Bangsberg, et al. 2003).

### **Antiretroviral therapy, adherence, and drug resistance**

*The Centre has been at the forefront of adherence-related research. Over the last several years, Centre research published in prominent international journals has pushed forward the understanding of adherence-related issues.*

-- Forecast (2005)<sup>12</sup>

The BC Centre for Excellence in HIV/AIDS has produced two critical sets of findings related to HIV and adherence. The first of these is related to clinical health outcomes pertaining to issues of mortality, drug resistance, and virologic suppression. The Centre

estimates that approximately two thousand people living in the Downtown Eastside are HIV positive; at least half of these should be eligible for treatment under current guidelines (based strictly on CD4 cell and plasma viral load), yet only approximately 350 people are taking antiretrovirals. At the 2005 Canadian Association of HIV Researchers (CAHR) conference in Vancouver, Julio Montaner reported that 45 percent of the patients eligible for antiretroviral therapy were not receiving it. In 2002, Robert Hogg and associates presented evidence that illustrated that poor adherence (“intermittent use”) was associated with increased mortality (Hogg et al. 2002). They also reported that low baseline CD4 cell count was associated with mortality (which has implications for therapeutic guidelines). In 2003, in a study that examined data from HIV positive individuals who had died, Evan Wood and colleagues reported that 32.8 percent had not gained access to therapy. Within this epidemiologic cohort, those least likely to access therapy were Aboriginal, female, living in poverty, and residing in the Downtown Eastside (Wood, Montaner, Tyndall, et al. 2003). A good proportion of the Centre’s published research findings focus on Vancouver’s inner city and address questions of access to and uptake of antiretroviral therapy (often examined alongside adherence issues). Publicly the Centre voices a commitment to engaging those who are currently not accessing treatment. Accessing treatment and maintaining adherence to treatment are often co-examined in the Centre’s research as both are theorized as resulting from “social, cultural, and medical barriers” (Wood, Montaner, Bangsberg, et al. 2003). Researchers are aware of the paradox that, although British Columbia provides free access to antiretrovirals (if a patient’s clinical measures are consistent with the therapeutic guidelines), there is a startling failure to engage in treatment (Strathdee et al.

1998). They suggest that a significant number of the deaths from AIDS are the result of “poor access to therapy among disadvantaged or marginalized populations” (Wood, Montaner, Bangsberg, et al. 2003, 2). Witnessing the use of dual-combination therapy (as opposed to the preferred triple-combination therapy) and its associated poorer health outcomes, they conclude that, “since provision of antiretroviral therapy is free in this setting, prescription of dual therapy to lower income individuals must be attributed to non-financial concerns, such as physician unwillingness to prescribe protease inhibitors to patients perceived as non-adherent” (Wood, Montaner, Bangsberg, et al. 2003, 2).

In a statistical analysis of the HIV/AIDS Drug Treatment Program (the HOMER<sup>13</sup> virtual cohort), Centre researchers found that there were significant differences in virological outcomes between injection drug users and non-injection drug users. But they also found that, after taking into account adherence, that injection drug users and non-injection drug users respond similarly to highly active antiretroviral therapy. Once the model was adjusted for adherence (and sex, age, baseline CD4 cell count, etc.), they found that virological response was consistent. These are important findings because they provide evidence to indicate that there is no clinical reason to withhold treatment to injection drug users. The paper concludes that “lower rates of virological response to HAART were primarily driven by lower levels of adherence among IDUs” (Wood, Montaner, Yip, et al. 2003, 659). On this basis, the authors recommended strategies to improve adherence, including “directly observed therapy programs, access to medical services without appointment, on-site pharmacists at medical clinics and improved access to addiction treatment” (ibid.). They found similar results in terms of immunological responses. After adjusting for adherence rates, after HAART, CD4 cell



count rates responded similarly for both injection drug users and non-injection drug users (Wood, Montaner, Yip, et al. 2004). Researchers at the Centre also concluded that discordant responses in viral load and CD4 cell count were associated with increased risk of death and were, in turn, also attributable to non-adherence (Moore, Hogg, Yip, et al. 2005).

Evidence from VIDUS also clearly demonstrates that injection drug users are less likely to be adherent to antiretroviral therapy than are non-injection drug users. Findings suggest a “significant interaction between drug use and adherence” (Palepu, Tyndall, Yip, et al. 2003: 526); “interruptions in ART are common among IDUs” (Palepu, Tyndall, Yip 2001, 32B); and that individuals with a history of injection drug use are more likely to be less adherent (Wood, Montaner, Yip, et al. 2004). One study reports that 70 percent of an epidemiologic cohort was non-adherent, and this was most strongly correlated to heroin injection use (Shannon et al. 2005). In addition to injection drug users, the Centre has identified a number of other “populations” that are more likely to be non-compliant. Researchers from the Maka project concluded that HIV positive residents in the Downtown Eastside continue to experience poorer health outcomes “because of issues of access and an *inability* to adhere to medication regimes” (Shannon et al. 2005, 1 [emphasis added]). In their analysis of up-take and HAART adherence for women engaged in sex work in the neighbourhood, researchers found that, even though these women were accessing social and health services, they were not accessing antiretroviral therapy. This was primarily as a result of a lack of education and information regarding the benefits of treatment. The researchers concluded that, in addition to increased education, directly observed therapy (DOT) programs are a suitable intervention with

regard to addressing the disparities in HAART access. Aboriginal individuals are also reported to be less adherent than non-Aboriginal individuals (Miller et al. 2006).

In this set of research, adherence and non-adherence are theorized in terms of risk: Aboriginal people, injection drug users, and the homeless become risk factors (Lupton 1995; Adkins 2001). Based on these important findings regarding adherence, the Centre's researchers suggest that those assessing "suitability for ART should consider social circumstances and drug use patterns" (Palepu, Tyndall, Yip 2001, 32B). This echoes other HIV researchers, who suggest that, when deciding to start patients on antiretroviral therapy, clinicians should consider ability, or readiness, to adhere (Carpenter et al. 1997; Carpenter et al. 1998).

The importance of adherence is highlighted in a study by Harrigan and colleagues, in which they document a clear relationship between the production of drug-resistant viral strains and non-adherence (Harrigan et al. 2005). While it was assumed from the onset of the global AIDS epidemic that drug-resistant viral strains might be produced, this paper confirms a direct link to adherence. This is an important research finding not simply because it links non-adherence to drug resistance but because it notes that those most at risk for developing resistant mutations are those with an 80 percent to 90 percent rate of prescription refill. While acknowledging that prescription-refill rates are not the most accurate indicators of adherence, the authors conclude that individuals who are highly adherent but are not maintaining perfect adherence are the *most likely* to develop drug-resistant viral mutations. The same paper also highlights a secondary factor leading to drug resistance – baseline virologic and

immunologic measures. The authors suggest that low CD4 cell count and high plasma viral load at initiation of therapy is an independent predictor of drug resistance. Richard Harrigan explains that this is the only study to have such a large data set to monitor or measure this as well as the only study that reports that resistance is also formed by baseline pVL and CD4 (viral load and CD4 cell count at initiation of therapy). This is a critical finding as clinicians often delay treatment until CD4 cell counts have dropped quite low and plasma viral loads have reached high markers. In other words, they delay treatment until it is absolutely necessary because of their concerns that patients who are non-adherent drug users will develop drug-resistant viral mutations. When I asked Harrigan how his colleagues at the Centre responded to this finding, his response was: “They said, ‘What’????” (i.e., they were surprised). Drug resistant viruses are not merely an individual health concern: because drug-resistant HIV strains can be transmitted from one person to another, adherence is a public health issue (Wensing et al. 2005). These findings further support the Centre’s ongoing demand to develop interventions that increase adherence.

In August 2006, I asked Richard Harrigan whether there was any evidence regarding the impact that the development of drug-resistant viral mutations was having on long-term clinical outcomes. I wondered whether, perhaps, the impact of delaying treatment due to concerns about adherence was countered by the effect of waiting until the CD4 cell count was too low and the plasma viral load too high. In 2006, he and his colleague, Robert Hogg, published evidence suggesting “that emergence of resistance was strongly associated with elevated risk of mortality” (Hogg et al 2006, 1576). The editor’s summary explains that this research supports other findings that highlight the

need for near-perfect adherence to antiretrovirals, particularly triple-combination therapy which includes non-nucleoside reverse transcriptase inhibitors (NNRTIs).

The Centre's second set of published findings explores possible causes or determinants of a lack of adherence and recommends strategies to improve adherence. Dr. Thomas Kerr (PhD, Educational Psychology, University of Victoria, 2003) has published a series of papers that addresses psychosocial factors that contribute to a lack of adherence among patients on antiretroviral therapy. He notes that, among the VIDUS cohort sample, 66 percent of the respondents were non-adherent and that the two most common reasons given for missing doses were forgetting and not waking up at the specified dosing time (Kerr, Palepu, et al. 2004). The emphasis on forgetfulness (i.e., forgetting to take medicines) is linked to the effect of advanced AIDS on cognitive ability ("neuropsychiatric complications of HIV disease"). In 2005, Kerr and colleagues reported that, in a study of injection drug users, the most common reasons provided for stopping antiretroviral therapy were serving time in jail and concerns about side effects (Kerr, Marshall, et al. 2005). The research conducted by Dr. Victoria Alfonso and Dr. Josie Gellar also addresses the behavioural determinants of adherence in HIV care (drawing, in part, on theories of adherence among women with eating disorders).

While these studies have primarily focused on the individual (self-esteem, cognitive ability), a small portion of the Centre's research also addresses larger structural barriers - a lack of stable housing, health services, and physician experience in HIV care. Focusing on the Drug Treatment Program, researchers at the Centre found that patients were more likely to adhere to antiretroviral therapy if they were being treated by

experienced clinicians (roughly defined by the number of HIV positive patients that they were caring for) (Delgado et al. 2003). This supports other research, which suggests that adherence and clinical outcomes are shaped, in part, by the patient-clinician relationship (Stone 2001). Furthermore, the Centre reports a correlation between improved adherence and pharmacy support specific to HIV/AIDS pharmaceuticals (Castillo et al. 2004). In this study, researchers found that patients who received their antiretroviral therapy at an “AIDS-tertiary care outpatient pharmacy” were more likely to experience positive clinical outcomes (suppressed plasma viral load) than were patients who received their antiretroviral therapy from off-site (i.e., community) pharmacies or from their clinician’s office. The authors conclude that their research supports the ongoing demand for providing pharmaceutical support that specifically addresses HIV/AIDS. In British Columbia, the Centre for Excellence operates and manages the main AIDS tertiary care outpatient pharmacy, which is located in St. Paul’s Hospital. It also supports pharmacy services by funding pharmacists at urban clinics specializing in HIV care, such as Spectrum Health (full-time position), the Downtown Community Health Clinic’s Maximally Assisted Therapy (MAT) program (full-time position), and the Vancouver Native Health Society’s Positive Outlook Program (half a day every second week). In another study, researchers at the Centre found that patients would intentionally stop taking their medicines when they experienced serious side effects as a result of the antiretroviral therapy (Heath et al. 2002).

Understanding the risk factors that contribute to a lack of adherence or discontinuation provides researchers and health administrators with the tools to develop or support specific interventions, like DOT, physician education, and pharmacy support.

Overall, most of the research the Centre has published on adherence is echoed by other key scholars who are studying adherence and antiretroviral therapy. All of this work suggests that a rate of at least 95 percent adherence is required in order to suppress plasma viral load, thus resulting in the best overall health outcomes. A scan of the Centre's publications pertaining to adherence and HIV illustrates that a big proportion of research specifically addresses challenges to adherence among inner-city populations, characterized primarily by injection drug use. In opposition to earlier clinicians, who recommended that antiretroviral therapy be withheld from those individuals deemed non-compliant (due to concerns about the development of drug-resistance strains), the Centre for Excellence researchers not only advocate treating injection drug users with antiretroviral therapy but also – and this is crucial - increasing possibilities for 95 percent adherence by creating innovative supportive interventions.

The Centre's research findings on the link between active illicit drug use and adherence is supported by international HIV research (Chesney, Ickovics, Chambers, et al. 2000); however, there is some evidence to suggest that injection drug users, once engaging in therapy, are just as likely to adhere as are non-injection drug users (Mocroft et al. 1999; Ware, Wyatt, and Tugenberg 2005).

More recently, epidemiologists have linked the reduction in plasma viral load to the efficiency of transmission through sex and intravenous (IV) drug use (Quinn 2000). It is suspected that individuals with undetectable viral loads are less infectious than are individuals with detectable viral loads. Given the obvious possible ramifications for public health, epidemiologists have focused on therapeutic regimens that emphasize

compliance. At the Positive Gathering Conference in October 2006, Julio Montaner reported that the Centre for Excellence has shifted its research agenda to prioritize understanding antiretroviral therapy as a form of prevention. All other research questions and projects will now be secondary (Montaner et al. 2006). If the Centre's research continues to support earlier findings by other international researchers, there will be a continued emphasis on adherence. This is because only near-perfect adherence to antiretroviral therapy will decrease viral load, thus helping to decrease the spread of HIV-AIDS. As Montaner emphasized during his presentation, it's not about individuals, it's about the *public*. In principle, he would like *everyone* to be on therapy. In justifying the massive expenditure this would entail, he commented: "Savings generated by short term deferral of HAART are overwhelmed by costs generated from new HIV infections." And he concluded: "treatment is good for you and good for society."

The current debates regarding HIV therapy and the question of adherence reflect debates regarding the treatment of tuberculosis: does the discrepancy in antiretroviral therapy access reflect patient non-compliance or structural and/or ideological barriers that prevent patients from accessing treatment?<sup>14</sup> While the Centre's research touches upon a range of factors that contributes to level of adherence - including regimen complexity (one of the drives towards developing a once-daily pill, like Atripla),<sup>15</sup> side effects, patient-clinician relationship, clinician reluctance, patient-related factors (forgetfulness), and a host of issues related to psycho-social context (mental health, addictions, stress, hopelessness) - the majority of its publications do not address structural or ideological barriers; rather, the focus is on individual risk factors, with an emphasis on expectation of agency among patients that may be unrealistic in light of the economic, political, and

social marginalization experienced by those living in the Downtown Eastside. In 2003, Evan Wood and his colleagues suggested that cultural barriers and physician reluctance to prescribe antiretroviral therapy due to concerns about adherence were contributing factors to a lack of engagement in HAART among Downtown Eastside residents, yet the majority of their recommendations for addressing the disparities in treatment do not address these issues (Wood, Montaner, Tyndall, et al. 2003); rather, as mentioned earlier, the majority of their research on adherence suggests that DOT programs should be considered. And, as I show in the following chapter, the Centre of Excellence partnered with the Vancouver Coastal Health Authority to establish one of the current DOT for antiretroviral therapy programs operating in the Downtown Eastside.<sup>16</sup>

However, findings from other HIV researchers suggest that an emphasis on adherence in the clinic may lead to quite the opposite effect from the one desired. For example, Toni Tugenberg and colleagues suggest that a physician's over-emphasis on adherence often works to overwhelm and discourage patients (2006). Feeling incapable of maintaining near-perfect adherence and worried about developing drug-resistant strains, in some cases patients decided not to take the medicines at all. In a similar study, the same research team suggests that the over-emphasis on injection-drug use and the stereotypes associated with it ("chaotic" lives, non-adherent, etc.) worked to reinforce ill-conceived understandings about adherence among drug users, thus contributing to the stigmatization of drug users living with HIV (Ware, Wyatt, and Tugenberg 2005). These findings echo Lerner and colleagues, who insist that labelling patients as non-adherent based on particular characteristics is both inaccurate and stigmatizing (Lerner, Gulick, and Neveloff Dubler 1998). They maintain that the emphasis on the relationship between



drug resistance and non-adherence has led some health care providers to withhold much needed antiretroviral therapy. For this reason, they recommend that clinicians avoid using the language of “compliance” and “adherence.” David Bangsberg and associates, pointing to the fact that studies suggest that HIV resistance is actually drug-specific, suggest that researchers and clinicians should pay more attention to which pharmaceutical regimens are being prescribed rather than simplistically assuming that non-adherence creates drug resistance.

### **Measuring Adherence**

Researchers at the Centre for Excellence have developed two different tools to measure adherence or readiness to adhere. The first, the Adherence Self-Efficacy Measure (ASEM), was developed by Thomas Kerr and includes ten questions that address forgetfulness, time management, food requirements, side effect management, perception of outcomes from medications, and relationship to drug use (Kerr, Marshall, et al. 2005; Kerr, Palepu, et al. 2004).<sup>17</sup> The second, the Anti-Retroviral Readiness and Motivation Scale (ARMS), includes forty-two questions that address the psycho-social factors of adherence, such as “social support, self-efficacy, outcome expectancy, overall commitment, level of personal strength, drug and alcohol use/addiction, and level of depression.”<sup>18</sup> The Centre’s newsletter reports that ARMS “will be the first measurement tool to determine whether HIV/AIDS patients will adhere to drug therapy.”<sup>19</sup> ARMS researchers suggest that the tool can identify factors that contribute to one’s readiness to begin therapy.

Most researchers and clinicians will admit that adherence measurements for antiretroviral therapy are, in certain contexts, crude and/or unreliable. In most studies coming out of the Centre for Excellence, adherence is measured by medication dispensing rates, or “prescription-refill data,” as opposed to actual consumption (Harrigan et al. 2005; Hogg et al. 2002). Research on DOT programs and adherence in the Downtown Eastside relies on the charting by health care professionals, who record which patients pick up their daily medicines and how often they do so (Tyndall et al. 2006). In the larger literature, adherence is typically measured by daily pill counts (conducted by outreach workers or nurses), electronic monitoring systems, physician assessment, patient self-reporting, and pharmacy reports (how often medicines are picked up and in what quantity). Most clinicians, including those with whom I spoke in Vancouver, suggest that one of the best indicators of adherence is virologic outcome (i.e., has the viral load been suppressed?). However, as there are other factors that can influence virologic outcomes, this measurement is not entirely reliable.

Researchers at the Centre of Excellence are very aware of the limitations of such a measurement strategy. As Dr. David Moore, an HIV researcher at the Centre, explained:

The measure of adherence we have used in our analysis is extremely crude – a calculated percent of the medication which patients are dispensed in the first year of therapy compared with the amount they should need. So when we say 95% adherent we really mean that patients received 95% of medications. True adherence is probably significantly less than this, but even this crude measure is an independent predictor of survival, time to virologic suppression etc. It is helpful from a programmatic perspective, but probably not that useful for individuals physicians.<sup>20</sup>

The Centre for Excellence estimates adherence by comparing how much medicine someone should require with how much they actually pick up from the pharmacy. Such a measurement does not account for lost or stolen pills or for the everyday idiosyncratic practices of individuals. As researchers at the Centre have pointed out, their estimates of adherence are most likely very conservative (i.e., predicting better adherence than is actually occurring). Castro (2005, 1219) has pointed out that an emphasis on counting pills limits our understanding of adherence as a “complex process embedded in the clinical and social course of AIDS.” It is safe to assume that adherence is multifaceted, that it is shaped by a range of complex factors, each of which interacts in novel ways for each person.

Although it is possible to measure blood levels associated with antiretroviral therapy through therapeutic drug monitoring in the lab, this is not currently being done. Each body metabolizes antiretroviral drugs differently, and, therefore, it is difficult to know which level is ideal. However, this type of laboratory monitoring is done for pharmaceuticals associated with tuberculosis, heart disease, and psychiatric medicines. In these cases, “the patient’s own body could betray her/his therapeutic infidelity” (Green 2004, 335).

### **Increasing Adherence**

So far, changes in pharmaceutical science have resulted in the best strategy for improving adherence. Moving away from handfuls of pills with complex directions that depend on timing, food intake, and refrigeration, today’s highly active antiretroviral therapies tend to be simpler (once a day) and do not need to be taken on a full stomach. Pharmaceutical

research on antiretroviral therapy is a rapidly growing industry where new products and innovations regularly transform treatment. The once-common handfuls of pills required to treat HIV have been replaced by once or twice-daily regimes. As pharmacologists and other scientists continue to try to extend the half-life of antiretroviral therapies, there is hope that, similar to advancements in pharmaceutical treatment for tuberculosis, that eventually patients will be required to take medicines as little as every two or three days<sup>21</sup>. Part of the drive behind this research is the never-ending concern with ensuring adherence over a lifetime.

As we witnessed earlier, the Centre of Excellence's research suggests that improving adherence for injection drug users to antiretroviral therapy demands novel intervention strategies such as DOT, increased treatment for addictions, low-threshold access to medical services, and on-site pharmacists at medical clinics (Wood, Montaner, Tyndall, et al. 2003; Wood, Montaner, Yip, et al. 2003; Wood, Montaner, Yip et al 2004). Aware that, despite DOT programs, there continues to be a measurable disparity among those accessing antiretroviral therapy, the Centre has recently suggested slightly more radical options. In May 2006, the *Tyee*, an online alternative news source, reported Dr. Tim Christie, medical ethicist at the Centre, as saying: "I'd like to see us putting a bus into that neighbourhood every day that would distribute anti-retroviral drugs for HIV/AIDS and pay patients an incentive amount each time they take their medication. In terms of reducing suffering and death, we'd be on a stronger ethical footing if we were doing more outreach."<sup>22</sup> While not all the researchers at the Centre were enthusiastic about this idea, it did, in fact, echo the suggestion made by Julio Montaner a year earlier. In November 2005, the *Province* headline read: "HIV patients may be paid to take drugs

– Radical Plan: Alternative is higher hospital bills and a shorter life, experts say.”<sup>23</sup> In this article, Montaner is quoted as saying, “This is the most cost-effective medical intervention we can think of.” This intervention has not been implemented, although, as we see in the following chapters, other “incentives” – like cigarettes, chocolate, and withholding money – are used in HIV treatment in the Downtown Eastside.

Linda Akagi, coordinator of the Outreach Pharmacy Program for the Centre for Excellence, has been involved in developing an adherence kit for Canadian pharmacists, its purpose being to provide additional support to patients through pharmacies. Montessori and colleagues (2004) recommend that, as a way to increase adherence, clinicians should focus on preventing side effects that may be painful, debilitating, and/or life threatening.

Other local HIV researchers have suggested that antiretroviral therapies be delivered with methadone maintenance therapy, either at privately owned pharmacies or through clinics, also as directly observed therapy (Conway et al. 2004). Research from the Centre for Excellence VIDUS cohort indicates that adherence is improved for patients who are receiving methadone (Palepu, Tyndall, Joy, et al. 2006), and it further suggests that treatment for addiction and HIV be combined. However, the idea of combining methadone maintenance therapy with the delivery of antiretroviral therapy is a source of concern for those who worry that such a situation would be rife with possibilities for coercion (i.e., withholding methadone until patients have taken their antiretroviral therapy). Even more problematic, in light of the relatively unregulated nature of pharmacies, the financial gain to be made from methadone delivery and DOT, and the

lack of training that pharmacist technicians receive with regard to providing health care to patients with complicated illnesses and social lives, is the suggestion that DOT programs be delivered through privately run pharmacies in the Downtown Eastside. A review of adherence interventions between 1996 and 2004 concludes that there was considerable variation from one study to the next, with, overall, only a small effect on adherence (there was a slight increased effect when the intervention involved participants who were typically non-adherent) raising questions about the actual impact of these interventions (Amico et al. 2006).

### **Expert Knowledge: Ideology, Evidence and Epidemiology**

“Ideology trumps science and reason and compassion in the weird world of Harper's Neoconservatism.”<sup>24</sup> So reads the 22 November 2006 by-line of an online news source reporting on the debates surrounding federal funding for Vancouver's supervised injection site in the Downtown Eastside. Science versus ideology – an age-old debate that has recently been reignited in the discussions surrounding research funding, public health initiatives, and the rights of Vancouver's inner-city poor. Politicians, international scientists, and advocates for drug addicts campaign for harm reduction services, providing “scientific evidence” to support their demands. The Centre for Excellence, as a leader in HIV research and an evaluator of the safe injection facility, is a powerful player in this struggle. On 21 November 2006, Julio Montaner was interviewed on CBC Radio's *The Early Edition*, where he spoke about Prime Minister Stephen Harper and his Conservative government's position on harm reduction, evidence, and the supervised injection site. Montaner passionately articulated that what we are dealing with comes down to a matter of “evidence versus ideology.” The Harper government's decisions

about the safe injection site were based on ideology rather than on scientific evidence - evidence that the Centre for Excellence had so clearly provided. Montaner's implication is that the Centre's scientific evidence is free of values, ideological imperatives, and moral judgments.

To suggest that scientific evidence and epidemiologic research is "valueless," or neutral, is to fly in the face of a long history of research within medical anthropology, which carefully documents the ways in which values are embedded within scientific evidence (Nations and Amaral 1991; Nichter and Kendall 1991; Rapp 1988; Comaroff 1982). Medical knowledge is presented as "natural," as universal and ahistorical, as based on absolute truths; yet, as discourse, we know that medical knowledge, like all knowledge, is socially mediated (Armstrong 1987). The social and historical character of medicine is denied by an ideology that purports that "medical facts" lie outside of the social world, that they are somehow a priori (Taussig 1980, 5). Authorship, and the individual biases and interests that go with it, is masked. As socially constituted and mediated, we know that medical knowledge embodies certain values and norms. As Comaroff (1982, 56) explains, historically "there has been an awareness that 'factual' knowledge might imply social values" in medicine as in other fields of social knowledge. However, even more important, and perhaps less recognized, is the fact that "the latent meanings implicit in bio-medicine lie in the very assertion that it is free from the influence of symbol and value" (1982, 59). Bio-medicine's claim to be above or outside of ideology, to be "value-free," is what leads Habermas to argue that "science is ideology par excellence" (Waitzkin 1989, 224). The controlling function of biomedicine is masked by the claim of benevolence and "objectivity."

Because biomedicine is able to successfully present itself as value-free, as not ideologically driven, it is able to influence, if not control, individuals and populations. For example, Emily Martin (1990) has illustrated how, in the United States, scientific language about the body, immunity, and cure reflect gender and racial stereotypes. It's not that the clinician relays her own values in communicating knowledge to the patient (she very well might, but that's beside the point), it's that all scientific and medical knowledge is inherently ideological. Medical language is controlling (and yet liberating) in its capacity to hide and/or silence experiences encountered in, for example, the world of prenatal diagnosis and human genetics. This is true not just for patients but also for the clinicians, who are themselves limited by the assumptions, words, codes, and discourse of medicine and human genetics (Rapp 1988). As Clarke and colleagues (2003, 166) argue, it is our job as social researchers to make visible the "dynamics of the social *inside* scientific, technological, and biomedical domains."

The process of concluding that non-adherence leads to drug resistance, and the process of transforming this finding into a "scientific fact," is socially mediated. Ludwig Fleck, in *Genesis and Development of a Scientific Fact* (1979 [1935]), examines the construction and history of scientific concepts, of how we come to know scientific facts. He argues that there is no "complete truth" or "complete error" in science and that facts are made collectively, often arising from "somewhat hazy," relatively unsubstantiated pre-ideas (Fleck 1979 [1935], 23). The "fact" is not the objective fact it is often presented as.<sup>25</sup> As Latour and Woolgar (1986 [1979]) suggest, when a fact becomes a fact, the "social" disappears from it. Thus, the scientific evidence addressing adherence, drug resistance, and antiretroviral therapy is presented as being disconnected from the social,



from ideology. It is considered to be apolitical. Yet, as Deborah Lupton (2000, 34) argues, “Cultural understandings of the body, health, and the causes of disease are all integral to the epidemiological construction of facts.” This is true not only of cultural ideas about the body, health, and etiology but also of ideas about what constitutes life itself, the *value* of life (and lives), the cost of treatment, and how we perceive particular types of people. In this context, questions of adherence are intrinsically informed by understandings not only of injection drug users but also of Aboriginal peoples, the homeless, and sex workers.

But epidemiology is not only informed by subjects, it also makes subjects. As others have illustrated, epidemiology plays an influential role in “making up people” (Hacking 1999), with its classifications and enumerating functioning to constitute particular types of subjects. Its reliance on quantitative methods necessitates categorizing risk factors, groups, and behaviours. The research on adherence, the counting and tracking of Downtown Eastside residents through virtual cohort studies, produces the “non-compliant patient” as subject. In this case, local epidemiologic research constitutes the non-adherent, or “difficult-to-treat,” patient (O’Shaughnessy et al. N.d.). As objects of scientific (or ethnographic) inquiry for anthropologists, historians, geographers, medical researchers, and others, the Downtown Eastside resident is constructed and known as a particular type of subject – the non-compliant subject. The effects of this subject-making may well contribute to the very disparities in health and illness that researchers mean to prevent or eradicate (Inhorn and Whittle 2001). What is the effect of adherence research being conducted at the Centre for Excellence in HIV/AIDS? The creation of the non-compliant subject easily lends itself to the creation of programs and

technologies for governing that subject, rendering her or him compliant not only to the recommendations of the clinician and other health care providers but also to society in general (see Chapters 4 and 5). In other words, concomitant with the creation of non-adherent patients is the need to create “innovative” surveillance interventions to transform them into compliant citizens (note that the term “compliance” has now been replaced with the term “adherence,” compliance or non-compliance being considered outdated terms with negative connotations). It is in this way that the scientific production of facts about adherence and drug resistance and the non-compliant subject are mutually constitutive: each produces the other.

### **The Meaning and Politics of Compliance**

As part of their global initiative to address adherence to long-term therapies, the World Health Organization (WHO) defines adherence as: “the extent to which a person’s behaviour – taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider” (WHO 2003, 3). This definition extends well beyond simply taking one’s medicines as prescribed. Speaking of adherence generally, the WHO (2003, 7) maintains that “in developed countries, adherence to long-term therapies in the general population is around 50% and is much lower in developing countries.” According to this organization, adherence is a “worldwide problem of striking magnitude” (7). Concerns about drug-resistant TB, HIV, and diabetes have only intensified the focus on compliant patients and drug adherence as drug-resistant viral strains are now deemed to be urgent public health priorities. Interestingly, among health care professionals there seems to be little consensus regarding what groups or populations are more or less likely to be adherent.<sup>26</sup>

Social theorists have conceptualized and/or theorized adherence and non-compliance in a number of different ways. James Trostle (1988) suggests that biomedical “compliance” should be considered as an ideological construct that supports the scientific authority and power of health care professionals.<sup>27</sup> As he explains, “though presented as a literature about improving medical services, the research literature about compliance is preeminently, although covertly, a literature about power and control” (1299). Building on the theoretical framework provided by Irving Zola (1972), Trostle (1988) illustrates how “compliance” functions as a tool to enforce the social control of patients, providing clinicians with licence to demand particular types of behaviours and lifestyles. He refutes the argument that the contemporary emergence of compliance is linked to advances in pharmaceutical science in the 1950s, before which there was not enough faith in the efficacy of medicines to worry about whether or not patients were taking them; rather, he suggests that the history of compliance should be traced to the development and bureaucratization of the medical profession and to the sales strategies of pharmaceutical companies.

Baron Lerner (1997) explores the medical semantics and history of “compliance,” noting that it was originally proposed as a biomedical concept, as a way to neutralize value-laden terms like “careless,” “uncooperative,” or “recalcitrant” – terms that had become synonymous with homeless, alcoholic, and immigrants. He illustrates how the naming of the behaviour as non-compliant “reinforced the widely held cultural belief that patients who did not follow physicians’ advice were both deviant and deserving of aggressive remedial interventions” (1428), thus reaffirming the authority of clinicians. Lerner, like others, traces the historical origins of compliance to a 1974 conference at

McMaster University organized by two Canadian clinical epidemiologists – David Sackett and Brian Haynes.<sup>28</sup> Furthermore, he suggests that the rapid rise of compliance as a medical issue worth researching illustrates the ongoing debates within clinical care surrounding patient decision making. Regardless of the “empowerment of patients,” many health care providers (not only clinicians) believe that good medicine requires having a certain degree of control over the patient. As Lerner proposes, it seems that compliance is a question of control and resistance.

Jeremy Greene (2004a) traces the history of compliance research to just after the Second World War. And he traces the term “compliance” to a medical sociologist, Milton Davis, who was a student of Talcott Parsons. Noting a rapid and prolific expansion of compliance-related biomedical literature in the years following the 1974 conference organized by Sackett and Haynes, Greene suggests that the reason for this cannot simply be attributed to an intensifying epidemiologic gaze and the application of new surveillance strategies; rather, the reason is to be found in the fact that the ideological power of the notion “compliance” works to reinforce the authority of physicians in the clinic. However, he also suggests that “the story of noncompliance is the story of an increasingly data-conscious medical profession inverting its critical gaze to behold as its subject the practice of medicine itself” (Greene 2004a, 342), thus providing young clinicians (trained in the social sciences) with the tools to reflect critically on traditional forms of medical authority and practice. Overwhelmingly, although in different ways, the social science literature on adherence focuses on how the concept of compliance functions as a powerful tool in the negotiation of the doctor-patient relationship.

A handful of anthropologists have explored the “problem of compliance” in clinical settings, and their theoretical framings vary (Kleinman 1978; Trostle, Hauser, and Susser 1983; Ferzacca 2000; Farmer and Nardell 1998; Farmer et al. 2001; Farmer 2000; Castro 2005; Greene 2004b). Drawing from ethnographic work on diabetes in the United States, and informed by Foucault, Steve Ferzacca (2000) theorizes compliance as a technology of self and an ethic of medical practice. Paul Farmer’s work, which is discussed in more detail in Chapter 4, is conducted within a political economy framework and identifies the structural barriers that prevent adherence in TB and HIV treatment. He recommends community-based DOT programs as interventions to address these barriers. Arachu Castro’s (2005) research on adherence attempts to bridge epidemiology, medicine, and medical anthropology, alerting her readers to the biosocial dynamics of adherence. Her emphasis is on the relationship between clinical and social processes in medicine and disease.

Analytically, I understand adherence as a “work object,” as an artefact that emerges from a particular social, historical, and political context (Casper 1994; Clarke and Star 2003), and I am interested in the ways in which it relates to questions of scientific authority (Rose 2006). What are the implications of our having constructed this particular scientific fact?

### **Concluding Thoughts**

*There's a world of difference between truth and facts. Facts can obscure the truth.*

-- Maya Angelou

In the urban clinics of the Downtown Eastside we learn that poor adherence leads to resistant viral strains of HIV. This is what the scientific evidence tells us. As a result,

clinicians and other health care providers in the inner city are hesitant to prescribe antiretroviral therapy to patients deemed particularly non-adherent (i.e., drug users, Aboriginals, the homeless). Yet, if we re-examine the evidence provided by the Centre for Excellence, we find a paradoxical logic at work.

The Centre's researchers maintain that injection drug use, homelessness, and Aboriginal status are risk factors associated with poor adherence (Palepu, Tyndall, Yip, et al. 2003; Wood, Montaner, Yip, et al. 2004; Miller et al. 2006). As a result, they recommend DOT programs, increased treatment options for addiction, and other supportive interventions (Wood, Montaner, Yip, et al. 2004; Montaner, Montessori, et al. 1998; O'Shaughnessy et al. N.d.). They also argue that health care providers should consider a patient's readiness and lifestyle before prescribing antiretrovirals (Palepu, Tyndall, Yip 2001, 32B; Hammer et al. 2006).<sup>29</sup> In some cases, this means that clinicians will not prescribe medicines until the CD4 cell count drops below 200 and plasma viral loads are high. Research on two DOT programs suggests that, on average, inner city patients were able to maintain an adherence rate of 84.5 percent (O'Shaughnessy et al. N.d.; Tyndall et al. 2007; Tyndall et al. 2006). Evidence from the laboratory research suggests that drug resistance mutations are most likely to develop with an adherence rate of 80 percent to 90 percent and with high baseline viral loads (Harrigan et al. 2005). The Centre's research on drug resistance and HIV also suggests that drug resistant strains are not a problem in the Downtown Eastside (according to a socio-demographic analysis that included postal codes) (Rusch et al. N.d.). Finally, drug resistance (specifically to NNRTIs) is associated with an increased risk of death (Hogg et

al. 2006). The Centre's local therapeutic guidelines recommend the use of NNRTIs over protease inhibitor-based regimens.<sup>30</sup>

The emphasis on delaying treatment because inner-city patients are perceived as less likely to adhere (as "not ready") means that their baseline plasma viral load increases while their CD4 cell count decreases. Combine this with DOT (which increases their adherence to an average of 84.5 percent), and the effect could be to increase the risk of drug-resistant HIV strains. Particular drug-resistant strains are likely to result in an increased rate of mortality. Many of the Centre's publications suggest that non-adherence among injection drug users is a large "public health" issue "due to the increased potential for the development of drug resistance and the transmission of resistance virus to others" (Kerr, Palepu, Barnes, et al. 2004, 407). Based on this, they advocate for therapeutic interventions like DOT. However, the research on resistance being published by Richard Harrigan and colleagues suggests that drug-resistant viral strains are not as prominent among Downtown Eastside residents as the epidemiologic research would have us believe (Harrigan 2005; Rusch et al. N.d.). If this is accurate, then DOT programs (which increase adherence to 84%) would appear to increase public health risk rather than to alleviate it.

In addition, Harrigan explained that, in a study that tracked socio-demographics and resistance, surprisingly, they found no correlation between the two.<sup>31</sup> If one thought that there would be more drug resistance in the Downtown Eastside (because drug users, Aboriginal people, and the homeless are more likely to be non-adherent), then one was proven incorrect. According to Harrigan, overall, there are probably more people living

with resistant strains in the West End (e.g., gay men on salvage therapy) than there are in the Downtown Eastside. The fact that there is no correlation between neighbourhood and resistance suggests that the emphasis on developing DOT programs in the Downtown Eastside (they are unheard of in the neighbouring West End) as part of a strategy to minimize drug-resistant viral strains is unfounded.<sup>32</sup> The finding that NNRTI drug resistance is more likely to result in death than is protease inhibitor-boosted ART would suggest that, rather than focusing on adherence risk factors, the Centre would do well to consider revising the therapeutic guidelines that recommend NNRTIs over protease inhibitors. Just when the evidence begins to suggest that the idea that poor adherence leads to resistant mutations is much more complicated than was first thought, new evidence suggests that antiretroviral therapy equates to a form of prevention in that it reduces viral load (thus demanding adherence), consequently providing more reasons for demanding compliant patients.

The Centre's researchers continue to advocate for DOT programs because there are no conclusive findings that measure the differing long-term clinical outcomes between (1) reaching an adherence rate of 85 percent and possibly developing drug resistant mutations and (2) being poorly adherent (e.g., 50 percent). It is impossible to know the long-term effects as there simply hasn't been enough research, in part because highly active antiretroviral therapy is still a relatively new treatment (compared to mono or dual therapy). Additionally, the research does not say that 85 percent adherence is the *only* rate at which resistance develops, although it does appear that this rate of adherence is most likely to lead to drug resistance. Thus, there is evidence to support the ongoing demand for strict adherence to antiretroviral therapy. However, as I have shown, the



assemblage of research findings from the Centre of Excellence does not support the theory that HIV positive patients in the Downtown Eastside are non-adherent, are thus developing drug-resistant strains of HIV, are thus posing a public health threat, and are thus clearly in need of daily DOT programs.

Yet, the one “fact” that health care providers in urban clinics continue to explain to patients is that Downtown Eastside residents are most likely to be non-adherent and that non-adherence creates drug resistance. Pamphlets at the inner-city clinics outline the urgent need for strict adherence to antiretroviral therapy. This speaks not to erroneous research findings but to the ways in which medical knowledge is translated into everyday clinical practice.

The result of the intense emphasis on adherence in HIV science, not just by the Centre Excellence but by researchers everywhere, is that clinicians may be reluctant to prescribe antiretroviral therapy to patients whom they think are not ready or capable of adhering. Although in conversation the Centre’s researchers clearly demand that injection drug users be afforded the same rights to health care and treatment as are other citizens, the emphasis on the connection between inner-city residents (i.e., injection drug users, the homeless, and Aboriginal people) and non-adherence functions to reinforce concerns about prescribing antiretroviral therapy to this population. Endless research (not only at the Centre but also internationally) documenting non-compliance among inner-city residents, coupled with the larger biomedical literature on concerns surrounding drug resistance, affects health care providers and their everyday decisions about whether or not to prescribe. While the Centre’s research addresses the disparities in HIV treatment and

access (recall that only about 350 are receiving ARV therapy in the community), it paradoxically works to discourage health care providers from starting patients on treatment. This is not necessarily a problem with the adherence research so much as it is a reflection of the disjuncture between medical research and clinical practice, a failure to understand how scientific research is produced, understood, and implemented in the clinic.

It also speaks to the power of a “fact.” How do scientists and scientific institutions come to believe their own science? How do scientists handle unknowns, ambiguities, and contradictions in adherence? We witness an interesting process occurring within the Centre for Excellence, where colleagues produce findings that contradict, or at least *complicate*, each other. While individual researchers at the Centre may be fully aware of the logic of each other’s argument, there is a powerful process at work that prevents them from changing their position regarding the efficacy DOT programs. This raises the question of how scientists come to believe their own evidence, even, or, rather, especially in the face of controversial or challenging evidence. It is possible that what we are dealing with is, in part, a range of internal interpretations of the evidence. The Centre is, after all, a social world composed of various actors; it is not a monolithic, stable entity but a site of (some) disunity. Perhaps we are dealing with a question of scientific controversy? The local HIV world of science and the larger global world of AIDS research are sites of ongoing scientific struggles, spaces of contestation and negotiation, where researchers struggle to legitimate and de-legitimate each other’s results (Fujimura and Chou 1994; Fujimura 1998). What an analysis of the adherence discourse highlights is how contested the scientific landscape is and how exactly a “fact” (such as “poor

adherence leads to drug resistance”) is constructed and contested (Figlio 1982). Scientific facts of adherence are inherently unsettled, being produced in particular historical, political, economic, and social contexts.

While social theorists have typically thought about adherence in terms of discourse or ideology, theorizing it instead as an “object” that is shared among “implicated actors” within a larger contested social arena allows us to expand our analysis beyond the clinic setting to consider the ways in which particular research institutions – in this case, the BC Centre for Excellence in HIV/AIDS - are continuously generating and regenerating the “facts” that come to make up the social category of adherence (Clarke and Star 2003). The Centre has been complicit in producing a scientific “factual” landscape about drug resistance and adherence that, although characterized by internal uncertainties and paradoxes, has a permanence and stability within clinical settings.

In the following chapter I extend the analysis of clinical adherence to the compliant patient, of whom, through DOT programs, compliance is demanded not only with regard to pharmaceuticals but also with regard to social life.

## **CHAPTER 4**

### **THE POLITICS OF DIRECTLY OBSERVED THERAPY: CHEMICAL INCARCERATION OR SUPPORTIVE INTERVENTIONS?**

“Look around: they’re the guards, and we’re the prisoners.”

-- MAT and POP program participant, 2005

#### **Introduction**

In this chapter I examine the consequences of the emphasis on adherence and resistance in the biomedical discourse surrounding HIV in Vancouver’s Downtown Eastside community as expressed in, among other things, surveillance strategies utilized in directly observed therapy (DOT) programs. These programs are marketed as “innovative,” “novel,” and supportive interventions that increase adherence, and the Vancouver Coastal Health Authority and the BC Centre for Excellence in HIV/AIDS turned to them to ensure the delivery of HIV pharmaceuticals to those whom the epidemiological literature deem least likely to comply – the residents of Vancouver’s Downtown Eastside.

I examine the adoption of DOT programs for the delivery of antiretroviral therapy by focusing on the state-sponsored DOT program known as the Maximally Assisted Therapy (MAT) program, which is one of many currently running in the Downtown Eastside. I examine the historical conditions under which this program arose. However, I am also interested in the ways in which the observation of pharmaceutical ingestion has taken on new forms in this intensely surveyed and monitored community, where DOT has been adopted for a range of both licit and illicit pharmaceuticals under the rubric of providing care and treatment to the inner-city poor. DOT takes on new meaning when the observation of prescribed pharmaceuticals is paralleled by the witnessing of illicit street

drugs in public health interventions constructed as progressive harm reduction strategies (Insite) or as clinical trials (NAOMI).

While health care is, for the most part, state-sponsored in the Canadian context, a neoliberal agenda has meant that DOT programs and the monitoring of patients is shared by or contracted out to NGOs, Christian humanitarian organizations, research institutes, and private corporations. Since the implementation of the first DOT program in the Downtown Eastside, known as the MAT program, in 1999, other observed therapy interventions have evolved, many of which are run through privately owned pharmacies (advertising “witnessed observed ingestion”) or local not-for-profit organizations. “Supportive housing” initiatives require observed therapy at their front desk, where housing residents may be required to appear up to three times a day in order to receive medicines. Not only do these programs and pharmacies dispense and observe the consumption of antiretrovirals, but they are also increasingly responsible for observing a range of prescribed medicines. In fact, observed therapy has been adopted across a spectrum of public health interventions.

This chapter is divided into three parts. First, I examine the history of DOT programs and their contentious application to the treatment of HIV. Second, I describe the various applications of DOT in Vancouver’s inner city and then focus on the MAT Program. Here, I consider the everyday clinical practices of DOT programs. Third, I consider the ways in which DOT programs function as spatializing practices whereby state-sponsored public health campaigns and medical research emphasize the containment of disease rather than its elimination. On a more general level, I am

interested in highlighting the unintended effects of these programs on health and on the everyday lives of the urban poor. I consider what such programs tell us about the relationships between public health, the value of life, and the state. How do these programs, which are supposedly aimed at addressing health, work to prescribe particular ways of life?

### **Global DOT strategies**

The basic tenet of DOT programs is that successful treatment relies on therapy adherence and that adherence is improved when observed by health care professionals. DOT programs entail supervised treatment: the participant is observed taking at least one of her/his prescribed doses, what some refer to as “supervised swallowing” (Volmink, Matchaba, and Garner 2000). DOT was created in the 1960s as a therapeutic management program used to treat tuberculosis (TB) in “hard-to-reach” populations and to prevent the emergence of multi-drug resistant TB (MDR-TB) strains associated with poor therapy compliance (Bayer and Wilkinson 1995; Farmer 2003; Volmink, Matchaba, and Garner 2000). This therapeutic regimen was inspired by therapy programs developed in Africa for the treatment of leprosy, filariasis, and malaria (Raviglione and Pio 2002). Pharmaceutical developments in the treatment of TB, particularly the arrival of antituberculosis chemotherapy in the late 1940s, revolutionized patient therapy. Long-term hospitalization in sanatoriums was no longer necessary, yet there was still a need for lengthy treatments and high rates of compliance (Bayer and Wilkinson 1995). DOT’s emergence as particularly effective public health policy has been traced back to Madras and Hong Kong in the late 1950s and early 1960s in the treatment of tuberculosis, most noticeably to Wallace Fox, who advocated for “supervised administration of medicines”

(Fox 1958; Ravilione and Pio 2002). The cost-effectiveness of such programs, coupled with positive health outcomes resulting from improved adherence, proved to be very attractive to international health experts. Soon, under the guidance of the World Health Organization Expert Committee on Tuberculosis, supervised medicine ingestion would become a standardized international strategy in the treatment of tuberculosis.<sup>1</sup> Advocated by the World Health Organization (WHO) as a standardized treatment for TB and adopted in 1990 by Canada as part of its national strategy for tuberculosis prevention and treatment (Fitzgerald 2000), DOT is a globally circulating technology with powerful implications for health, disease, and social control.<sup>2</sup> Directly Observed Therapy Shortcourse (DOTS), according to the WHO's website, is the "heart of the Stop TB strategy," and it has convened a committee to expand DOTS programming internationally.<sup>3</sup>

Historically, in Canada, DOT programs have only been used to treat Aboriginal peoples and tuberculosis. Understanding how Canada attempted to govern and treat the "untreatable" and "non-compliant" sheds light on the development and implementation of new strategies, but there is little research on these programs in the Canadian context.<sup>4</sup> Today, in North American urban centres, DOT programs are being adopted for the delivery of medicines and treatment to impoverished inner-city residents who have been deemed "untreatable" or "hard-to-reach" due to poor treatment compliance or a failure to utilize treatment initiatives (usually in relation to TB but increasingly for HIV).

### **Adopting Directly Observed Therapy for HIV: DOT-HAART**

The reported success of DOT in the treatment of tuberculosis spurred those working in the field of HIV/AIDS to consider it with regard to the delivery of antiretroviral therapy, which, as we saw in Chapter 3, according to both local and international epidemiological studies, demands near-perfect adherence. This is the case in the inner city and prisons in North American sites and in resource-poor settings like Haiti and nations within Sub-Saharan Africa. While the use of DOT is gaining popularity (HIV conferences like Conference on Retroviruses and Opportunistic Infections, Canadian Association of HIV Researchers and the International AIDS Society continue to have papers and posters reporting on the success of DOT-HAART), it remains a debated and contentious issue (Liechty and Bangsberg 2004).

On an international level, DOT for HIV is being recommended for less-developed nations. For example, anthropologists Farmer and Kim (2001) have been advocating the use of this strategy in “resource-poor settings” (e.g., less-developed countries like Haiti and Peru), where HIV treatment programs continue to be absent or highly inefficient due to the high cost of pharmaceuticals and the lack of health system infrastructures to support the programs. Paul Farmer has become a particularly strong advocate for the adoption of DOT programs globally, participating with the WHO’s HIV/AIDS committee for the study of adherence (Behforouz, Farmer, and Mukerjee 2004; Farmer and Kim 1998; Farmer, Léandre, Mukherjee, Gupta, Tarter, and Yong Kim 2001; WHO 2003). Interestingly, in August 2006, at the Sixteenth International AIDS Society Conference in Toronto, Paul Farmer said he regretted that they had used the term “supervised” in their Haiti projects, and he downplayed the visual surveillance technologies of DOT programs.



As indicated in Chapter 3, the concern that poor adherence to antiretroviral therapies leads to drug resistance and that poor adherence to therapy is directly correlated to increased plasma viral load (non-suppression of HIV RNA rates), which, in turn, leads to overall poor health outcomes, has spurred many HIV clinicians and researchers to advocate for DOT for highly active antiretroviral therapy (HAART). This, combined with concerns stemming from the epidemiological evidence regarding poor adherence rates among intravenous drug users, people who are homeless, the mentally ill, and Aboriginal peoples, has led to DOT's being increasingly adopted and adapted in the treatment of HIV among the urban poor.

Modified DOT programs (i.e., those including other intervention strategies) are quickly becoming an international biomedical strategy in the therapeutic management of HIV.<sup>5</sup> Although many of the new drug treatments for HIV are once-daily, some patients are still on twice-daily regimens. As a result, many of the programs that are being developed from DOT models are actually modified DOT programs, with only one dose per day being observed (in a twice-daily regimen). Indeed, the programs' names reflect this – Directly Administered Antiretroviral Therapy (DAART), Modified DOT (MDOT), DOT for HAART, and Maximally Assisted Therapy (MAT).<sup>6</sup> In North American urban centres like Edmonton, Boston, and San Francisco, these new enhanced DOT programs encompass social and health demands that lie outside of the strictly biomedical realm (Clarke et al. 2002; Mitty et al. 2006; Wohl et al. 2003). Modified DOT programs allow for some self-administration of medicines, while “virtual DOT” uses video-phone technology (which is installed in participants' homes) to monitor antiretroviral doses (Lucas 2001). Several of the DOT programs include cash “incentives.”<sup>7</sup> They are

considered to be just one part of a larger strategy for addressing adherence among inner-city residents, alongside, for example, changing medication regimens from twice-daily to once-daily, linking HIV treatment to mental health services and drug treatment, and creating programming that responds to the needs of patients. Medicine ingestion may be observed by health-care providers at clinics, by community-health workers, by volunteers, by “peers,” and, in some cases, by family members. In the Downtown Eastside, ingestion is increasingly being observed by pharmacists or pharmacist assistants.

The deployment of DOT programs in the treatment of HIV and inner-city populations occurs amidst ongoing debates regarding the effectiveness and feasibility of DOT for HIV *and* TB (for example, see Garner 1998).<sup>8</sup> The differences between the diseases and the treatment strategies have led others to question the feasibility of adopting DOT for HIV, especially since there is ongoing debate regarding the efficacy of DOT programs in TB treatment. For example, some researchers have questioned the outcome measurements, suggesting that self-administered therapy programs have the same clinical outcomes (Garner 1998; Volmink, Matchaba, and Garner 2000). Garner insists that these measurement models fail to identify which *part* of the DOT programs are aiding in therapy compliance, suggesting that the “supervised swallowing” component may, in fact, play a very small role. Advancements in pharmaceutical technology from complex, multi-drug antiretroviral regimens to once-daily or twice-daily regimens made the adoption of DOT programs feasible, where every dose could be observed daily. Epidemiological research indicates a high success rate (measured by scientific standards) for DOT for TB programs: compliance is reported to be either equal

to or better than it is for those not enrolled in DOT programs (see Fitzgerald 2000). Likewise, researchers have indicated a relatively good success rate for HIV treatment when used with DOT, noting improved CD4 cell counts, decreased plasma viral loads, a reduction in opportunistic infections, a decrease in mortality from AIDS, and an overall increase in general health (AIDS Alert 2005; Reynolds 2003). Touted as “effective interventions,” DOT programs are being increasingly adopted in inner-city communities of large urban centres like Edmonton, Baltimore, Los Angeles, and Vancouver as a way of reaching the inner-city poor, whom medical professionals typically define as “untreatable” or “hard to reach”.<sup>9</sup>

Yet, there are HIV researchers who have spoken out against the unilateral adoption of DOT for HAART, pointing to evidence that indicates that rates of adherence in the self-administration of antiretrovirals are equal to those found in DOT (Liechty and Bangsberg 2003). Epidemiologist David Bangsberg and colleagues (2003) have suggested that the assumption that individuals in resource-poor settings cannot adhere is unfounded and that DOT programs may be intensely stigmatizing. And, as others have pointed out, research on the success of DOT programs does not identify the components of these programs that increase adherence: is it supervised swallowing, free drugs, monetary incentives, education, free food, addictions counselling, or other components (Volmink, Matchaba, and Garner 2000)?

In some settings DOT programs are recommended as a means of ensuring that resource-poor populations have access to and are receiving treatment (Mitty et al. 2002). Clinicians and researchers who advocate for DOT programs for HIV treatment position

themselves as advocates for the marginalized, demanding rights to treatment for those deemed unworthy or undeserving of treatment by other health care professionals. For example, BC Centre for Excellence researcher Dr. Thomas Kerr was quoted in *The Tyee*, an on-line alternative news source, as saying, “Continuing to let things go on the way they are is unacceptable. From every perspective, human rights, medical and economic, we have to find ways to get more people into treatment. It’s simply the right thing to do.”<sup>20</sup> According to Sue Currie, MAT’s original program director, “We are supportive and non-judgmental – we don’t tell people that they can’t have treatment if they have hepatitis C or if they’re doing drugs.”

These researchers and health care professionals construct themselves in contrast to those clinicians who think that if you don’t take your medicines regularly, then you shouldn’t take them at all, thus denying treatment to those incapable of adhering to a strict regimen. DOT programs were favoured by most of the epidemiologists, clinicians, social workers, and patients with whom I spoke. For example, Heather Hay, director of Vancouver Community (the division of Vancouver Coastal Health Authority under which HIV/AIDS, Addictions, and Aboriginal Health falls) wrote: “Supporting people who want to take medications is a positive step forward for the health of our community as long as participation in ‘maximally assisted’ and ‘directly observed’ therapy programs is voluntary and accompanied by informed consent.”<sup>21</sup> What seems particularly interesting is that all HIV researchers and administrators support DOT programs for the delivery of HIV medicines in Vancouver’s inner city, yet there is intense disagreement regarding how these programs should be implemented, who should manage them, and what form they should take. In 2005, the Vancouver Coastal Health Authority initiated an advisory

committee to address the current state of DOT programs, with the hope of standardizing their components in the Downtown Eastside, including a range of “experts” and key stakeholders. After one meeting, it was disbanded due to intensely divisive internal politics.

### **Directly Observed Therapy in Vancouver’s Inner City**

The BC Centre for Excellence in HIV/AIDS and the Vancouver Coastal Health Authority advocate DOT as policy. Health administrators with the HIV/AIDS and Addictions Branch of Vancouver Coastal Health Authority have been working towards standardizing DOT programs that provide antiretrovirals as well as increasing the number of DOT programs regionally (e.g., there are no such programs in neighbouring Whalley, the impoverished inner-city community of Surrey, where reports of HIV/AIDS are growing). Also, the Downtown Community Health Clinic has a DOT program as part of the national strategy for treating TB.<sup>1,2</sup>

However, in Vancouver’s Downtown Eastside, DOT programs take many different forms and are often employed not only as an international public health policy developed for increasing adherence but also as part of an apparatus of biomedical surveillance. Supervised swallowing is common in the inner city, yet it is rarely spelled out in DOT’s policy language. Becoming standard medical practice among many clinicians working in the inner city, DOT has resulted in TB medicines, methadone, sleeping pills, narcotics, ARVs, even Tylenol 3s being daily dispensed at specialized public health programs or local pharmacies, where impoverished inner-city patients, who

are considered incapable, untrustworthy, or otherwise not responsible enough to handle their own treatment, are supervised and monitored.

There are two formal DOT programs that specifically target the distribution and support of antiretrovirals - the state-sponsored Maximally Assisted Therapy (MAT) program and the Aboriginal NGO-run Positive Outlook Program (POP). The Pender Community Health Centre, one of the Vancouver Coastal Health Authority clinics in the Downtown Eastside, has established a DOT program in partnership with a local private pharmacy, Gastown Pharmacy (located on Carrall Street), where antiretrovirals are dispersed in combination with methadone.<sup>13</sup> The Portland Hotel Society has a formal system of medicine observation within its Portland Hotel, and it is starting new initiatives in some of its other hotels. The Lookout Emergency AID Society is a not-for-profit organization whose purpose is to assist the mentally ill and those suffering from addictions to secure housing, and it also offers support, delivery, and observation of pharmaceutical treatment to residents of its housing facilities. There is a home nursing program run by two community health nurses, and it specializes in engaging “vulnerable patients” in treatment. It provides outreach to twenty participants, delivering medicines and observing therapy compliance.<sup>14</sup> Privately owned commercial pharmacies also offer observation of medicine ingestion.<sup>15</sup> Not only do they dispense methadone, but they are also increasingly responsible for observing a range of medicines, including antiretroviral therapy, narcotics, sleeping pills, psychiatric medicines, and more. Some pharmacies offer observed therapy through their “free delivery,” whereby a pharmacy technician provides home delivery of medicines to local residents and observes medicine ingestion in the patient’s home.

DOT programs that aim to increase adherence to antiretroviral therapy continue to be developed and deployed in the community. The most recent of these is the MAKKA project, another pilot project being supported and driven by the BC Centre for Excellence. MAKKA includes a range of intervention strategies targeting impoverished women living with HIV. At this stage, MAKKA is still in its early development stage and operates primarily as a research project (with CIHR funding), documenting “risk behaviours” associated with sex work and drug use. However, it is also in the midst of training local women as “health advocates.”<sup>16</sup> The initial long-term plan for this pilot project is that it, too, will be transferred to the health authority, where it will be incorporated into the planned regional DOT strategy. Vancouver Native Health Society, building on its Positive Outlook Program, recently received funding to establish a similar peer-based DOT program that focuses on outreach, therapeutic relationships, and the training of Aboriginal, HIV positive individuals as “community health counsellors.” This model is similar to that advocated by Paul Farmer and the Partners in Health team in Haiti and Boston (Behforouz, Farmer, and Mukerjee 2004).

Although not in the Downtown Eastside, the Dr. Peter Centre, a beautiful state-of-the-art facility located in Vancouver’s West End, also operates a DOT program as part of its Day Program in the nursing clinic. While, theoretically, the Dr. Peter Centre staff and administration serve the residents of the Downtown Eastside in addition to the predominantly gay male population of the West End, in fact the everyday policies and practices of the program mean that many Downtown Eastside residents are not “suitable” participants. Participants must be able to make scheduled appointments with the intake worker, and this is not always possible for Downtown Eastside residents. I met a handful

of Downtown Eastside residents who had attended the Dr. Peter Centre - often individuals who had moved out of the neighbourhood in an attempt to get away from the illicit drug market. But I also met individuals who had attended the Dr. Peter Centre but had been asked not to come back because of “bad behaviour.” Participants were expected to be respectful to each other and to staff – something that some Downtown Eastside residents found challenging (as is seen in the next chapter). Even though it is not located in the Downtown Eastside, the Dr. Peter Centre serves as an interesting point of comparison for the diverse approaches to providing treatment to the inner-city poor.

### **Maximally Assisted Therapy**

Brian Harrigan (until 2005 the director of Administration and Operations for the BC Centre for Excellence in HIV/AIDS) explained that, in the initial years of the Vancouver AIDS epidemic, the Centre recognized the need to develop some sort of distribution system for HIV drugs for men living in the West End. This was because, in British Columbia, HIV medicines are regulated and distributed differently from other medicines.<sup>27</sup> A centralized distribution centre was developed at the outpatient pharmacy of St. Paul’s Hospital, where HIV positive men could come in and pick up their medicines weekly and touch base with a pharmacist who offered support and advice related to management of side effects. However, as the disease began to progress and move from primarily gay men to injection drug users, the Centre witnessed new challenges in HIV treatment as it followed and researched the Vancouver Injection Drug Users Study (VIDUS) cohort. In particular, it noted that the distribution of medicines through the downtown out-patient pharmacy was not working for individuals engaged in intravenous drug use, and it needed to develop new interventions. In November 1999, the



disparity in antiretroviral use and a lack of adherence among residents in Vancouver's Downtown Eastside spurred the Centre to start a MAT program as a pilot project. A slightly modified version of DOT, MAT was conceived by the Centre as a strategy for reaching "hard-to-treat" populations living in the inner city who were not compliant with antiretroviral therapy.

The initial idea was to develop a program that provided not only medicine distribution but also a "supportive, safe environment" where people could pick up their medicines and be offered other social supports. Brian Harrigan explained that part of the idea was to attempt to show that, in spite of the ongoing debate in the 1990s regarding the feasibility of prescribing HIV medicines to injection drug users, who were considered to be "untreatable,"<sup>18</sup> these people could succeed in taking their medicines. Intravenous drug users (and people living in resource-poor settings) were thought to be incapable of adhering to the complex demands of HIV treatment. Evidence clearly indicated that, across North America, physicians were not prescribing HIV treatment to patients with chronic and acute drug histories because of (1) concerns regarding the cost of medicines and (2) concerns about poor adherence creating drug-resistant strains with larger public health consequences (Solitto et al. 2001; Bayer and Stryker 1997). The BC Centre for Excellence firmly held that drug users could adhere to complex regimens and should be treated with antiretrovirals.

Michael O'Shaughnessy, one of the co-founders of the Centre for Excellence, explained:

Well, it was a very simple idea, right? Is that, we had started to see profound changes in the outcomes of people with HIV disease who are on treatment. I mean, uh, the death rate, dropped. The numbers of people who died in the hospital went from one a day, died of HIV, went from one a day, to five a month. So remarkable change in the outlook in patients who were compliant, i.e., took drugs and took 'em when they were supposed to. So, I was sitting around with some folks and I thought - how could we extend this benefit to IDUs? To IDUs who have refused to seek treatment? And that's when we started to talk about MAT and DOT. That was the rationale behind it. We thought about it - so how could we increase the number of folks who could partake of the benefit? Pretty simple idea.

The program was started as a collaborative “pilot project” with the understanding that the health authority, then the Vancouver-Richmond Health Board, would eventually take over and provide ongoing support and funding. The project was initiated by the BC Centre for Excellence as *both* a research project and a therapeutic program. According to Dr. Michael O'Shaughnessy and colleagues: “The DOT portion of the program is part of an on-going trial protocol to compare two once daily therapy regimens” (O'Shaughnessy et al. N.d.). *Forecast*, the Centre's journal, reports: “MAT/DOT researchers are running a series of protocols comparing available regimens in terms of their effect on viral load, specifically considering the proportion of randomized patients with plasma HIV RNA <40 copies/mL at week 24 on an intent to treat basis as the primary analysis.”<sup>19</sup> Today, the MAT program, combined with the Vancouver Native Health Society's DOT program (the Positive Outlook Program), continues to be both a site of research for Centre epidemiologists and a program delivering antiretroviral therapy under observation.

Centre researchers explained that part of the challenge of establishing the DOT program involved how to attract eligible HIV positive patients. While for TB DOT is

enforceable by law, HIV treatment is “optional.” The program had to provide some sort of incentive in order both to attract patients to the clinic and to get them to engage in treatment. Patients could only attend the program if they could confirm HIV infection, were eligible for antiretroviral therapy (at that time the guidelines recommended therapy to patients with CD4 cell counts below 500 and/or plasma viral loads above 5,000 copies/mL), were “judged by their physician to be at risk for non-adherence,” lived in the Downtown Eastside, and were able to attend the program on a daily basis (O’Shaughnessy N.d.). At the time, the MAT approach was perceived to be quite innovative – a care model that addressed the needs of those living with HIV. O’Shaughnessy described the plan for attracting patients:

I worked with staff in VIDUS.<sup>20</sup> They all have been involved in the Downtown Eastside for a long time in drug and alcohol treatment programs. And so they said there was a few key things we could do. One is put a telephone in, right? Simple thing, ’cause there are no public phones, right? Um, Telus quit doing that, because - or quit maintaining and installing them - because they were robbed so often. So, that was one of the things. Um, other things are, um, we had nurses, who had been in the community, and if there was a problem they could talk to the nurse about ’em. We had, um, physicians, uh, addict-friendly physicians involved, right? So that, if they needed to see one of the physicians they wouldn’t, um, they wouldn’t be trying to stick them on methadone, or, or speak down to them. Or whatever, you know, but someone to actually listen to them. They could get lunch, right? Uh, when we, you know, talk to addicts, they said, well, how about getting something to eat, right? And I had seen the power of the food programs ... And I may have forgotten some things. But I think they were the cornerstones of it. And also you know the staff needed to be not threatening to the addicts and, you know, we never had, we never had a real problem there.

Dr. Julio Montaner, director of the BC Centre for Excellence and one of the key advocates in the initial development of the MAT program, explained that the pilot project

was envisioned as a program that would adapt to the needs of individual patients, including providing “minimal, moderate, and maximum assistance” in HIV treatment. DOT would be the top-end of a program that offered a range of support tailored to individual needs. As the son of a physician who worked in a TB hospital in Argentina, Montaner was very familiar with the DOT model of treatment and its reported positive health outcomes among TB patients. While Montaner clearly supports DOT strategies as a way of treating “these kinds of people,” he explained that the failure to adequately treat impoverished inner-city residents was, in fact, a failure on the part of the “social people” – those administrators and state actors responsible for housing, food, and support. He asked, “Why would you take your medicines if you didn’t feel like your life was worth anything? Why would you prevent others from getting HIV?” He has voiced frustration that plans to establish and develop a multidisciplinary, holistic HIV/AIDS clinic in the Downtown Eastside continue to be thwarted due to political struggles with the Vancouver Coastal Health Authority. Pointing to the success of the Dr. Peter Centre, Montaner asks why a similar facility has not been opened in the Downtown Eastside.

Fully resourced with nurses, social workers, a pharmacist, and a dietician, the MAT program sought to treat those who weren’t able to access treatment elsewhere. Sue Currie, who left the VIDUS project to join Brian Harrigan and Michael O’Shaughnessy to develop the MAT program, explained that they wanted to create a program that was a “one-stop shop,” where all needs could be addressed, where patients could “stabilize themselves.” The patients engaged in DOT at any of the programs are those deemed “ready” to engage in therapy, most likely due to CD4 cell counts and pVL, but requiring additional support with regard to taking daily medicines. In fact, it appears that if you

take HIV medicines in the Downtown Eastside, then you will be observed doing so. Of the approximately 305 people taking HIV medicines, only six pick up their medicines from a pharmacy on a monthly basis.<sup>22</sup> Everyone else is connected to a program, clinic, or pharmacy, where their ingestion of antiretroviral drugs is observed. In comparison, at the Dr. Peter Centre, the twenty patients who receive daily observed therapy have a much more fluid program. A number of them simply store their medicines in the centre's "mail-boxes" and fridge and are not required to have any contact or interaction with the nurses.

Today, Vancouver's MAT program includes registered nurses, a pharmacist, and support workers and is available seven days a week. On a weekday, staffing includes two nurses, one community health care worker, a pharmacist, and a support worker. It is located in the back part of the Downtown Community Health Clinic, reachable through a long hallway that leads through the waiting room past the offices and pharmacy. The program offers a wide range of services to men and women, including outreach, a drop-in, a free cereal breakfast, counselling and support. It has worked closely with the local community in creating a program that they consider to be "community-based." In June 2005, there were seventy-six participants in the MAT program, about thirty-eight of whom picked up their medicines daily; the other thirty-eight picked up dosettes for weekly, bimonthly, or monthly distribution. Outreach, which is conducted in the afternoon on foot, is simply medicine delivery: on an average day, within a ten-block radius of the clinic, two to three participants are tracked down and delivered their medicines. The nurses note that, during "welfare week," the number of outreach visits rises dramatically to around fifteen because patients don't come into the clinic to pick up their medicines during the few days after payday.

The Positive Outlook Program (POP) is a drop-in HIV clinic that, since 1997, has been operating out of the Vancouver Native Health Society. The original director explained that this program arose out of a need in the community. With a small staff and few resources, POP began providing outreach to patients who were having trouble taking their medications. In the beginning, it saw ten to twenty people per day; today, over two hundred people per day visit POP, searching for respite, food and nourishment, and treatment and support for HIV. POP has four outreach workers, two drug and alcohol counsellors, two nurses, and a half-time mental health worker. It offers services seven days a week and provides care, treatment, and support to all people living with HIV/AIDS, focusing specifically on the need to improve access and utilization of care for Aboriginal people. By creating an environment that is non-judgmental, supportive, and has minimal barriers, POP has succeeded in developing an integrated, innovative, and comprehensive health care model that improves the utilization of health care services and increases adherence to what are often complex therapeutic regimens. Like MAT, it provides outreach to patients unable to attend the clinic and work closely with a team of physicians who specialize in providing HIV and primary care to people living with chronic and acute addictions. As the nursing director of this program has explained, it is adaptable to the needs to the client, requires no appointments, and has an open-door philosophy.

In October 2005, POP had approximately eighty-four people enrolled in its DOT program, twenty-six of whom picked up their medicines daily, the rest doing so every three days, weekly, or biweekly, depending on the individual patient's desires. Recognizing the importance of holistic health, POP's main attraction is the daily hot

lunch, served to one hundred to two hundred people daily. Providing “incentives” to encourage participation in public health programs like DOT is a practice shared among many organizations, including those in the United States. In Vancouver’s inner city, where hunger and malnourishment are common, providing food is a powerful incentive for participants to pick up their medicines.

Early research findings from the MAT program suggest that it was effective in increasing adherence and in providing additional support and care to inner-city residents (O’Shaughnessy et al. N.d.). The Centre for Excellence continues to research the impact of DOT programs like MAT and POP on the health outcomes of participants, reporting in 2006 that participation improved adherence (overall 92 percent) and resulted in plasma viral load suppression in 83 percent of the participants (Tyndall et al. 2006). Unfortunately, such results, which are favourable for a community considered to be non-compliant, do not tell us what components of the program work to improve adherence. Recent reports from the Centre for Excellence suggest that these DOT programs “achieve a relatively high rate of adherence and plasma viral load suppression” (Tyndall 2007, 39a). The Centre’s review of the program, focused on the years between 1998 to 2004, indicates that 82.5 percent of the participants engaged in therapy were able to suppress plasma viral load (measured here with a pVL less than 500) and, more startling, that a little over 20 percent of participants died after five years.<sup>22</sup> But these researchers are cautious in claiming the success of these programs, pointing out that the lack of a “control” group for comparison makes it difficult to provide adequate measurements.

There are two ways that, in everyday clinic settings, concerns about adherence are linked specifically to drug users. First, health care providers working with Downtown Eastside residents, whether on the 10C AIDS ward at St. Paul's Hospital or in the community clinics, believe that there is a direct correlation between poor adherence and the patients' receipt of money. For individuals receiving financial assistance from the state in the form of income assistance or disability, payday occurs on the fourth Wednesday of each month. Research from the Centre for Excellence verifies that patients are more likely to leave the hospital against medical advice when they receive their monthly income assistance cheque. They concluded that, "among HIV/AIDS patients who had been admitted to hospital, those who left against medical advice were more likely to be injection drug users and were more likely to leave on days when welfare cheques were issued" (Anis et al 2002, 636). Known as "welfare day," "welfare week," "payday," "mardi gras" - or, as it was referred to by a clinician on the 10C AIDS ward - "Santa Claus Day," health care providers working with impoverished inner-city residents regularly link the receipt of funds with compliance. As two community health nurses explained: "A difficult time is 'Mardi Gras' – the day that most of our clients receive their monthly welfare cheques. The party lasts until the money runs out, which is usually just a few days. The ability of many of our more street-active clients to stick with any routine of medication or health care visits during this time is limited to non-existent. Clients in hospital often leave against medical advice on cheque issue day."<sup>23</sup> Attempts are made to address the "single cheque day barriers" in health care. For example, the MAT program increases outreach and provides "carries" (i.e., pills to go) to participants the day before they receive their cheque. At the provincial level, some positive changes



were made as a result of the Centre's research. Patients who are HIV positive in British Columbia usually qualify for disability support – about \$825 per month. In the past, if these people were in the hospital, they would only receive a portion of their monthly stipend - \$435. Recognizing that this was contributing to patients' leaving the hospital against medical advice, the government changed its policy.

Second, there is a widespread belief among health care providers that drug-using patients will simply sell or trade their medicines on the street for illicit pharmaceuticals. Some physicians demand observed therapy for drugs that are considered “valuable” on the market. And, indeed, some patients do seek prescriptions from physicians to sell on the street, as the following story illustrates. In November I attended a doctor's appointment with Cam, a young Aboriginal man who was HIV positive. Rather suddenly, about six months before, he had stopped taking his medicines when he had been banned from the Downtown Community Health Clinic's MAT program for intimidating a nurse with whom he'd had an argument. Cam was following up with the infectious disease consultant regarding his health and treatment. After the consultant concluded that it wasn't urgent for him to start his antiretrovirals, Cam asked if he could have a prescription for sleeping pills. The attending physician, clearly uncomfortable with the request, explained that Cam would have to see his regular physician for such a prescription as he only prescribed HIV medicines. Afterwards, Cam complained to me that the doctor hadn't given him the sleeping pills. When I asked if he was having difficulties sleeping, he said no, he had wanted to sell them on the street so that he could purchase crack cocaine.

Although there is a suspicion that patients taking HIV medicines may try to sell or trade them for illicit drugs or money, there is little evidence to support this. The fact that HIV medicines are provided free to all eligible patients in the Province of British Columbia means that there is no local market for HIV medicines. When I asked HIV participants whether they had ever sold or traded their HIV medicines, the majority said no, that they valued them for their healing capacity and that, in any case, they didn't think there was a market for them. A few mentioned that they had heard that if they crossed the border into the United States, it was possible to sell them there. However, the possibility of Downtown Eastside residents crossing the border in the United States to do this is so remote as to be virtually non-existent. Few participants whom I interviewed or talked with had passports or any other form of legal identification (e.g., BC driver's licence). In this post 9-11 era, crossing the American border without identification is all but impossible. Besides which, the cost of travelling to somewhere like Seattle would not be feasible for the large majority of inner-city residents. While there is a prolific street trade in both licit and illicit pharmaceuticals in the Downtown Eastside, HIV medicines are not part of it, even though they figure prominently in a complicated global therapeutic economy (Nguyen 2005).

### **Patient's Perspectives on DOT**

"Therapeutic outcomes" tell us little about the health and well-being of individuals living in the Downtown Eastside or their lived experience of treatment. How do patients in this community experience DOT? My original interest in DOT programs was ignited when I was working as a research assistant on another research project in the Downtown Eastside. During monthly interviews with impoverished women that were conducted over

a one-year span, I would hear participants comment in passing about having to get to the MAT or DOT program. When I asked what these programs were, women sometimes responded by telling me that, because they could not be trusted with their medications, they had to consume them at the clinic under the observation of a health care provider. In the years since then, I have noted that the comments of DOT program participants reflect a range of contradictory experiences associated with these “supportive interventions.”

Janice, a woman I have known for many years in the Downtown Eastside, attends the MAT program on an irregular basis. She is officially a client, but a different set of nurses delivers her medicines to her home, which means that she is not required to pick her medicines up at this site on a daily basis. I would describe Janice as a tough, strong survivor. Over the years, I have rarely seen her in a fragile state. However, in 2005, her cousin died, and she was visibly shaken. She came to the MAT program the following day and told me how glad she was to have someplace where she could come and feel supported. In the patient lounge area, she quietly mourned the loss of her cousin. During her many years of living in the inner city, Janice has attended both the MAT and POP programs, switching back and forth, depending on her relationship with staff members. She expressed a degree of resentment that her doctor would not allow her to pick up her prescription for T3s until she had a blood test. She explained that her physician now dispenses all her medicines daily as part of the MAT program. She says it's not fair to treat everyone in the community the same way – that sometimes medication is lost or stolen. She is aware that health care providers are concerned about patients' selling or trading medicines on the street in order to purchase illicit street drugs. As a long-term drug dealer in the community, Janice is well aware of the street value of both licit and

illicit pharmaceuticals. As she explained, the odd person talked about selling their pills in the United States, but pill specificity, travel costs, and a lack of documentation (passports or birth certificates) made this virtually impossible for inner-city residents like herself.

Jack attends the MAT program daily. Although he has minimized his drug use and found stable and safe housing outside of the Downtown Eastside, he continues to attend the MAT program to pick up his medicines. When I asked why he would come all this way when he could arrange to take his medicines home with him for a week at a time or pick them up daily at the Dr. Peter Centre, he told me it's so he doesn't get lonely. Joshua had similar feelings about the MAT program. At thirty-nine years of age, he has been attending the program since it first opened in 1997. He told me that it provided him with a place of refuge. Diagnosed with inoperable and untreatable brain cancer in 2005, Joshua was supported by the nurses and health care workers at MAT until his death on 26 October 2005. He told me that it was the only place he had. This is indicative of the therapeutic relationships that are nurtured by particular nurses and other health care providers at these programs. Many nurses and clinicians go out of their way to accommodate the unique needs of various individuals. One clinician bought cereal for her patient (who, at the time, was not eligible for the cereal program) and left it so he could eat in the morning. Another clinician provided cigarettes to the nursing staff to give to one particular client as an incentive for him to pick up his medicines daily (unfortunately, when the clinician went on vacation without leaving enough cigarettes, the patient got upset and did not want to take his medicines). Many other patients voiced similar feelings to those of Jack and Joshua, which I found hard to understand until I realized that the alternative to such programs was utter abandonment (Bichl 2005a, 2005b). DOT

programs demand daily visits and supervised swallowings; however, in some cases, they also provide the basis for important therapeutic relationships. For some, these are the only relationships they have.

Some of the health care providers display incredible dedication to their patients. Noting that one of the POP participants was not picking up her antiretroviral therapies, the nursing coordinator outreaches the woman at her home – a small, dark room on the ground-level of the Marie-Gomez Social Housing Project. When we first arrived, the woman told us to leave, saying she doesn't want her medicines or the food that the nursing coordinator has brought along. But eventually, with persistence, the nurse convinced the woman to let her in, give her some food, and drop off her medicines. The woman was coughing, was clearly malnourished, and could not have weighed more than one hundred pounds. She clearly required medical attention. Although she refused to go to the hospital, she did allow the nursing coordinator to arrange a home visit from the clinician. Of course, not all the health care providers displayed such commitment, and sometimes those who did, did so inconsistently. As mentioned earlier, patients' being banned from programs, either temporarily or permanently, often resulted from negative interactions between patients and health care providers.

This chapter begins with a quotation from a MAT and POP participant with whom I worked closely over the course of the research for this project. Aboriginal and in his late thirties, Cam was homeless for almost the entire two years that I knew him. He had attended both programs over a number of years and, at different times, had been banned from both for “bad behaviour,” or what nurses reported as “aggressive outbursts.”

He was overtly critical of these programs as he resented being told what to do, when to do it, and how to do it. Yet, because there was nowhere else to go, he continued to return to these two sites. Sometimes this meant participating in team meetings with staff members, at which he was expected to apologize for swearing at or threatening them; at other times, he would quietly enter after having been banned for a series of weeks, hoping that his return would go unnoticed. Sometime his outbursts involved throwing chairs and engaging in physical fights with other participants; at others they involved verbal intimidation. Yet, he was also considered a “favourite” among health care providers in the Downtown Eastside. He was almost always forgiven and allowed back into the programs. However, what he highlights for us is the possibility that those who do not want to have their ingestion of medicines observed, who do not want to attend programs daily, and who directly “talk back” end up being silenced in the local debate surrounding the efficacy of DOT programs.

And, as I suggested in Chapter 1, we witness this resistance as a form of iatrogenic violence. Cam’s direct criticism of these types of programs, of the overall surveillance strategies in the community, and his non-conformative behaviour resulted in him being banned from the programs. He was then unable to pick up his antiretroviral therapy from the MAT clinic. Although alternative arrangements could have been made for him (e.g., he could have picked them up daily at a pharmacy), he did not follow up, being too upset that he had been banned – this time for a reason that he felt was incredibly unjust. A year later, he has still not resumed his antiretroviral therapy.

The emphasis on pharmaceuticals and the demand for DOT has worked to contain not only the disease but also the individuals themselves. The practice of directly observed therapy, where patients simply pick up their daily medicines from a clinic or pharmacy without ever having a paper prescription in their hands, means many patients don't even know what they're taking. Some simply show up, swallow what they are handed in a little cup, and then leave. When I ask participants to tell me what medicines they are taking for HIV currently they explain – the little blue one, the big orange one, the triangle. Methadone maintenance, DOT for HAART, witnessed therapy for narcotics and benzodiazepines: taken together these programs function as a form of what one nurse referred to as “chemical incarceration” - part of the spatializing practices of state-sponsored health care, which work to contain not only the epidemic but also the unruly bodies (Ferguson and Gupta 2002). Antiretroviral therapies, according to one street-wise woman, are daily dispensed and observed because they are expensive; there is a constant concern that they will be “wasted.” Unused pills are reportedly collected by street nurses, re-packaged, and sent to Africa. This woman was forced to have all her swallowings observed daily at the pharmacy. She was even forced to pick up her T3s daily and was never given carries. As her partner explained, “they are taking away choices all the time.”

“Carries,” as has been mentioned, is the term used to refer to medications that you can take with you, that do not have to be observed in the clinic or pharmacy sites. Most residents explain that carries for methadone are only given if your urine is drug-free – that is, if it screens negative for at least six weeks - which, they add, is just about impossible in the Downtown Eastside. Without carries, or, alternatively, without ever becoming pharmaceutical-free, the patient is tied to the community as leaving would

mean becoming sick due either to withdrawal from methadone or to lack of treatment. In the Downtown Eastside, DOT has become normalized. Many physicians refuse to give prescriptions that may be filled at particular pharmacies: there are continual discussions among health care providers and local residents regarding which pharmacies or DOT programs are acceptable and which are not. Clinicians do not like pharmacies that don't directly supervise the swallowing, while, for their part, patients prefer those that let them take their medicines with them.

One day, while observing clinical interactions, I watched a patient and clinician negotiate methadone maintenance. Methadone maintenance therapy is delivered on a daily observation basis through clinics and pharmacies in the Downtown Eastside (as well as in other parts of the city and province). The young man was requesting that the clinician reduce his methadone dose from 85mg to 80mg. The doctor asked why, and the patient replied: "I need to get off this stuff. I don't want to be tied here forever. I want to be able to go home, to see my family up north." In reply, the doctor asked, "what is the chance that you will ever not be an addict?" Back and forth it went between the patient and the doctor until, finally exhausted by the debate, the patient said, "Fine doc, whatever you say." And off he went with a prescription for 85mg.

### **Observing Illicit pharmaceutical consumption**

More recently, DOT has taken on new meaning as Insite, Canada's first supervised injection site, and prescribed heroine trials known as the North American Opiate Medication Initiative (NAOMI) have been launched in the Downtown Eastside. These public health interventions, considered to be innovative harm reduction treatment and



prevention strategies, are centred on the observation of illicit drug use (intravenous drug use) in state-run facilities. Though they do not provide antiretroviral therapy and are not framed as “observed therapy” initiatives, these programs are part of a spectrum of treatment interventions aimed at the urban poor living in the Downtown Eastside, and they offer a glimpse into the ways in which bodies continue to be managed and monitored through public health initiatives.

These initiatives are why Vancouver’s inner city is being internationally lauded as a progressive harm reduction model. The supervised injection site aims to reduce harms caused by public injection drug use (i.e., fixing in alleys) by providing a medically supervised facility in which local residents are observed injecting cocaine, heroin, and other illicit street drugs. Similarly, the heroin trials aim to reduce harm by providing a well-lit room, where participants inject under the watchful eye of a health care supervisor (usually a nurse).

While both of these initiatives, one a pilot program (Insite) and the other a clinical trial (NAOMI), have proven to be effective in curtailing deaths from overdoses and bacterial infections, their biggest value appears to be in their role of surveillance, of monitoring local drug users. Both are layered with extensive research, or evaluation components, that have become powerful forms of capital in the competitive world of health research. In these programs, each participant seeking a safe place to inject automatically, and often without knowing it, becomes part of a massive medical research industry that scrutinizes their blood, drug use, and sexual practices, then theorizes them and translate them into numbers.

Insite and NAOMI are most likely only the beginning of a series of public health strategies being considered and developed for the Downtown Eastside. Two research colleagues working in addictions told me how they had submitted a proposal to the mayor of Vancouver and his office (at the request of the Mayor's Office) that outlines a project that, under DOT, would offer Downtown Eastside residents prescribed pharmaceutical replacements for cocaine addiction. Convinced that these programs would result in positive health outcomes, including a decrease in HIV and hepatitis C infection rates, both researchers passionately tried to convince me such programming was a good thing. The Centre for Excellence has also submitted a proposal for a similar cocaine-replacement program. And, collaborating with drug-user advocacy groups like Vancouver Area Network of Drug Users (VANDU), Centre researchers are also advocating for a safer-smoking facility, where crack-cocaine inhalation would be observed within a clinic setting. In fact, as one Portland Hotel Society administrator explained to me, the current safer injection facility includes a room at the back, which they had planned on eventually converting into a crack-smoking room. Due to lack of political support and problems with ventilation, this plan had not been realized.

### **Concluding thoughts**

Many epidemiological studies claim that, based on scientific standards measured by CD4 cell counts and HIV RNA virus load, therapeutic management programs such as DOT are successful. Yet, as I discuss in Chapter 1, critical medical anthropologists have warned us that we should “question the alleged neutrality of such standards and recognize them as an instrument of governmentality,” that we need to understand the ways in which values are embedded with therapeutic and diagnostic assemblages (Lock and Nichter 2002, 4).

The success of these biomedical technologies are based on (abstract) disembodied “data” about “disease” (aetiology) – data that are disconnected from the very individuals who participate in the program and from the current social milieu of the Downtown Eastside. These measurements conceal the unintended consequences of these programs as well as the more complicated, immeasurable components of health.

Paul Farmer advocates for DOT programs that are supportive, that are based on therapeutic relationships, that are community-based, and that minimize the supervised swallowing component. Yet, the problem with advocating for such programs is that, in a neoliberal era, the everyday clinic, under intense every-day stress, besieged by misinterpreted or erroneously communicated scientific evidence, and staffed by under-resourced workers who put in long hours for little pay, “ideal” DOT programs crumble into surveillance strategies, where patients become numbers, security guards circle about, and nurses stand nervously behind bullet-proof windows.

DOT programs in the Downtown Eastside presuppose a particular type of subject – a “chaotic,” “damaged,” “incompetent,” “diseased” subject who is non-compliant not only with treatment regimes but also with the normalizing gaze of the state. DOT patients are not only the untreatable but also the ungovernable - the “addicts,” “sex workers,” “Aboriginals,” “mentally ill,” “homeless,” and “criminal.” DOT programs aim to treat those who appear to be falling through the cracks, to engage them in a health care system in which they have been traditionally marginalized. Yet, more surveillance and monitoring does not necessarily equal better health.

HIV positive patients are imbricated in a myriad of state systems that govern their health, sexuality, parenting, housing, employment, and so on, it is possible that refusing treatment and, thus, observation is the only form of control they feel they can assert. I suggest that DOT programs are juridico-medico spaces within which questions of personal autonomy and competency are constantly negotiated; within which compliance to rules and regulations is demanded, behaviours policed, and morality governed. Implicit in these programs is a strategy of containment as individuals are tied to the Downtown Eastside through daily dispensing programs, unable to leave for more than a day or two unless they can provide clean urine tests, which supposedly attest to their ability to follow through with treatment and/or to be responsible for expensive medicines. In this sense, DOT programs speak to a tension between surveillance and containment.<sup>24</sup> Justifications for new plans to move drug users from street market cocaine to prescribed pharmaceuticals presume that “evidence” and “health outcomes” are neutral, objective measures; however, it functions to effectively create a public health jail (without the cinder blocks), within which people are daily tied to pharmacies and clinics. Independence in the inner city can only be achieved through the act of resisting pharmaceuticals – by *not* taking your medicines, by not engaging with public health interventions.

As we see in the next chapter, for some of the participants in the Downtown Eastside, immediate positive health outcomes are clearly associated with their participation in DOT programs. But perhaps our obsession with engaging patients in pharmaceutical treatment has resulted in our concealing the larger structural and ideological forces that continue to shape health and the lack of it. In Chapter 5 I consider

two specific themes that emerged in the everyday context of DOT programs: “rationality” and “chaotic” lives.

## CHAPTER 5 CHAOS, COGNITIVE IMPAIRMENT, AND COLONIALIST LOGIC IN THE DOWNTOWN EASTSIDE

In this chapter I consider two related concepts that emerged in the directly observed therapy (DOT) clinics of Vancouver's Downtown Eastside: chaos and cognitive impairment. Both of these concepts are directly connected to the theorizing of adherence with regard to the urban poor, and both are part of a series of hidden universalizing assumptions that underlie treatment interventions for HIV in the inner city. I examine the notions of chaos and cognitive impairment by looking at a number of sites that provide HIV treatment or DOT: the Downtown Community Health Clinic's Maximally Assisted Therapy (MAT) program, the Portland Hotel Society's medicine delivery system, and the AIDS ward, 10C, at St. Paul's Hospital. These three divergent sites provide an interesting opportunity to compare the ways in which HIV treatment is delivered as well as to highlight the ways in which tropes about the inner-city HIV positive patient traverse multiple clinical sites.

First, I look at the Portland Hotel Society, whose Portland Hotel provides an opportunity to compare how DOT and the "problem of adherence" are tackled by non-governmental organizations. It also provides an opportunity to consider how theories of the brain and cognitive impairment are deployed in clinical practice to construct the drug-using patient as *unable* to adhere. I look at the ways in which medical researchers and health care providers understand choice (as in the choice to take medicines or not) and its relationship to the (drug-affected) mind. In part, their understanding has been transformed by new visualization technologies that document changing brain structure

and function, making the biological seem more tangible. I examine the role that the brain-imaging technologies on the AIDS ward in St. Paul's Hospital plays in clinicians' discussions of their patients ability to decide whether or not to engage in treatment.

Second, I consider how unchallenged assumptions that circulate in public health discourses and represent impoverished inner-city residents as "chaotic" and "disorderly" function to conceal the structural and ideological influences that contribute to disparities in health. DOT programs in the Downtown Eastside presuppose a particular type of subject – a "chaotic," "damaged," "incompetent," "diseased" subject – someone who is both infected and infectious, and who is non-compliant not only to treatment regimens but also to the state.

Last, I reflect on how notions of chaos and cognitive impairment, as they are applied to HIV positive residents of the Downtown Eastside, are eerily reminiscent of colonialist logic regarding the racial other. I suggest that it is incumbent upon us to consider how medico-scientific knowledge about brains and addiction is deployed as a means of masking the clearly raced nature of disease and biomedical interventions for HIV in Vancouver's inner city.

### **Portland Hotel Society**

The Portland Hotel Society (PHS), formed in 1993, is a large not-for-profit organization located in Vancouver's inner city. The PHS and its staff are well known in the community for their advocacy work related to housing and harm reduction initiatives. They run seven hotels, including the well-known Stanley, Washington, Sunrise, and the Portland, for a total of 450 housing units (Gurstein and Small 2005). Those living in the

latter are considered to be the “hardest-to-house” and, as the PHS regularly reports, have often been banned from all other hotels and housing facilities in the Downtown Eastside due to “behavioural problems.” The PHS aims “to promote, develop and maintain supportive affordable housing for those whose housing needs are largely ignored and, as a result, are socially isolated” (Gurstein and Small 2005). Unfortunately, its policy to never evict means that drug dealers live alongside some of the most vulnerable residents in the Downtown Eastside, leading one health care professional to suggest that the PHS “facilitates drug use.” The PHS articulates its “no-eviction” policy as being part of a framework that provides not just housing but also a “home.”

This “home,” however, is intensely institutional, with video monitoring and surveillance. Gaining entry into the building off Hastings Street requires being buzzed in by the front desk staff, who monitor the door through the video surveillance system. You enter through two separate doors, the first one a large metal one. The next door won’t open until the door behind you has closed. Every door in the building, including the elevators, requires an electronic key for entry and exit – either that, or front desk staff must buzz you through.

There are at least sixty-four video cameras monitoring surveillance throughout the Portland Hotel, including the doctor’s office on the second floor, and administrative staff observe these on six rotating screens at the front desk (and presumably elsewhere). The chief executive officer of the PHS, who is also part of the management team, explains that the need for surveillance stems from the need to provide safe work environments for *staff*. As well, twenty-four-hour supervision is in effect, promoted as part of a “supportive



housing” policy. The effect is to create a building that is more like a state institution than a hotel. This was made clear to me by one young man when he explained that he had been forced to turn down a woman’s invitation to return to her room for the night when he found out that she was living at the Portland Hotel: “It’s like a jail, you can’t get out when you want to leave.”

The health care coordinator for the PHS described its system of HIV care and treatment at length. Besides herself (she has been a full-time health coordinator with the society since 1993), the Portland Hotel has a half-time nurse, a counsellor, and a physician available for six three-hour sessions each week within the housing facility itself. At the time of our conversation, 2 June 2005, the Portland Hotel housed eighty-eight residents, thirty of whom were HIV positive. The health care team has an accurate account of who is positive since all participants are required to get blood work done in January of each year, when they are provided with a five-dollar honorarium and food for doing so. Individuals who are HIV positive are encouraged to get blood tests measuring their CD4 cell count, viral load, and liver function every four months. This is done at the Portland Hotel. And, according to the coordinator, any resident with a CD4 cell count below 200 is taking antiretroviral therapy. The PHS dispenses all medicines, including antiretrovirals, methadone, psycho-pharmaceuticals, and narcotics, for the majority of residents through the front desk. Methadone is dispensed between 8:00 AM and 6:00 PM, but other medicines are available around the clock.

As the Portland Hotel is not a designated pharmacy, most medicines received are individually prepackaged and delivered from Buckshon’s Pharmacy. Methadone is kept

in a locked fridge in a cupboard behind the desk, and all other pills are kept in two drawers below the front desk in individually marked plastic containers. Most residents pick up their medicines first thing in the morning, when many also pick up their methadone; however, for the most part (depending on the prescription), they are free to do so whenever they choose. If residents don't show up at the front desk for their medicines, staff members attempt to find them in their rooms. Compliance is monitored: records are kept to show who has taken their medicines and who has not. Of the eighty-eight residents living in the Portland in June 2005, only *one* resident was allowed to take a weekly supply to her room.

The health care coordinator of the Portland Hotel Society (PHS) reported that they use incentives that she admitted were “probably illegal and immoral” in order to encourage participants to take their medicines. As others have said, individuals with mental illnesses (often personality disorders) require the most support at the Portland Hotel. And this means more “incentive” to take their medicines. As part of this incentive, the PHS works in conjunction with the St. James Community Service Society to dispense monthly income assistance payments. The health support worker picks up the funds from the St. James Society, and the PHS staff dole them out daily. On occasion, they will not give money to a resident unless he or she has taken her/his medicines; and sometimes this happens twice a day (e.g., when patients have twice-daily dosing requirements).<sup>2</sup> Provincial income assistance is already nominal, forcing residents to live in utter poverty, sometimes on as little as \$125 per month (after housing). Dispensing the monthly income assistance daily comes to a little less than four dollars per day.

As I illustrate in Chapter 3, research documenting inner-city adherence suggests that patients in this area are most likely to be non-adherent. As a result, health care professionals at these programs create incentives to lure these patients in. Providing incentives to encourage participation or attendance in public health programs like DOT is a practice shared among many organizations, including many in the United States. In Vancouver's Downtown Eastside, providing food, even if it's just a bowl of dry cereal and a cup of weak coffee, is believed to help attract patients in to pick up their medicines. When I began the research at the Downtown Community Health Centre's MAT program, almost every person with whom I spoke in the first three months asked whether I had heard about the "cereal" issue. After the program was transferred from the Centre for Excellence to the Vancouver Coastal Health Authority in 2001, a number of changes were made in its daily management. Food was no longer provided to all participants as part of the incentive to attend, yet it increasingly became part of the strategy for treating HIV as particular medicines needed to be taken with food. Only those individuals who were taking antiretroviral medicines that had to be taken on a full stomach were put on what became known as the "cereal list." In a community plagued by poverty and hunger, the selectiveness of the list caused endless debates and arguments in the Health Centre, involving administration, physicians, staff, and participants. One physician, frustrated that, despite her continual request that her patient be put on the list, bought a box of cereal and gave it to the staff specifically for that person. In July 2005, as the Health Authority sought to rebuild and regionalize the MAT program, the cereal list disappeared and it became policy to offer cereal to everyone.

As I discussed earlier, researchers at the Centre for Excellence, including director Julio Montaner, have advocated for a new incentive strategy in order to improve adherence – one that would see patients paid to take antiviral medicines.<sup>2</sup> The practice of providing incentives, although utilized in many programs in both Vancouver and across the country, continues to raise ethical issues due to its possible coercive nature. Montaner’s justification for his new incentive strategy, which he revealed at the International AIDS Society meetings in Toronto in 2006, comes from the growing evidence that “treatment is prevention.” Nonetheless, such an initiative raises important questions regarding the fine line between caring and coercion.

Even with incentives, and even with disincentives (like withholding financial assistance). Portland Hotel staff reported that some residents refused to take any medicines or to engage in any health care. The nursing coordinator recounted the story of one resident, a Vietnamese male in his late thirties who had been diagnosed with schizophrenia, who refused to take his medicines even when his money was withheld. A reported heroin dealer, he probably didn’t rely on his monthly welfare funds to get by. The coordinator explained that, between the language barrier and the mental illness, they had generally failed to engage this man in treatment. When asked to have blood work done, he insisted that they were trying to steal his blood and punched the MDS lab technician who was trying ... well, to take his blood. Some residents agree to take some of their medicines, but others do not. One male resident carefully separated his HIV medicines from his other medicines, refusing to take them. Most residents actually swallow their medicines in front of the staff, although, on occasion, they leave with their

medicines shoved into their pockets. Staff found one resident who, not having been observed ingesting her medicines, succeeded in stockpiling them in her room.

The Portland Hotel staff, like other health care providers in the Downtown Eastside, point to a serious gap in services for mental health treatment, noting that the current public health model is ill-equipped to deal with individuals who have both addictions and mental illnesses. Additionally, the coordinator noted that recent restructuring and cutbacks in social service programs under the current neoliberal regime in British Columbia has meant that residents who used to be serviced by the Strathcona Mental Health team were now being “dumped” on other agencies, like the PHS.

The daily observation of the ingestion of medicine at the Portland Hotel is thought to be instrumental in providing much needed health care to the hotel’s residents, whom one managerial staff member referred to as “damaged.” DOT allows health care providers to provide treatment and care that they could not otherwise provide. DOT means that Dr. Gabor Maté, resident clinician, can prescribe narcotics without having to worry that residents will sell them on the street. Even with DOT, though, residents find ways to resist or negotiate therapy, sometimes “checking” pills, or hiding them in their mouths and spitting them out later. But the health care system also adapts to such resistance – and, when this practice is suspected, Maté prescribes liquid morphine. As the Portland Hotel Society health care coordinator explained, “Whatever we have to do, we do.”

The staff members at the PHS are known to be an eclectic bunch – the front desk staff, deemed “mental health workers,” include a wide range of artistic young people who

circulate between the PHS's various facilities (including Insite – the supervised injection site, which has a certain social cachet in the Downtown Eastside). Jane, a young Cuban woman, has a background in music and plays at local clubs on Commercial Drive. Emily worked in landscaping for four years when she decided to drop off a resume. Another young man, a local photographer, has a gallery exhibition at the PHS-run Interurban Gallery. Indeed, it appears that working at the Portland Hotel requires a certain type of character; but few of these people have any kind of health or addictions training (besides what they receive from the PHS once hired). Patients vie for the attention of the front desk workers, and some sit around trying to talk to them; however, for the most part, the staff remain aloof and display little interest in the stories the residents have to tell.

There are usually two staff members working the front desk at the Portland Hotel, which tends to be quite a busy place. Residents receiving methadone or narcotics must sign for them, but other medicines are simply given out. The system of medicine delivery at the Portland Hotel is not without its problems. Some residents receive morning, noon, dinner, and bedtime medicines. Those insisting they receive their medicines early, for example, at 10:00 AM instead of noon, must negotiate with staff members, who remain firm in their refusal. Residents threaten not to come back; they engage in name-calling; they yell and scream. In June 2005, I observed a young man, clearly experiencing withdrawal, enter the hotel and ask for his medicines. When staff refused to give them to him because it wasn't time, he became enraged: "You can't withhold my pills! Give me my pills! I put them here!" He threatened violence and then proceeded to hurl homophobic epithets at the two female workers. He ended his rant by storming out of the

room shouting yet more angry epithets. His heated and emotional response seemed to barely affect the two women. When I asked whether that type of “negotiation” occurred frequently, they said sometimes daily, sometimes three times a day, and sometimes not very often. Such interactions appeared to them to be completely normal.<sup>3</sup>

Gabor Maté,<sup>4</sup> who has a particular interest in attention deficit disorder and who gives regular public lectures on this subject, explained during an interview in November 2005 that adherence to treatment is directly connected to “counter-will,” what he theorizes as a subconscious force in humans that is put in place by “nature.” For him, resistance to treatment is a reaction to feeling that you are being coerced. He demonstrated how counter-force is an innate response. Asking me to hold my hand in the air, he pushed against it and asked me to reflect on my automatic response – to maintain my hand in the same position, perhaps even to push back. He used this as an analogy for how PHS residents respond to taking medicines. He explained that the natural response to counter with force – oppositionality - was an immature response: “And the less mature the person, the stronger the counter-force, so it’s an automatic thing, a subconscious thing, and it serves a natural function in life ... If I’m very immature, then any expectation on your part will evoke a counter-will in me. So these people are very immature emotionally, so as soon as they feel pressure, their reaction is counter-force and the more you increase the counterforce, the more intense the oppositionalities become.”

Many caregivers in the Downtown Eastside perceive local residents as childlike or immature. They often justify paternalistic health care practices like withholding welfare funds, refusing to adjust methadone doses, and not allowing individuals to make

decisions about their own lives by saying, “They’re like children.” On a tour of the neighbourhood and the Portland Hotel Society’s investments in the Downtown Eastside, one of the Portland Hotel Society’s management staff explained to me the society’s housing philosophy. In other hotels or housing situations, if someone floods the bathroom more than once, he or she would be evicted. At the Portland Hotel, if someone floods the bathroom by plugging the tub, the first step is to remove any stopper from the tub. If it continues to happen, the person will not be evicted; however, the tub will be removed. Proud of their policies to not evict and to house the “unhousable,” Portland Hotel staff members do not see these practices as coercive but, rather, as necessary strategies in providing a “home” to the “damaged.”

### **Neurocognitive impairments and AIDS**

Concerns about brain functioning and its impact on decision making is evident not only in the Downtown Eastside community but also in the 10C AIDS ward at St. Paul’s Hospital. Treating very ill HIV positive patients, many of whom are suffering from a range of neurocognitive impairments, the ward has an automatic door lock system. Patients deemed incompetent wear “transmitter bracelets” that automatically lock the doors when they get too close, thus preventing them from exiting. Besides the geriatric ward, this is the only ward in the hospital to have such a measure. Patients who consistently tear off the transmitter bracelet are assigned a security guard, who follows them around the ward or sits outside their room.

In December 2005, while I was observing on the ward, health care providers and clinicians were faced with the dilemma of evaluating the competency of one of their



patients as her disease had progressed to the point where she appeared to lose cognitive function (according to hospital staff, a result of AIDS-related dementia). In her mid-forties, she had been in and out of the hospital for six months, with a CD4 cell count of less than ten and a viral load registering over 100,000. This young woman, who was receiving intravenous antibiotics for cryptococcal meningitis, had a history of refusing antiretroviral therapy. When she was on treatment, she frequently discontinued it without consulting a health care provider; as well, she frequently left the hospital “against medical advice.” As her disease progressed, she continued to refuse antiretroviral therapy. The health care team was faced with the dilemma of how to evaluate her current state of mind. According to the clinician caring for her, she appeared disoriented, displayed poor judgment, had urinary and bowel incontinence, and a flat affect. But was she depressed or was she experiencing AIDS-related dementia? If she had AIDS-related dementia, they asked, could she make a competent decision regarding her care and could she continue to refuse antiretroviral therapy? During morning rounds, as part of their ongoing evaluation of her treatment, a team of physicians visited the patient to see how she was doing. As the team (which included the attending, two clinical associates, residents and interns, a pharmacist, and myself lingering in the back) approached her bed, the attending asked her how she was feeling. She stared back at us silently, looking carefully at each one of us. After a bit of an awkward silence, with her watching us and us watching her, the patient in the bed beside her yelled out: “Tell them where it hurts! They’re doctors!” When the woman still didn’t respond, the helpful neighbouring patient repeated: “Tell them where it hurts! They’re doctors!” The young woman continued to stare at us. Her gaze was not blank, and it shifted between each one of us, carefully

measuring us. The attending asked the neighbour whether she had spoken with the patient at all that morning, and she said, “Yes, we talk all the time.” Finally, the attending suggested that they return later, with less of a crowd, when the woman might feel more like talking.

As we stood at the nursing station, one of the clinical associates working on the AIDS ward suggested they consider treating her with electroconvulsive therapy (ECT) as it is currently considered an effective treatment for depression in pregnant women. He explained that the association of ECT with the classic film *One Flew over the Cuckoo's Nest* (Forman 1975) meant that many people regarded the practice as inhumane and unethical but that changes in technology had now made it an effective therapy in the treatment of depression. The physician suggested that, after ECT, the patient, no longer feeling the symptoms of depression, would consider starting antiretroviral therapy. The nurse-in-charge recommended they consult with the hospital ethicist (this was not done). In the end, two psychiatrists were consulted, and, after some discussion, they recommend that she not be forced to take treatment or engage in ECT.

During a follow-up interview with the clinical associate who was tending this patient, I asked him how cognitive impairment was measured and evaluated? He explained that this was done through blood work and a CT (computed tomography, also known as CAT) scan. This patient's CT scan supported the conclusion that she had AIDS-related dementia as the imaging showed cortical atrophy. Yet, as the attending clinician explained, under the Mental Health Act, the woman could not be certified as she wasn't considered to be a danger to herself or to the community. They could not force her

to receive care or to stay in hospital against her will, even though the imaging technology indicated that her brain matter was atrophying. As the HIV specialist explained, “People are allowed to be demented. There are lots of demented people walking around.”

### **Brain function, illicit drugs, and competency**

As other social researchers have illustrated, neuropharmacology research and new imaging technologies affect not just everyday medical practice and perceptions of competency but also the making of subjects (Cohn 2004; Dumit 2000; Rose 2003). Questions of cognitive impairment, competency, and brain functioning are themes that cross-cut conceptions of compliance among Downtown Eastside residents. A nurse specializing in addictions explained to me that there is a “degree of cognitive impairment in this population” due to a myriad of factors, including “addictions, HIV-related dementia, and psychiatric disorders.” She offered anecdotal evidence to support her claims, explaining that patients say they don’t want treatment but continue to go to the hospital – an indication that clearly they do want treatment. She also suggested that many do not understand why they need to get tests done and that the fact that they leave the hospital against medical advice, when they are clearly suffering from a life-threatening disease, is a further indication that they are experiencing cognitive impairment. Similarly, the pharmacist for the MAT program explained to me that drug use (by which she meant illicit drugs like cocaine and heroin) leads to “organic brain dysfunction,” which explains why “clients here are not competent to remember testing.”

The link between illicit drug use and “brain cell destruction” is used as a rationale for DOT policies that limit choice. This was highlighted by a discussion on decision

making between two nurses from the MAT program. The first nurse explained to me that, because new studies indicate that drug use destroys the part of the brain responsible for decision making, as health care providers, nurses now had to be more “autocratic” in their medical practice. The other nurse thought their patients could make some decisions but that they needed to be provided with clear, obvious choices.<sup>5</sup> The first nurse then retracted part of her argument, stating that she didn’t mean to imply that *all* of the patients were incapable of making decisions; however, she argued that, because 90 percent of them were chronic drug users, their decision-making abilities were definitely impaired.

Assumptions about brain function, competency, and compliance are central to daily practice at the MAT program. In August 2005, recommendations for ingesting ddI (also known as didanosine, or Videx), one of the reverse transcriptase inhibitors used in antiretroviral therapy, were revised. New guidelines suggested that participants had to have an empty stomach when taking ddI, so MAT participants who partook of the free cereal provided needed to wait at least ninety minutes after eating before they could take them. But many participants also needed to have a full stomach in order to take other medicines in their treatment regimen. The possibility of coming to the program, eating breakfast, taking their medicines, and leaving with the ddI on the understanding that they would take it ninety minutes later was not an option. Staff voiced concerns about the “forgetfulness” of participants. As one nurse explained, “Their brains are forgetful.”

I asked the medical director of addictions and HIV/AIDS for the Vancouver Coastal Health Authority about the links between brain functioning, drug use, and decision making. He explained:

Yeah, well the evidence, research evidence is getting more and more clear that there are changes in the physical structure and function of nerve cells in the brains of people using drugs for a long period of time, especially opiates. But I don't think that that means that they're not competent decisions. That's a very different thing. The changes are within the reward pathways and they persist even with months of abstinence, so um, it probably explains why people who are, have been dependent on opiates are a very high risk of relapse even if they've been abstinent for a long time. S\_\_\_ and A\_\_\_ in California, who have done this thirty-year follow-up on heroin users, there was a group of people, who had been abstinent for, fifteen years, or more. And of that group 25 percent had relapsed. Very, very different with alcohol --um, if you've been abstinent for five years you have a 95 percent chance of staying abstinent long term ... I know lots of addicted physicians who used to be dependent on opiates and now are back in practice, some of the healthiest people I know. I'm sure that they have a very small chance of relapse, but the brain's probably changed in ways that put them biologically at increased risk of relapse for the rest of their life. But I don't think it takes away their ability to make decisions. They're competent to make decisions about their lives and other peoples' lives as physicians 'cause those changes are in the rewards pathways, they're not in the cortex - you know, judgment, decision making.

Narratives of brain changes in drug users and the mentally ill circulate freely among health care professionals in the Downtown Eastside. They also figure in the epidemiologic research on adherence at the BC Centre for Excellence in HIV/AIDS. For instance, Dr. Thomas Kerr's research on the "psychosocial determinants" of adherence highlights the role of biological factors. Although his research emphasizes forgetfulness and sleeping through dose times as factors relating to non-compliance, he links the former to the biological effects of illicit pharmaceutical use: "The complications and the

associated implications for remembering are likely further exacerbated by long-term use of illicit drugs, which in turn may explain the high rate of forgetting” (Kerr, Palepu, Barnes, et al. 2004, 412).

There is little discussion regarding the impact of methadone on the lives of patients, whether on their health or their minds. Anyone who works in the Downtown Eastside is aware of the enormous number of patients receiving methadone in the community. In the MAT program at the Downtown Community Health Clinic, twenty-nine out of eighty patients were receiving methadone. Methadone maintenance therapy is considered part of the harm reduction strategy in the Downtown Eastside, its purpose being to assist patients in withdrawing from (primarily heroin) addictions, and it requires directly observed therapy. Pharmacies receive the methadone in powder form and mix it with juice, which patients must drink at the pharmacies while being watched by pharmacy staff. “Carries” are only permitted under extremely rare circumstances, and only if urine drug screening tests have come back clean for other illicit drugs. Participants report that the physical withdrawal symptoms from methadone are much more powerful and much more painful than are those from heroin. This means that patients rarely miss picking up their methadone scripts. Minor adjustments in the amount of methadone can cause serious withdrawal symptoms. Most patients explain that, once you start methadone, you will never be able to get off of it. Errors in writing out prescriptions, errors made at pharmacies, or mis-communications between clinicians and pharmacies regularly result in patients crying and yelling because their prescriptions have been incorrectly filled, resulting in painful withdrawals. Some patients with whom I spoke reported, usually disdainfully, that clinicians regularly attempted to start them on

methadone maintenance, even though they did not use heroin. One clinician told me that sometimes he starts patients on methadone in the hospital even if they say they don't want it. He explained, "It's for their own good."

Methadone doses that are too high lead to individuals "nodding out," their eyes closing as they talk to you, almost falling asleep. Participants report on the debilitating short-term and long-term side effects of methadone. Responding to a query I had about a patient's state of mental health during clinic observation, a physician said to me: "That's what you call a methadone-induced lobotomy." Even though it is clear to many health care professionals that methadone, as a synthetic opiate, has a serious impact on day-to-day functioning, it is the *illicit* drugs that are understood as affecting brain function and structure. The effects of illicit drug use (crack, cocaine, and heroin), AIDS-related neurocognitive impairments, and fetal alcohol spectrum disorder (usually in the case of Aboriginal people) are the usual discourses employed when it comes to explaining brain (dys)function.

There is a rich and comprehensive literature from law, philosophy, and medicine that explores bioethical dilemmas surrounding the intersection of autonomy and compliance, especially among the mentally ill, children, the elderly, those who refuse treatment of life-threatening diseases, and, more recently, the addicted. What is relatively new to these debates is the way in which new visualizing medical technologies, specifically brain imaging technologies like positive emission tomography (PET), computed tomography (CT), and magnetic resonance (MRI) scans and neuropharmaceutical research enter into them. These new technologies become part of

the rationale for justifying coercive practices and, in part, are used to explain why patients live the lifestyles they do. Visual technologies have the effect of making biological factors seem more concretized, or more “real.” They provide evidence that biological factors are contributing to patients’ ability or inability to be compliant – even though the evidence from such brain imagining technologies remains contested (Dumit 2000). As Dumit highlights in his study of PET scans, these technologies are used as evidence to distinguish between types of individuals: they visually *show* abnormalities and differences (Rose 2007). What was previously defined as a social disorder becomes a brain disorder. Scans provide proof that parts of the brain are not functioning “normally,” that structural changes are actually occurring within the brain. Yet, Dumit (2000, 220) also demonstrates the challenges in brain imaging technological research, explaining that such scans are better understood as “hypothesis generating” rather than as “hypothesis confirming.”

In the Downtown Eastside, as a result of the increasing reliance on theories of cognitive impairment, there has been a shift from a focus on risky behaviours and personal responsibility to a focus on the *inability* to decide based on physiology (recall the earlier quotation from Shannon and colleagues). When self-governing models of power (i.e., being responsible for one’s own health) fail to work, new forms of governance emerge. As a local physician specializing in addictions explained: “They’re adults. They make decisions for all kinds of complicated things just like we do. And their decision to use drugs on a day-to-day basis - yes it’s a conscious decision, but it’s driven by some pretty serious and biological compulsions.” The biomedical subject is refashioned from a “morally corrupt” subject to an individual with neurocognitive



impairments who cannot, by definition, make competent decisions regarding his or her health care. In the Downtown Eastside, the combination of addictions, AIDS, and mental illness contributes to the construction of the inner-city patient as particularly susceptible to brain disease. This may, perhaps, be less stigmatizing than “madness,” but it constructs the patient as completely powerless, as without reason, and, therefore, as requiring the intense surveillance and regulation of programs like DOT.

However, the idea that individuals make choices and informed decisions each day, and engage in risky behaviours by choice, has not disappeared. These narratives occur alongside of, sometimes intersecting with, the new emerging narratives of cognitive impairments and “incompetency.” This was powerfully illustrated to me when I attended a doctor’s appointment at Vancouver Native Health Society’s medical clinic in December 2005 with a thirty-eight-year-old Aboriginal man with whom I had been working. It was a few days after the death of Francis McAllister, a thirty-seven-year-old Aboriginal man who died on the street. As Daniel, a soft-spoken, lumbering, six-foot-eight fellow, sat patiently waiting for his doctor to finish her paperwork, he quietly said to her, “Too bad about Francis.” To which she replied, “Some people make bad choices,” leaving both of sitting in shocked silence.

Other physicians and health care providers have a more nuanced understanding of decision making as they daily attempt to weigh the odds of prescribing treatment that, without 95 percent adherence life long, runs the risk of resulting in drug-resistant strains of HIV. One clinician explained to me that, as far as he was concerned, when it comes to deciding whether or not to engage in therapy, “the patient is sovereign.”

## **Chaotic**

As I outline in Chapter 4, DOT for HAART programs are deemed viable solutions to problems of cost, drug resistance, and non-adherence in HIV care among the urban poor. This is because it is believed that inner-city patients cannot be trusted with their medicines: they will sell them, trade them, lose them; they are forgetful (they won't remember to take their medicines); the "chaotic nature" of their lives renders them incapable. Others have suggested that long-term drug use changes brain function and chemistry, with the result that patients truly are unable to make healthy decisions for themselves and, thus, require almost parental guidance.

While DOT programs are developed under the rhetoric of improving adherence, they are part of an assemblage of adherence strategies that construct subjects as non-compliant and as diseased, and that attempt to shape them into manageable citizens. The goal is not only to treat their infections but also to ensure "stability" - the antithesis of "chaos." "Chaotic" is one of the most frequently used terms to refer to the lifestyle of Downtown Eastside residents. Repeatedly, health care providers, advocates, administrators, and researchers talk about the "chaotic" nature of "this population." At workshops and AIDS conferences researchers and clinicians refer to the inner-city poor as "difficult patients," as "chaotic populations," and as "hard to treat"; they applaud each other for the challenging work they do with "those populations." Not only is the term "chaotic" used in everyday clinical settings, but it is also discussed in the epidemiologic literature produced by the Centre for Excellence. Thomas Kerr and colleagues, for example, argue that, "given the chaotic lifestyles of many IDUs it is also understandable

that this [falling asleep] may be more of a problem with this particular population” (Kerr, Palepu, Barnes, et al. 2004, 412).

But what does the word “chaotic” convey? If we understand it to reflect the standard dictionary meaning – “a condition of disorder or confusion” - then what is it about these peoples’ lives that appears to be so disordered? It seems a poor characterization of the lives that I witnessed through my daily interactions during fieldwork. Not only did local residents - many of them addicted, homeless, and ill - show up for appointments with me, but they also showed up on time and frequently called to find out if I was going to make it.<sup>6</sup> In contrast, I often had to wait for extended periods of time to see clinicians or administrators, and on a number of occasions not only did professionals not show up for appointments with me but they did not bother to contact me to let me know they couldn’t make it. If anyone had lifestyles that could be described as “chaotic,” it appeared to me to be the researchers, clinicians, and administrators whom I observed juggling multiple research projects, multiple administrative duties, family commitments, travel for conferences and workshops, medical practices, supervising graduate students, and so on. Their cell phones, pagers, and blackberries rang, beeped, and vibrated regularly; they left meetings early, arrived late, and sometimes answered calls and returned e-mails while seeing patients.

Participants must be referred to the MAT program by a physician. Usually, patients in the Downtown Eastside see clinicians at one of the inner-city clinics – the Pender Community Health Clinic, the Downtown Community Health Clinic, or the Vancouver Native Health Society’s medical clinic. Physicians are expected to refer

patients that they consider to be “unstable” or attempting to manage “chaotic” lifestyles, thus requiring additional support and treatment intervention in. “Stabilizing” participants is seen as a central goal of the MAT program. Sue Currie, former program director of MAT, explained that, while the plan was to address barriers in antiretroviral treatment, the heart of the program concerned helping participants become more “stable” by helping them to access food and nutritional supplements, to fill out complicated disability forms for additional financial support, and to find alternative housing: “The MAT program was a success regardless, I think; it’s successful in stabilizing persons and getting folks healthier, regardless of whether the HIV meds worked.”

Transforming a patient from chaotic to stable is the measure of success. These two contrasting concepts are embedded in everyday practice: they are the defining measurements of health, of one’s ability to adhere and of one’s readiness to begin treatment. One’s ability to be “stable” is one’s ability to comply to the expectations of public health demands, policies, and rules.

The construction of the Downtown Eastside patient as chaotic justifies public health practices that deny patients’ agency. As a nurse from one of the DOT programs explained:

For most of our patients we deliver the medications to them. If the person is not too chaotic we will pour a weekly dosette with ARV's and the other meds a patient is taking. We usually cannot safely leave the bulk of the meds in their home so they stay in the health unit med cupboard and on the patient's chart. Other folks we cannot leave a weekly dosette, we must visit daily and actually give the ARV's and meds. These are very chaotic folks who would lose, misplace, or generally be unable to manage a dosette and identify the need help to put those pills in their mouth.

Here, chaotic translates into irresponsibility or the inability not only to keep one's medicines at home but also simply to swallow.

This fixation on chaos and stability in the community transcends the DOT programs, marking prevention, harm reduction, and general public health programs in the Downtown Eastside. Stability is a metonym for public order, as is illustrated by the research and evaluation of the supervised injection facility, which continues to report on changes in "public order." In Vancouver's inner city, the drug market is more visible than it is in other communities, where private homes or offices shield it from public scrutiny. The purchase and consumption of illicit drugs often occurs in public spaces - the streets, alleys, and sidewalks - observable to anyone passing by. Vancouver's successful bid for the 2010 Olympics, the Vancouver Agreement for urban development, and pressure from private merchants in Gastown and Chinatown have increased the level of pressure to "do something" about the public drug market and street-level sex industry in the Downtown Eastside.

Researchers at the Centre for Excellence have documented the supervised injection facility's impact on public chaos in the community (Wood, Kerr, Small et al. 2004; Wood, Kerr, Lloyd-Smith et al. 2004). The standardized measurement for public disorder includes five criteria: (1) public drug use, (2) injection-related litter, (3) discarded syringes, (4) suspected drug dealers, and (5) number of police patrols (Wood, Kerr, Small et al. 2005). Results supported anecdotal evidence that the supervised injection site decreased public injection use and litter associated with drug use (including syringes). More recently, researchers at the Centre for Excellence have begun advocating

for a medically supervised safer smoking facility, which they claim will also “address concerns of public order and open drug use among crack cocaine smokers” (Shannon et al. 2006). Since the launch of the supervised injection facility, community-based advocacy groups like Vancouver Area Network of Drug Users (VANDU) and the Portland Hotel Society have suggested that the intensity of crack-cocaine smoking in the community has created a demand for a similar facility.<sup>7</sup> Again, these public health interventions are based on particular ideas of acceptable behaviour, of reducing the chaotic and uncontrollable character of local residents who inject or smoke drugs in public. Residents who attend the supervised injection site, who take methadone, and those who inject heroin three times a day at the prescribed heroin trials (NAOMI) under the observation of nurses, are considered drug addicts who are now “in control” of their using practices. They are also, of course, now carefully regulated and monitored by the state (Boyd 2001). These public health interventions highlight the way in which both biomedicine and the state make distinctions between acceptable drug use and non-acceptable drug use. I suggest that these interventions are less about decreasing pleasure (as Bourgois [2000] has argued in the case of methadone) and more about establishing an assemblage of monitoring and surveillance systems. These research trials and public health interventions effectively promote programs that demand a particular type of compliant citizen – one who is governable and who is monitored by the public health surveillance system.

Health care providers recognize that the question of “chaos” is quite complicated. They maintain that residents of the Downtown Eastside are chaotic, but some of their explanations of why this is so reflect structural inadequacies in health care delivery rather

than the biological characteristics of drug users. Speaking of the difficulty of treating inner-city residents in the hospital, a local addictions physician explained that patients in the hospital who were using drugs were “creating chaos in the hospitals. So you know it’s only creating chaos ’cause the hospital staff don’t know how to deal with these issues. They’re not trained and they have all kinds of attitudes and values and beliefs that go counter to creating a good environment for drug users.”

Health care professionals associate chaotic and disordered lives with poor housing, untreated mental illnesses, addictions, and a lack of compliance. “Stable” patients are reliable, adherent, and capable of taking their medicines (perhaps even unobserved). Recall that, in the Downtown Eastside, only six out of 308 patients have been deemed stable enough to take their antiretrovirals on their own. Indeed, some patients do require support and care as part of their treatment. Anyone who is sick with a chronic, debilitating, long-term disease understands the importance of family, friends, and resources when it comes to staying healthy. As impoverished, often isolated citizens, many Downtown Eastside residents lack the social support many Canadians take for granted. Yet, the core component of the majority of the DOT programs operating in the Downtown Eastside is the supervised swallowing. Patients enter the clinic and go to the door or window where medicines are delivered. There, a nurse hands them a cup or a small envelope containing the medicines and a small cup of juice. The patient swallows the pills and walks away. He or she may go and eat lunch, get a bowl of cereal, or hang out socializing with other program participants; however, meaningful engagement with DOT program staff is rare unless there is an emergency.

At the British Columbia Canadian Nurses in AIDS Care (CANAC) Annual meeting in February 2006, Shelley Dean, the guest speaker, presented a paper on the MAT initiative. The theme of the meeting, “Adherence and Antiretroviral Therapy: Nursing Implications,” addressed the importance of adherence in antiviral therapy, principles of adherence, readiness measures, and Dean’s case study, which explored intervention strategies targeted at psychiatric patients. Dean, a registered nurse, has a long history of working with DOT programs for both antiretroviral therapies and TB medicines. She was part of the initial team that developed the MAT program in the storefront Hastings Street location, and then she went on to work for the BC Centre for Disease Control’s Division of Tuberculosis Control Program. In July 2005, the local Health Authority seconded Shelley back to the MAT program to help address a number of challenges that the program had been experiencing. There was ongoing dissatisfaction with MAT, and some physicians had stopped referring patients due to internal conflicts about the way the program was being run. Additionally, the Health Authority hoped that the MAT program would end up being the model for programs to be implemented in other areas of the Lower Mainland.

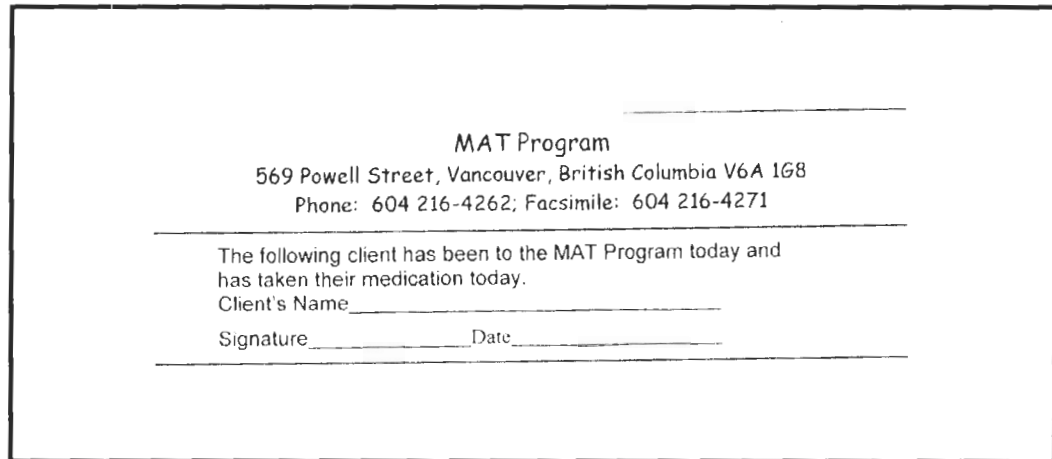
Invited to speak about MAT’s success in reaching patients typically marginalized from health care services, Dean’s presentation focused on a case study of a psychiatric patient involved in the program. She explained that, among “this population,” MAT’s greatest success was with patients who had mental illnesses. She gave a detailed description of one of the program’s most successful stories. Nate, an Aboriginal male, was twenty-eight years old when he first came to MAT with fetal alcohol spectrum disorder (FASD), a mental illness, HIV, and hepatitis C. Nate grew up in northern British



Columbia and, as a young boy, travelled back and forth between two reserve communities - Moricetown (Kyah Wiget) and Gitanyow. Abandoned as a young child, he would go begging door-to-door on the reserve, looking for food. This “very chaotic” young man was also an injection cocaine user and regularly smoked crack cocaine. On three different occasions, Nate had served time in jail for assault. Beginning when he was nineteen years old, Nate has spent time in provincial psychiatric institutions (including Riverview Hospital) on three separate occasions. As an Aboriginal man with a history with the law and a psychiatric disorder, Nate used to have his monthly income assistance distributed through the St. James Society, an organization contracted to dispense state-provided income assistance to individuals who need to receive their funds more than once a month. This arrangement is often made with citizens – especially those with untreated mental illnesses, learning disorders, and addictions - who are deemed incapable of managing their monthly income assistance cheques. While local residents wait in line for their allowance, drug dealers line up to make deals with them, thus preying on those individuals who are often the most disadvantaged in the community.

Trying to figure out how to engage Nate in treatment, Dean and the staff at MAT arranged to have his income assistance dispensed through the social support worker at the Downtown Community Clinic rather than at the St. James Society. Knowing that he had a soft spot for chocolate, they also often bought chocolate bars to give to him when he came in. While these initiatives definitely helped lure Nate into the clinic, additional incentives were also needed. Nate is one of three or four patients at the MAT program who, after ingesting their antiretroviral drugs, receive a slip of paper that reads: “The following client has been to the MAT program today and has take their medication

today” (see figure 3). Once Nate has the slip of paper, he takes it to the worker who dispenses his funds and is provided with his daily allowance.



The image shows a rectangular form with a black border. Inside the form, the text is centered. At the top, it says "MAT Program" followed by the address "569 Powell Street, Vancouver, British Columbia V6A 1G8" and phone/facsimile numbers "Phone: 604 216-4262; Facsimile: 604 216-4271". Below this, there is a statement: "The following client has been to the MAT Program today and has taken their medication today." This is followed by two lines for "Client's Name" and "Signature" with "Date" written below the signature line.

**Figure 3. MAT program documentation.**

The MAT program directly observes Nate’s ingestion not only of antiretroviral medicines but also of his daily psychiatric medicines. The staff also worked to help stabilize his housing, acknowledging the role of stable housing in effective treatment. Again, unstable housing is directly connected to one’s competency. Dean recounted a story about Nate’s exploitative housing situation to help illustrate his vulnerability and inability to care for himself. The manager of the single-room occupancy (SRO) hotel in which Nate lived frequently rented out his room to local sex workers who were looking for a place to bring dates, forcing Nate to leave the room when it was needed for this purpose. The MAT program staff helped Nate find alternative housing, placing him first in the Portland Hotel, which, as a “social housing” project with twenty-four-hour staffing, was deemed a better alternative than the SRO. Because the Portland houses local residents who are not wanted in any other housing facilities it is full of drug dealers, who, of course, continued to take advantage of Nate. In late 2005, Nate finally moved to a new

social housing facility that was deemed considerably safer than the Portland. Dean also arranged for Nate to receive “primary care” – that is, assistance with bathing – every Monday at the MAT clinic.

When I first met Nate, he was in a wheel-chair, had a halo traction brace, and was in St. Paul’s Hospital on the 10C AIDS ward. After he was discharged, I frequently saw him outside the Portland Hotel, wheeling himself down Hastings Street in his wheel-chair, still with his halo brace. Clearly, Nate is an individual who does require additional support in his life. His mental health is reported to be quite impaired; the MAT staff members explained that they weren’t quite sure, when they asked him about switching his money distribution from St. James Society to the Downtown Community Health Clinic, that “he really understood what he was saying.” They explained that, due to his severe schizophrenia and chronic drug use, he has “brain damage”. CT scans have shown that the portion of his brain that controls impulse has been destroyed and that not only will it not improve but it will also continue to deteriorate. Nate’s lack of impulse control is considered a threat to the well-being of others: he is deemed “dangerous” and therefore suitable neither for home care (where the tending nurses would be at risk) nor for a mental health boarding facility (where he might lose his temper and hurt fellow residents). Nate is now thirty-two years old, and it is hard to imagine him as a dangerous man. He is sweet, soft-spoken, likes to tell jokes, and loves to go to movies with his girlfriend, whom he met at Riverview Hospital.

The MAT program’s success with Nate was verified by a CD4 cell count of 520 and an undetectable viral load. And, indeed, these are incredible results for anyone

living with HIV. However, as an infectious disease specialist commented, medicine might keep him from dying from an AIDS-related illness, but his chances of living a long, healthy life are limited. Like so many Downtown Eastside residents living in dire poverty with chronic addictions and untreated mental illnesses, Nate's premature death is almost inevitable – from a drug overdose, a violent encounter, or a motor-vehicle accident on Hastings Street. The antiretroviral therapies suppress the viral load and ward off opportunistic infections, but Nate is barely surviving. This is one of many paradoxes present in public health in the Downtown Eastside. It is assumed that he is dangerous and incompetent. While Nate may very well have serious developmental or mental illnesses,<sup>8</sup> the assumption is that he is completely incapable. I joined him and a MAT staff member for lunch one afternoon. The staff at his new housing facility had complained that he was leaving the burners on in his room. The staff member looked at him and asked, "Are you using them to light cigarettes then forgetting to turn them off?" As he sat there shivering, he explained that his apartment was freezing and that this was the only way to warm it up. The support worker for the social housing project had assumed that he was "forgetting" to turn the burners off and had reported this to Shelley Dean. I then asked Nate, "Did they ask you why you were leaving them on?" His response: "No." Many health care professionals and advocates imagined that provincial strategies to deinstitutionalize mental illness - that is, to move treatment for mental illnesses from psychiatric institutions to the community – was a progressive move. Unfortunately, deinstitutionalization, coupled with a public health system that is not prepared to deal with community health and a lack of community funding, has created the very conditions that Nate faces daily. But Nate is *not* representative of most of the participants at MAT.

Many do live in precarious housing conditions, many have serious drug addictions (seventy-one out of eighty participants were active, chronic drug users – not including marijuana use), and many are seriously ill. And many are intelligent, articulate men and women.

The combination of theories regarding the impact of drug use on the brain, the administrative language of public health officials, and the complicated everyday clinical experiences involved in working with individuals who often don't take their medicines and who live lives that are very different from those lived by the nurses and clinicians providing care has resulted in health care providers' framing and seeing patients as "chaotic" and, therefore, in need of supervision and regulation.

### **Concluding Thoughts: The persistence of colonial logic**

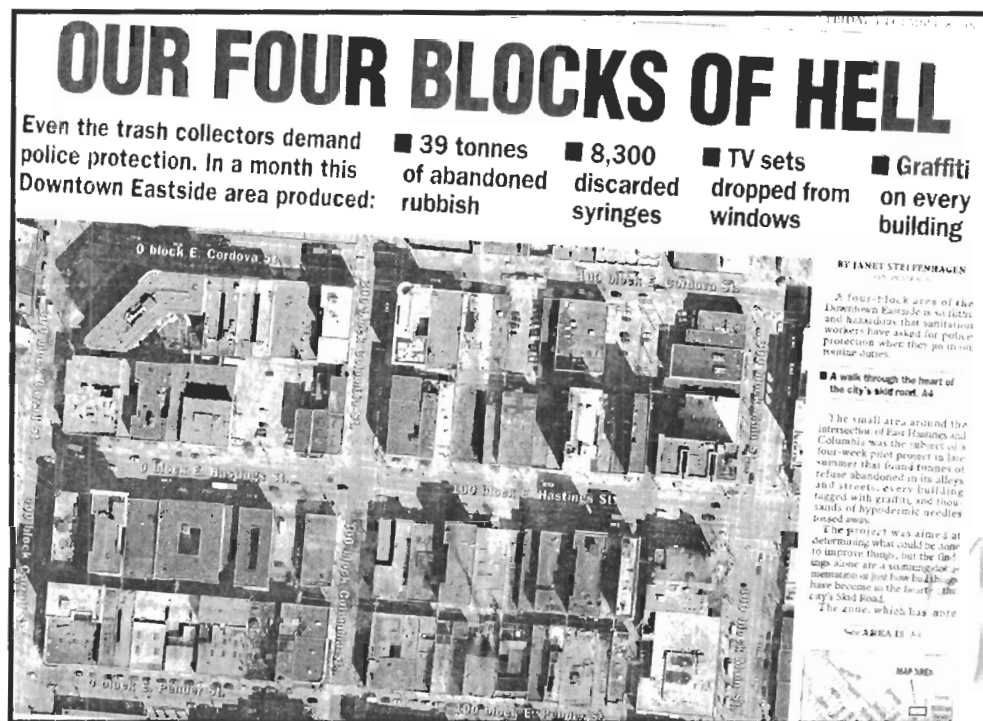
Largely absent from our depictions and descriptions of the Downtown Eastside is the way in which history, colonialism, and race have shaped the lives of local residents and influenced the way in which we think about this community.<sup>9</sup> Like many other anthropologists, those of us working in racialized spaces like the Downtown Eastside are forced to reckon with ethnography's colonial history while simultaneously working in colonized spaces and imagining postcolonial futures (Comaroff and Comaroff 2003). It is a racialized space – marked by its long history as a place of refuge for new immigrants of colour (Chinese and Japanese), a place of convergence for Aboriginal people across Canada travelling to the West Coast, and a historical homeland to local Coast Salish peoples.<sup>10</sup> While not all residents in the Downtown Eastside are First Nations, in complex, often contradictory ways, Aboriginality seems to play a central role in everyday

life. It is difficult to come up with a number that accurately reflects the Aboriginal population living in the Downtown Eastside – identity politics among Aboriginal peoples in Canada is intensely complicated, and statistical methodology for counting people highly problematic; however, as other researchers have noted, one can't help but notice that First Nations are overrepresented in the Downtown Eastside (Culhane 2003).

In the Downtown Eastside, as in Canada more generally, history plays a central role in understanding current health and illness disparities. The process of colonization has been a pivotal force in the construction of Aboriginal health and illness. As Kelm (2001, xix) explains, “Aboriginal ill-health was created not just by faceless pathogens but by the colonial policies and practices of the Canadian government.” Historical studies examining the intersection of medicine and colonialism in Canada highlight the ways in which the Canadian state has used public health (and disease) as a governing strategy to monitor and manage Aboriginal peoples. Such studies have also highlighted the ways in which particular populations have been constructed as “non-compliant” and, thus, requiring more coercive sanctions surrounding public health.<sup>11</sup> The history of First Nations health care is dismal. Targeted with coercive health policies and practices like quarantine and isolation in the treatment of TB, First Nations were more likely than others to become ill at the hands of Western medicine (Lux 2001). As in other colonial nation-states, in Canada treatment modalities were often developed in order to keep disease away from the white-settlers rather than to effectively treat local indigenous populations. Indeed, disease epidemics often spurred changes in the Indian Act (Lux 2001). Social practices of the state, such as forcing young Aboriginal children to

attend residential schools, also had a devastating impact on Aboriginal health and well-being.

The deployment of the concept “chaos” is reminiscent of colonial discourse that constructs the racialized other as “disordered” and “unruly” as opposed to the civilized character of the Empire and its citizens. In the case of colonial South Africa, Jean Comaroff (1993, 306) has documented how the “talk of civilizing Africa had given way to a practical concern with the hygiene of black populations,” with how “persons were disciplined and communities redistributed in the name of sanitation and the control of disease.” The logic of contemporary biomedicine is a colonial logic. Just as in South Africa, so in the Downtown Eastside: under the guise of “cleanliness and health” residents are disciplined and regulated, the purpose being to transform them into new citizens. The rhetoric of chaos, as well as continual references to “this population,” “these kinds of people,” and “those people,” functions to distance, or “other,” Downtown Eastside residents. Like colonialist discourse on the racialized other, “chaos” is part of a postcolonialist rhetoric that masks racializing assumptions. It implies that Downtown Eastside residents live in a savage state, are closer to “nature,” are “primal.” It is, in a word, pathologizing (Vaughan 1991).<sup>12</sup> This is supported by news media images of the Downtown Eastside that construct the space as “abnormal” and “uncivilized,” by by-lines that refer to the zone as a “living hell” or comment on the garbage and filth (see figure 4) (Robertson 2006).



**Figure 4. Media Representations of the Downtown Eastside.**  
**Source: The Vancouver Sun, December 8, 2006.**

Further, the return to theories of the biological in order to explain one's ability to adhere to antiretrovirals or to comply to regulations is reminiscent of colonialist discourse on Aboriginal peoples and racialized others. These theories mirror colonialist tactics of governance, which rely on ideas about "nature" to justify abandonment and coercion. These arguments, couched in new scientific evidence, are eerily similar to eugenic arguments from the 1930s through to the 1970s, which held that those deemed "incapable" according to scientific measures were forced to undergo sterilization (e.g., the Leilani Muir case in Canada) or other coercive public health practices. Except that this new discourse refers not to inherited traits but to biological deficiencies that are primarily drug-induced. As Nicholas Rose (2003, 407) notes, "diseases of the will have become diseases of the brain," and this is aptly demonstrated in the 1997 *Science* article entitled "Addiction Is a Brain Disease, and It Matters."<sup>13</sup> These theories, and the



production of this new medical knowledge, influence everyday medical practice in the clinic as well as policies surrounding compliancy. And they more often than not do so erroneously. I suggest that the deployment of these tropes about “chaos,” “damaged” character, and “brain disease” are postcolonialist tactics that rely on claims of scientific knowledge to justify colonialist practices of governance and regulation (White 2000). These discourses erase Aboriginality and colonialist histories from contemporary discussions of public health and HIV treatment. Yet, as mentioned, Aboriginal people make up approximately 50 percent of the DOT programs, and, increasingly, they are the focus of the epidemiological research coming out of the Centre for Excellence in HIV/AIDS.

The assumptions embedded in medico-scientific knowledge about the brain shape the way in which inner-city populations are imagined and “treated.” The assumption that all Downtown Eastside residents are chaotic and incapable of adhering, and that chronic drug use translates into brain damage, means that public health programs whose intent is to improve the health of the marginalized end up simply containing local residents through demanding daily attendance. Like methadone maintenance, these programs function as a form of what the MAT nurse referred to as “chemical incarceration,” as one feature of the spatializing practices of the state-sponsored health care system, which functions to legitimize the inequities in HIV treatment. DOT programs are juridico-medico spaces within which questions of personal autonomy and competency are constantly negotiated; within which compliance to rules and regulations is demanded, behaviours are policed, and morality is governed.

## **CHAPTER 6**

### **THE POLITICS OF PRESCRIBING: IAS GUIDELINES, MEDICAL PRACTICE, AND NEGOTIATING AGENCY**

#### **Introduction**

Recent research in the social studies of science has highlighted the political and contested nature of guidelines and protocols developed for therapeutic and clinical practice (see Berg et al. 2000; Berg and Timmermans 2000; Clarke and Star 2003; Fujimura 1998). Presented as unproblematic “objective” findings based on clear “evidence,” clinical guidelines attempt to universalize prescribing and therapeutic practices, to erase idiosyncratic localized particularities, and to enhance efficiency of care. The construction of these artifacts, or technologies, of medicine occurs as part of a “political process” whereby scientific facts, expert knowledge, and authority are contested and established (Fujimura and Chou 1994).

Clinical practice for HIV/AIDS is also shaped by therapeutic guidelines developed to improve standard of care for patients, to provide up-to-date knowledge to clinicians, and to ensure the cost-effectiveness of antiretroviral therapy. These guidelines, too, are products, or “effects,” of scientific debates and disciplinary struggles regarding how scientific claims about treatment and drug development should be evaluated. Here, I examine therapeutic guidelines for HIV/AIDS as cultural texts in which stories are unfolding, in which knowledge and expertise is being contested, and in which particular types of scientific “facts” and evidence are being privileged. This chapter contributes to my ongoing exploration of the production and contestation of scientific knowledge in the field of HIV/AIDS, particularly as it relates to the delivery of therapeutic interventions.

There are multiple guidelines for the treatment for HIV, including those produced by the International AIDS Society, the US Department of Health and Human Services (DHHS), the British HIV Association, the British Columbia Centre for Excellence in HIV/AIDS, and the World Health Organization (WHO). There are guidelines for specific “populations” (i.e., injection drug users, those in resource-poor settings), age categories (infants, adolescents, and adults), and pregnant and breastfeeding women. In this chapter, I focus on the guidelines developed by the International AIDS Society (a series of published guidelines in the *Journal of the American Medical Association*) and the BC Centre for Excellence in HIV/AIDS (1995; and in a web-based form released in 2006).

This chapter is based primarily on a small subset of interviews I conducted with HIV experts involved in developing guidelines, on informal discussions with clinicians who were making decisions regarding initiating therapy, on clinical observation, and on a close textual reading of the two sets of guidelines. These guidelines affect many implicated actors – people who have HIV and seek treatment, clinicians and other health care professionals, HIV scientists, and pharmaceutical companies and their shareholders. Although presented as objective and evidence-based, these guidelines are sites where particular facts are made, authoritarian battles are waged, power and influence are fought over, and capital, in many forms, circulates visibly.

### **International AIDS Society Guidelines for Treatment: Evidence, objectivity, and peer review**

#### *Treatment Guidelines*

*The International AIDS Society–USA commissions expert panels to issue recommendations and guidelines for patient care in areas where there is controversy or insufficient data for definitive approaches to care or treatment. Funding for the*

*guidelines is provided by the International AIDS Society–USA; commercial support is not accepted. Panel members participate on a volunteer basis.*

-- From <http://www.iasusa.org/pub/index.html> (accessed 5 June 2006)

Given the rapidly evolving nature of pharmaceutical science as it relates to HIV, a panel of experts was formed to develop international treatment recommendations for the clinical management of this disease. The panel was first commissioned in 1995 by the International AIDS Society (IAS) – perhaps the world’s largest body of HIV/AIDS researchers and clinicians – but it continues to meet and revise the guidelines on a regular basis. These particular guidelines are published, after a peer-review process, in the *Journal of the American Medical Association (JAMA)* as a “consensus statement.”<sup>2</sup> They are revised every year or other year, depending on the current state of research findings. According to the first publication, in 1996, the objective of the guidelines is “to provide clinical recommendations for antiretroviral therapy for human immunodeficiency virus (HIV) disease with currently [mid-1996] available drugs. When to start therapy, what to start with, when to change, and what to change to were addressed” (Carpenter et al. 1996m 146). The IAS guidelines are succinct – between eight and fifteen pages long – and they are considerably shorter and more precise, for example, than are the guidelines produced by the US Department of Health and Human Services (DHHS) (over a hundred pages) or the World Health Organization. The DHHS guidelines are “national” recommendations meant for the American context and are created by a multidisciplinary American panel (with no international committee members). The DHHS guidelines are updated approximately twice a year and are available free of charge on the DHHS website. The IAS guidelines, on the other hand, are meant to have a more universal application, are developed by a panel of clinicians, and are more accessible to busy

clinicians who might have little time to read through the more comprehensive and lengthier documents.

The IAS committee comes together once every year or two to review all current research surrounding HIV treatment, from drug development to care, and to translate this research into “best practice” for clinicians. The guidelines are not meant to be “restrictive” but, rather, to guide clinical practice and to improve standard of care by ensuring consistent and up-to-date clinical practice. The IAS guidelines evaluate existing clinical trial results and make recommendations based on the evidence they provide. When the evidence is murky, or not very compelling, the committee puts forth recommendations based on its experience and knowledge. In 2006, the guidelines were modified to include rating criteria to measure the evidence. Inserted into the document is a box that provides readers with a scale, or measure, adopted from other American biomedical associations, and which the panel used to evaluate clinical trial results. The insertion of criteria and the added comments regarding the weighing of evidence alerts us to some tension regarding what recommendations were being made and on what basis. And, in a conversation I had with one of the committee members, I found that he believed that this weighing and evaluation of “evidence” in the development of the guidelines clearly demonstrated that they were indeed “objective.”

The IAS guidelines were developed as a tool for clinicians who are operating in nations that have access to new medicines (“relatively unrestricted choices of drugs and diagnostics monitoring tools”); clinicians who work in resource-poor settings are referred to the WHO guidelines (Yeni et al. 2006, 252). Although the IAS guidelines claim to be

“international” in scope, they clearly reflect global disparities in access to antiretroviral therapy. They are distinctly cultural texts. Like other clinical guidelines, the IAS guidelines were developed as a way of reducing variation in therapeutic and diagnostic practice that cannot be substantiated.

### **Delaying therapy**

*Current literature is controversial in providing evidence to determine optimal time to initiate therapy...*

-- Wang, Masho, and Nixon (2006)

Therapeutic guidelines for HIV/AIDS are not so much “clinical care” guidelines as they are recommendations regarding prescribing practice - when to start patients on antiretroviral therapy and what specific medicines to use. Most HIV clinical guidelines tend to address: when to initiate therapy, when to change therapies, what specific drugs to use, the role of laboratory testing in treatment (resistance testing, pVL, and CD4 measures), adverse effects, and the role of adherence in treatment.

Antiretroviral therapy remains the only effective biomedical intervention for HIV. Research clearly indicates that, with antiretroviral treatment, patients with HIV live healthier and longer lives. And HIV remains one of the only infectious diseases for which treatment is intentionally delayed. Diagnosis of HIV infection does not mean one will begin taking medicines; in part, this is because individuals diagnosed with HIV infection can remain symptomless for up to ten years or more. Initiation of drug therapy depends on many variables, but it is generally dependent upon the physician’s recommendation after she or he reviews the virological (viral load) and immunological (CD4) markers. It is quite common for individuals to be positive for over ten years before they begin taking

medicines. The recommendation to delay treatment of HIV is based on concerns about drug resistance and the adverse effects of long-term therapy. Many antiretroviral therapies are considered toxic and produce a range of long-term and short-term side effects. According to Dr. Richard Harrigan, director of research labs at the BC Centre for Excellence in HIV/AIDS, evidence regarding the long-term impact of resistance on the clinical outcome of patients is only unclear because research is still under way. As discussed in Chapter 3, research that he and his colleagues have carried out in Vancouver suggests that there are four determinants of drug-resistant mutations – a high baseline viral load (the viral load is very high when the patient begins treatment), low CD4 cell count at initiation of treatment, a history of intravenous drug use,<sup>2</sup> and a less than 95 percent prescription refill rate (considered to be indicative of adherence) (Harrigan et al. 2005). Such evidence regarding resistance and its possible effect on public health continues to be central in the development of clinical recommendations for treatment.

In the clinic, nurses and clinicians emphasize adherence as the main contributor to resistance. Of course, this also emphasizes the patient's "willingness" or "readiness" to take medicines (i.e., her/his "choice"); whereas the baseline CD4 cell count and plasma viral load are determined not by the patient but by the clinician, who decides when to start medicines. The study by Harrigan and associates was the first to explore the multiple determinants of drug resistance, so it is quite feasible that many front-line clinicians and health care professionals are unaware that adherence is only one of a number of factors related to resistance. Thus, even though multiple factors are involved in drug-resistant mutations in HIV, adherence is still considered to be the mostly likely factor to influence resistance (almost twice as likely as any other).

The decision when to start antiretroviral therapy is one of the most contested issues in HIV treatment, and it is regularly modified in the IAS therapeutic guidelines. Since the initial guidelines were published in 1996, they have consistently recommended that, regardless of viral load or CD4 measures, patients who are symptomatic or presenting with opportunistic infections should initiate therapy. Deciding when to initiate therapy for patients who are asymptomatic is less straight-forward. In part, this is due to debates regarding which measure should be considered the main indicator of treatment.

In 1996, the IAS guidelines weighed both virologic (viral load) and immunologic (CD4 cell count) measures in their recommendations as to when to begin therapy. They suggested therapy not only for patients with plasma viral loads higher than 5000 to 10,000 copies but also for those with CD4 cell counts below 500 (Carpenter et al. 1996). In 1997, the panel changed its recommendation to emphasize only the virologic measure, suggesting therapy for “all patients with plasma HIV RNA concentrations greater than 5000 to 10 000 copies/mL *regardless* of CD4+ cell count” (Carpenter et al. 1997, 1964; emphasis added). In 1998, the panel reiterated its statement emphasizing plasma viral load, but in 2000 it returned to balancing both CD4 and viral load measures, suggesting that clinicians treat patients with a CD4 cell count less than 350 *regardless* of viral load and treat patients with viral loads greater than 30,000 *regardless* of CD4 cell count. By 2002, just two years later, the panel advised that “CD4 cell count [is] the major determinant of initiating therapy.” It recommended treatment for patients with CD4 cell counts below 200 and said that patients with viral loads “above 50,000 to 100,000 copies/mL should be closely monitored (clinicians may consider treating)” (Yeni et al. 2002, 224). In 2004, the guidelines continued to emphasize immunologic markers as the



defining measure with regard to initiating treatment (CD4 less than 200), but they noted that evidence continued to suggest that virologic measure should also be considered, pointing specifically to a study conducted by the BC Centre for Excellence in HIV/AIDS, which showed a direct correlation between baseline viral loads above 100,000 copies/mL and mortality.<sup>3</sup> The 2006 IAS guidelines recommended the same strategy. A month later, however, a preliminary research report published in the *Journal of the American Medical Association* suggested that HIV RNA level was of “limited clinical value in shaping the decision to initiate antiretroviral therapy” because the findings suggested that baseline viral load was not a predictor of CD4 cell decline over the future course of one’s illness (Rodríguez et al. 2006, 1505).

But outside of the dispute regarding what the indicator should be, there is also considerable debate regarding when exactly to begin treatment. In 1996, the guidelines suggested early and “aggressive” treatment, recommending that physicians initiate antiretroviral therapy for all those with CD4 cell counts below 500 (the average CD4 cell count for a non-HIV infected adult is about 1000). In 2000, the guidelines advised treatment for anyone with CD4 cell counts below 350; and by 2002, they had dropped that measure to just 200. In 1995, researchers were suggesting that “the time to hit HIV [is] early and hard” (Ho 1995, 450). Delaying treatment, which is favoured by some, was based on the concern about serious side effects. This concern continued to resurface, and in 2000 Dr. Keith Henry (2000, 306) demanded that the therapeutic guidelines be revised to reflect a “more cautious, patient-focused antiretroviral therapy” approach. In fact, drawing on published research, he suggested that a case could be made for delaying therapy until the CD4 cell count had dropped to 100 (*ibid.*). And the 2006 IAS guidelines

indicate a return to a slightly more forceful approach, suggesting patients be considered for treatment at the 350 cell count mark. This reflected research that had been presented at the Conference on Retroviruses and Opportunistic Infections (CROI) in 2006 by Lichtenstein and colleagues, who found that drug toxicities were less likely to occur in patients who started treatment early, and they challenged studies that suggested delaying treatment due to concerns about drug side effects. Lichtenstein concluded that there was “no reason to delay HAART treatment.”<sup>6</sup>

The changing nature of the guidelines, knowing when to treat, and deciding on what basis, clearly has an impact for those living with HIV. I observed patients in the clinic with HIV specialists, and it was clear that they were frustrated by their lack of direct control over when they were able to start taking medicines. For instance, in September 2005, I met Justine, a twenty-nine-year-old Aboriginal woman, at a local clinic where she had an appointment with the HIV specialist. Justine was demanding that the clinician start her on antiretroviral therapy. She had been diagnosed with HIV just a year before, but it was not clear how long she had actually been infected. Because her CD4 cell count had not dropped below 200, according to both the local BC Centre for Excellence in HIV/AIDS and the international guidelines as defined in 2005 and 2006, she was not considered a suitable candidate for treatment. The HIV specialist that day explained that, according to the guidelines, she was not considered ready for the medicines; however, Justine insisted that she start treatment, and she recounted how her boyfriend had been told the same thing but was now very sick. She said that she didn't trust the doctors. She had recently been in hospital for one week for shingles, and she had been told by the attending physician on the AIDS ward that she should start

antiretrovirals. Her CD4 cell count had never dropped below 202, its lowest point occurring during the episode with shingles. In the past year she had also suffered from pneumonia. Her regular physician at another inner-city health clinic had refused to start her on treatment. The day I first met Justine in the clinic, she was extraordinarily agitated and frustrated because she was forced to demand access to antiretroviral therapy. Later, when we sat down for an interview, she told me that all the doctors were the same.

In the hospital, she had been told that her HIV was progressing as though she had been infected for a decade and that it was imperative that she start medicines. In our discussion, she justified her demands to start treatment by pointing to what the people in the hospital told her as well as her increasing illnesses (i.e., the shingles and pneumonia) as evidence that she needed medications. The clinicians who refused to give her treatment, or those who hesitated, using the guidelines as their evidence as to why she should *not* start treatment, were deemed “bull-headed.” She did not care that the guidelines stated she could not begin treatment until her CD4 cell count dropped below 200: she wanted treatment now.

Other patients also resisted the prescribing practices, and sometimes this meant not starting medicines even after the clinical measures clearly supported initiation of therapy. However, resisting or evading medicines is much easier to negotiate than is receiving medicines. Health care professionals and clinicians are acutely aware that they need to be respectful of patients’ decisions not to engage in therapy, even if it goes against the guidelines. But engaging in therapy when it is not supported by the guidelines is something altogether different.

Clinicians explained to patients that, if their measures weren't consistent with the recommendations in the guidelines, then even if the clinician wrote the request for therapy to begin, it was unlikely that it would be approved by the committee at the BC Centre for Excellence in HIV/AIDS. In British Columbia, distribution and delivery of antiretrovirals has been centralized through one institution: each prescription for antiviral therapy must be approved by the BC Centre for Excellence in HIV/AIDS Drug Treatment Program. Prescribing practices are expected to reflect the local guidelines.

The complicated relationship between the IAS guidelines, everyday clinical practice, and the negotiation of treatment between the patient and clinician is highlighted in patients' medical records. Gabriel was a thirty-seven-year-old Aboriginal man living in the Downtown Eastside. When we met in 2005, he had been HIV positive for ten years and had never taken antiretroviral therapy. Tracing his medical records back to 2001, we are able to witness the ways in which the guidelines inform, or don't inform, clinical practice and decisions to start patients on therapy. We see the slipperiness of concepts like "readiness" and the ways in which it is deployed in the clinic setting.

Gabriel first came to Vancouver after being released from a correctional institution in Saskatchewan. In a referral letter from Dr. Stephen Sanche, a physician specializing in infectious diseases at the correctional institution where he was housed in October 2001, it was stated that Gabriel's plasma viral load was at 80,000 but that his CD4 was 633. Because of concerns about the elevated viral load, Sanche recommended that Gabriel "should seriously consider treatment." In another referral letter, dated September 2002, the doctor noted that his CD4 had dropped to 341 (21.3 percent) and his

viral load to 40,000. He also noted that Gabriel had not had any opportunistic infections and that he reported feeling relatively well. He stated that he and Gabriel had had discussions regarding starting antiretroviral therapy but that Gabriel had indicated that he wanted to wait until he was released from the institution. The same letter also states: “He has given some consideration to initiation of antiretroviral therapy, but he steadfastly states that he is not willing to appear in public wearing shackles.” Apparently, HIV care and treatment was only available off-site. Gabriel would have been transported from the facility wearing restraints, or shackles. Unable to endure the humiliation of being seen in public in this way, he refused HIV treatment.

During his time in Vancouver, the Drug Treatment Program had only three records of HIV blood work for Gabriel: September 2003, December 2003, and December 2004. Gabriel’s viral load was over 100,000 copies/mL and his CD4 was 300,230 and 120 cells/ $\mu$ l (13 percent), respectively.<sup>5</sup> Besides the blood work in his file, there is almost no mention of HIV treatment or care in his medical chart. When he first arrived at the clinic in November 2002, the attending physician noted that Gabriel “[thought] he’d like to start HIV meds.” Gabriel returned on 17 December and asked for a copy of his records. The physician wrote: “he does not like the area.” There is no record of another visit until March 2004. During part of this time, Gabriel served time at Matsqui Institution, a medium-security correctional facility located about seventy kilometres from Vancouver (designated as an “Aboriginal intensive facility”).<sup>6</sup> He returned in March 2004, after being released on 3 February.

There is no other mention of HIV treatment and care until 28 December 2004, when the attending physician noted that Gabriel's CD4 was 120, that his viral load was over 100,000, that he was asymptomatic, and that he "want[ed] to start treatment." The physician also noted that Gabriel had lost over twenty-seven kilograms during the past year. Gabriel was referred to an infectious disease specialist, and the medical notes from that consultation read as follows:

*January 11, 2005*

*HIV REVIEW*

*Major social issues – housing. Living in BALMORAL  
Working with D \_\_\_ on housing. Today desperate & emotional  
Realizes that he needs to get on with things  
Long discussion about options*

The same day, Gabriel decided to go and stay at a recovery house in Surrey. By this time, his CD4 has dropped to 120 cells/ $\mu$ l, well beyond the most conservative estimates for starting patients on antiretroviral therapy, and his viral load continued to be more than 100,000 (see figure 5). The clinician wrote that, even though the CD4 had dropped, it was "not critical that he begin ARVs right away." But he added that he would order them so that there would be no delay when Gabriel was "ready to start," suggesting that there had been some discussion about Gabriel's willingness, or "readiness," to start therapy. 3TC/Tenofovir/Efavirenz were requested but Gabriel never picked them up. A few months later, when Gabriel and I talk about his HIV, he explained: "Well, they had ordered me meds, and, and, and I guess because I wasn't in a structured lifestyle, didn't have a place 'n what not, they didn't wanna, didn't want me to start on them."

IAS Guidelines for treatment (for asymptomatic HIV disease): CD4 and HIV RNA		Gabriel's CD4 and HIV RNA	
2000	a viral load > 30,000 regardless of CD4 cell count		
2001	(No new guidelines released by IAS)	633	80,000
2002	≤ 200 cells/μl; CD4 >200 - 350 Treatment decision should be individualized and consider pVL, "patient interest in and potential to adhere," and toxicity	341	40,000
2003	(No new guidelines released by IAS)	300	>100,000
2004	CD4 <200; 200 cells/μl -- 350 cells/μl to 'consider'	230 (120)	92,300' (>100,000)
2005	(No new guidelines released by IAS)	No test	No test

**Figure 5. Comparing guidelines with practice.**

In 2001, according to the IAS guidelines, Gabriel was considered eligible for treatment. In 2002 and 2003, he might have been treated (mostly on the basis of his plasma viral load) if he had been deemed able to adhere. In 2004, both his counts would have made him eligible for treatment. In 2005, we can safely assume that both Gabriel's counts would have worsened without treatment and, therefore, that he would have been deemed appropriate for treatment (at least according to the immunologic and virologic measures).

Since Gabriel's plasma HIV RNA and CD cell count measures made him a suitable candidate for antiretroviral therapy, his health care providers and/or he himself based their decision that he was an inappropriate candidate on other factors. The guidelines for treatment indicate that a patient's "willingness" or "ability to adhere" to

treatment should be an important factor when considering whether or not they should start therapy. Was Gabriel “ready” for antiretroviral therapy? Recall that, on his visit to the Vancouver Native Health Society medical clinic on 28 December 2004, the attending physician noted that he had wanted to start treatment. After the consultation with the infectious disease specialist, it is not clear whether or not Gabriel had changed his mind. In another medical chart at the Vancouver Native Health Society, this one dated 10 March, a nurse wrote: “Doctor ordered meds for Gabriel back in January - Gabriel still not in good housing, needs assessment as when to start”; but there is no reference to what Gabriel wanted. Come 2 April, Gabriel was living on the street again. He saw another physician at the Vancouver Native Health Society clinic for what appeared to be a persistent cough. The notes for this visit read:

*living on the street. smoking rock. states contemplating going for treatment. eats 1 meal a day. pneumonia. low cd4.  
not interested in ARV until he gets a place to stay.*

He was prescribed antibiotics for his cough. But his HIV treatment is never again mentioned in this particular medical chart. Gabriel’s social “ills” (his housing, his frustration, his addiction) are medicalized (treated with medicines, charted frequently in his medical notes), while his HIV (and hepatitis C infection), the actual viral diseases, are socialized. Medical treatment for both these illnesses was delayed until Gabriel was “motivated” enough to “change his lifestyle.”

Thus, the guidelines act as critical instruments in therapeutic practice not only by providing practical measures and suggestions as to when to start medicines but also by providing clinicians with tools with which to justify their clinical practice, to “manage”



and deflect their patients' demands. As Dodier (1998, 53) has argued, "the use of these rules by medical experts depends on the manner in which they 'frame' the individual with whom they are dealing." The IAS guidelines are mobilized in different ways, depending on the patient, the doctor, and the context.

### **Balancing scientific measurements with "patients' readiness"**

The IAS therapeutic guidelines for HIV/AIDS are particularly interesting because they balance scientific measures (virological and immunological) with non-quantitative, behavioural assessments (one's "readiness to adhere"), yet the veneration of so-called scientific objectivity in prescribing practice is neither challenged nor questioned.<sup>6</sup> The 1997 guidelines were the first of the IAS series to emphasize the role of adherence in evaluating the decision to start treatment. As discussed in Chapter 3, although little was known about viral resistance in 1997, it was expected that it would become an issue in the treatment of HIV just as it had in the use of antibiotics and in the treatment of TB. The 1997 guidelines state that "therapy should be considered for all subjects with HIV infection and detectable plasma HIV RNA who request it and are committed to lifelong adherence to the necessary treatment" (Carpenter et al 1997, 1964). In 1998, the committee makes the same recommendation: at least to patients "who are committed to the complex, long term therapy" (Carpenter et al. 1998, 80).

Generally, guidelines impose a rules-based approach to clinical care, which erases individual particularities; yet, the emphasis on the "readiness to adhere" to therapy in the HIV guidelines means that every immunologic and virologic measure must be weighed with a subjective, non-quantitative assessment of the patient and their clinical interaction.

What is most interesting is not so much the weight given to “readiness to adhere” as the fact that “readiness” is not perceived to be a problematic category, as though it is something that any physician could easily measure and evaluate. This has been one of the most controversial issues surrounding treatment for individuals who are chronic or acute drug users: should physicians prescribe medicines to injection drug users or the homeless, who may be less likely than others to adhere to complicated, daily therapeutic regimens? Are they “ready” or able to commit to a life-long course of therapy within the context of homelessness, drug addiction and poverty?

Under relatively normal clinical settings, clinicians may feel that readiness can be evaluated simply by asking the patient whether he or she is ready to start treatment. However, the evaluation of readiness becomes problematic when the patient is already deemed “unruly” or “undisciplined.” This would, of course, apply to Downtown Eastside residents, who are perceived of as “problematic,” “difficult-to-treat,” and “chaotic.”

I highlighted in Chapter 3 that Dr. Thomas Kerr, researcher at the BC Centre for Excellence in HIV/AIDS, has created a measurement tool whose purpose is to evaluate one’s readiness to engage in antiretroviral therapy: the Adherence Self-Efficacy Measure (or ASEM) (Kerr et al. 2005 and 2004).<sup>9</sup> The purpose of the ASEM questionnaire is “to get a better understanding of the kinds of things that are difficult for people when taking HIV medications.” A short, one-and-a-half-page survey, the ASEM asks patients to rate their answers on a confidence scale between 0 and 100. It asks if patients remember the number of pills that they must ingest daily, if they remember to fill prescription refills, if they are able to obtain food required for specific medicines, and so on. On page 2 it

reads: “A number of situations are described below that can make it hard to take your HIV medications as directed.” But there are only two situations described, and both of them relate to drug use: (1) “When using drugs” and (2) “When your [sic] are dope sick.” The ASEM does not provide patients with an opportunity to account for homelessness, depression, lack of a refrigerator with which to keep particular medicines cold, or treatment fatigue.

While the guidelines provide clinicians with clear “evidence-based” scientific measures regarding when to initiate treatment, the emphasis on “readiness to adhere” provides them with a fall-back: the slipperiness of measuring the latter means that clinicians can easily suggest that patients are not ready to adhere, refuse to prescribe to them, and justify this refusal on the basis of the recommended guidelines. The measuring of evidence erases the moralistic nature of this particular component.

### **Developing local guidelines for idiosyncratic patients**

In October 2006, the BC Centre for Excellence for HIV/AIDS released its own therapeutic guidelines for the treatment of HIV/AIDS as part of the provincial Drug Treatment Program.<sup>10</sup> According to its webpage, “The BC HIV/AIDS Therapeutic Guidelines are a consensus of the Centre's Therapeutic Guidelines Committee. This information represents the committee's interpretation of current treatment of HIV/AIDS and related conditions. The guidelines are reviewed quarterly and revisions are mailed to physicians throughout the province.”<sup>11</sup> These guidelines are a dramatically modified and shortened version of those once available from the Centre of Excellence. In 1993, the Centre released the “Therapeutic Guidelines for the Treatment of HIV/AIDS and Related

Conditions,” which, later revised to include well over a hundred pages, provided comprehensive information and guidance to clinicians on everything from testing to antiretroviral treatment, from accidental exposures to the treatment of pediatric AIDS cases.<sup>1,2</sup>

In 2006, Dr. Julio Montaner reported that studies continued to suggest that treatment may act as a secondary form of prevention. In August 2005, just two weeks before the IAS meetings in Toronto, Montaner and his colleagues from the Centre published an article in the *Lancet*, which argued for expanding treatment as a long-term, cost-effective strategy aimed at stalling the growth of the epidemic (see Montaner et al. 2006). Observational studies of mother-to-child-transmission (MTCT) and discordant couples (where one person is negative and one person positive) suggest that individuals with low viral loads are less infectious than are those with high viral loads. In October 2006, presenting at a small conference (the Positive Gathering Conference) in Vancouver for people living with HIV, Montaner explained that there was added “value” in treating patients with antiretroviral therapy. Not only does the individual patient benefit clinically from drug therapy but this hypothesis, “treatment is prevention,” also makes HIV therapy a “public health” concern. Montaner makes a powerful argument for the cost-effectiveness of treating on a wide scale. During the presentation, he explained that “savings guaranteed by short-term deferral of HAART are overwhelmed by costs generated from new HIV infections.”

Based on this reasoning, virological markers would play a more central role in deciding when to initiate treatment and, indeed, therapeutic guidelines would need to be

revised to account for this more aggressive approach. Yet, the therapeutic guidelines most recently released by the Centre read: “HAART is not currently recommended for asymptomatic HIV infected patients whose CD4 cell counts are above 350 /mm<sup>3</sup> *regardless of other laboratory parameters (including viral load)*” (italics added). When questioned about the discrepancy between the guidelines and what he was advocating, Montaner explained that the notion that “treatment is prevention” is only “a hypothesis.” There is as yet no proof, and, until he can provide evidence, he is unable to translate his conviction into policy. In the meantime, as director of Centre of Excellence, Montaner has mandated that, for the next five years, all research at the Centre will focus on this question and that all other projects will be secondary to it.

Yet, the current recommended guidelines don’t reflect evidence from Montaner’s own research team, which indicates that mortality increases for patients who start treatment with a baseline viral load of over 100,000 copies/mL (Wood, Hogg, Yip, et al. 2003). Although there is evidence that suggests otherwise, including a revised 2006 paper by the same authors (see Wood et al. 2006), such evidence would imply that virological measure should be weighed more heavily in treatment guidelines, yet it doesn’t appear in the provincial guidelines and is only mentioned in a note in the IAS guidelines (“consider treatment for patients with high plasma viral load > 1000 000 HIV-1 RNA copies/mL or with rapid decline of CD4 cell count” [IAS 2006m 829]).

What’s interesting is that the delivery of medicines in the local context is defined by the Centre for Excellence: it approves every prescription based on the therapeutic guidelines it develops. The Centre reports that only a small proportion of the people in

the Downtown Eastside who need antiretroviral therapy are actually receiving it, yet its own guidelines, which, for the most part, are consistent with IAS guidelines (at least until 2006, when the IAS changed its recommendations to initiate therapy at CD4 cell count of 350), limit who can be on therapy. In 2001, Brian Harrigan reported that approximately 400 people were receiving treatment through MAT/DOT programs (Forum for Collaborative HIV Research 2001) - about 100 more than Downtown Eastside currently engaged in therapy (six years later). But the continual shift in therapeutic guidelines, from originally treating a CD4 cell count below 500 to treating a count below 200, means that considerably fewer people are eligible. Thus, the Centre's own guidelines limit who is eligible for treatment.

### **Clinical Practice – Everyday prescribing practices**

There is ongoing debate among clinicians from all fields regarding whether or not clinical guidelines restrict the freedom of doctors, whether they act as a form of surveillance or truly improve quality of care. One HIV researcher suggested to me that national or regional guidelines like those produced by the BC Centre for Excellence in HIV/AIDS (or Veterans Affairs in the United States) are simply policy documents whose focus is cost-recovery and fiscal responsibility. While he suggested that no guidelines have ever suggested that therapy was not effective, they do recommend pharmaceuticals that are relatively equal in effectiveness and safety but less expensive to the state's coffers. For instance, if two drugs are seen to be close in effectiveness - say one drug is considered to be only 5 percent to 12 percent more effective than another but costs considerably more, the less effective drug will most likely be recommended. But what is the cut-off point? At

what percentage does cost-effectiveness become less important than the quality of the drug chosen?

Clinical practice from a range of fields is governed by similar therapeutic guidelines, and there has been increasing discussion regarding the influence of these guidelines on everyday practice.<sup>2-3</sup> Do they negatively affect medical practice? Do physicians comply? What happens when clinicians don't comply? Research from the Centre for Excellence suggests that its own guidelines do shape the prescribing practice of clinicians (Montaner, Hogg, Yip 1997). And, indeed, one clinician, who recently moved to Vancouver and practises at St. Paul's Hospital, observed that he had never seen such prescribing consistency at any other hospital.

In the BC context, the guidelines are meant to support and guide clinical practice, but they are not hard-and-fast rules. Reportedly, the Centre for Excellence's committee for approving drug requests rarely actually denies a request; instead, it sends letters to the prescribing clinicians suggesting that the prescribed antiretroviral regimen is not recommended, that the Centre is approving the request, but that should the treating physician require additional information on more preferred treatment options, he or she can contact the Centre. I saw such letters at the DOT clinics. In one such case, the prescribing physician had requested an antiretroviral therapy regimen that was considered particularly outdated. In the end, the patient had been referred to the infectious disease consultant, so there was hope that the regimen would have been changed. Although there is a danger that guidelines may become bureaucratic instruments that restrict practice, this was not reported in the Vancouver context.

## **Contesting Prescribing Practices: Nevirapine or Efavirenz?**

*Many people do not realize that this quality of care is due to the existence of the BC Centre for Excellence in HIV/AIDS (BCCfE), and that it is the BCCfE's Therapeutic Guidelines Committee – not BC PharmaCare – that determines who gets what HIV drugs. Once Health Canada approves a drug, the BCCfE has always had complete autonomy to decide whether and how to include the drug in the treatment guidelines.*

-- Dr. Paula Braitstein (2005, 2)

Guidelines for HIV do not simply shape clinical prescribing practices: they define what specific drugs clinicians should or can use. And, as in other medical fields, this has focused attention on the relationship between guidelines, clinicians, and pharmaceutical firms.<sup>14</sup> There are concerns that the guidelines committees are too influenced by the pharmaceutical industry. Because the guidelines recommend specific drugs, they not only have implications for clinicians, patients, and health care insurance plans but also for pharmaceutical companies and their shareholders. Because of the enormity of the HIV therapeutic citizenry, a recommendation to use one particular drug can increase a company's trading share enormously. The World Health Organization estimates that, in 2006, 38.6 million people have HIV, providing pharmaceutical companies with massive global markets even in light of the push for Big Pharma to donate medicines or lower prices for resource-poor settings (WHO 2006). In 2005, WHO reported that, globally, only 20 percent of those in need of antiretroviral therapy (defined by WHO therapeutic guidelines), 1.3 million out of 6.5 million, were actually accessing it (WHO 2006). One IAS guidelines panel member told me that, after the guidelines are released, they have high-level pharmaceutical medical directors demanding to see the committee members so that they can present them with evidence proving that their drug should be the recommended drug. Pharmaceutical market shares drop, skyrocket, or stabilize based on the decisions of a small panel of clinicians. Similarly, changes in guidelines that suggest



that clinicians should treat earlier (before the CD4 drops to 200) also result in dramatic financial costs/savings for medical insurance providers, public health care services, and nations. In the BC context, this creates a particular paradox: the Centre for Excellence must not only be fiscally responsible to the Minister of Health with regard to the HIV medicine budget but it must also develop the local therapeutic guidelines that define when (and thus how many) people are on treatment.

Dr. Julio Montaner is acutely aware that cost-effectiveness is the most powerful language of politicians and policy makers. At a public presentation at the University of British Columbia in March 2007, Montaner explained that he doesn't care about saving money, that he only cares about saving lives. Yet he is fully aware that politicians consider those public health interventions that save money. Consequently, his "treatment is prevention" campaign is based on an economic analysis that suggests that, in the long term, millions of dollars will be saved if HIV is aggressively treated now.

During AIDS Rounds at St. Paul's Hospital in April 2006, Dr. Mark Tyndall responded to a question from the audience about the use of Nevirapine over Efavirenz, stating that, in British Columbia, "cost is the major reason why we've gone to Nevirapine as preferred NNRTI and the 2NN study would support that."<sup>15</sup> Here, he justifies the Centre for Excellence's policy of prescribing Nevirapine, which bucks the national trend and is the less expensive alternative, by referring to a much-contested study. In fact, British Columbia is the only province in Canada to support the 2NN study. Efavirenz is available through the Centre for Excellence's Drug Treatment Program, but "restrictions apply."

Others have suggested that decisions to include particular drugs in guidelines are influenced by the relationship between pharmaceutical companies and research centres (Taylor and Giles 2005). This, too, has been a concern on the local HIV research landscape, with rumours suggesting that the decision to recommend Nevirapine over Efavirenz is less about cost or the 2NN study than it is about the relationship between Boehringer Ingelheim, the maker of Nevirapine, and the Centre for Excellence. In 2002, Boehringer Ingelheim gave Julio Montaner the Distinguished Researcher Award in HIV – a \$1 million award for excellence in HIV research and treatment. Montaner donated the funds to the University of British Columbia, where it was used to set up a professorship in HIV health outcomes (which Dr. Robert Hogg eventually filled). Nonetheless, there were serious concerns that prescription practice for HIV in the Province of British Columbia was being influenced by drug companies rather than by “evidence.” On a global scale, outside of the field of HIV, there has been increasing pressure for clinicians and researchers to account for “conflicts of interest” with drug companies. They must note in publications whether they have received travel grants, research awards, or own stock in particular company shareholdings. Critics have noted that fully teasing out the relationship between pharmaceutical industry funding and prescribing practice is difficult. Some suggest that even funding for conferences (travel, accommodations, and meals) has been linked to increased prescribing practices that favour the sponsoring drug company (Choudhry, Stelfox, and Detsky 2002; Alberts, Bennett, and Woolf 2002; Taylor and Giles 2005). Attempts to fill guideline committees, like the IAS therapeutic guidelines committee, with researchers who have no possible conflicts of interests with industry is, essentially, impossible.

## **Concluding Thoughts**

Understanding how guidelines are created, how knowledge is contested in their making, the scientific controversies surrounding the evidence used, and the divergent ways in which they are deployed highlight the politics of making “facts” (Fujimura and Chou 1994). Guidelines for HIV do not rely solely on the biological or the cellular; rather, they balance these measures with qualitative psychosocial determinants – one’s “readiness” to adhere and one’s commitment to therapy. The emphasis on readiness to adhere reflects the moralizing nature of therapeutic guidelines. “Readiness” is not scientifically measurable. It is based on theories of adherence that, as discussed in Chapter 3, are value-laden and ideologically driven. The emphasis on readiness that one sees in the guidelines creates a similar paradox: clinicians decide that patients in the Downtown Eastside are not ready to adhere because they have “chaotic” lifestyles (e.g., Gabriel’s lack of safe and secure housing, his addiction to crack cocaine) and so they delay treatment. This decision, rather than being recognized as morality-based is represented by the IAS guidelines as “evidence-based medicine.” Thus the guidelines effectively mask the subjective, moralistic reasoning of the clinician or other health care professionals involved in treatment and care of the patient.

The IAS panel members reinforce the peer-reviewed nature of these guidelines, the fact that the recommendations are a consensus, and the weight of evidence as proof of their objectivity. Yet this is clearly an unstable field, where clinicians, HIV scientists, and pharmaceutical firms negotiate various recommendations (albeit informally). In clinical practice, at least locally, the guidelines are mobilized to negotiate the clinical encounter rather than to confine or restrict prescribing practice. They are part of a trend towards

evidence-based medicine, yet, in actual everyday practice, clinicians, researchers, and policy makers deploy them strategically, depending on the framing of the patient.

## **CHAPTER 7 PHARMACEUTICALS, VACCINES, AND THE POLITICAL- ECONOMY OF HIV MEDICINES IN BRITISH COLUMBIA**

*Why fight to push expensive drugs down people's throats when they are homeless or living in SROs? The pharmaceutical companies are making big profits. They should leave us a legacy of social housing down here, not pissant little stipends on drug trials.*

*--Ann Livingstone<sup>1</sup>*

### **Introduction**

The production, circulation, and consumption of drugs in the Downtown Eastside has been and continues to be the focus of extensive research projects, state interventions, and public health campaigns – but almost exclusively the focus has been on illicit drugs – those criminalized under Canadian law. Cocaine, heroin, crack cocaine, crystal meth<sup>2</sup>, and marijuana are studied, traced, mapped and seized in the community. But prescription drugs, what Lakoff (2005, 197) calls “ethical pharmaceuticals,” are equally important in the community in terms of frequency and intensity of use, their market value, and their ability to mask, cure and treat dis-ease of the body and mind. They are valuable commodities sold and traded on the street, especially narcotics and benzodiazepines. As I noted in Chapter 4 in my exploration of local DOT programs, the value of prescription drugs on the street is well known by physicians practicing in the neighbourhood and those working in the hospitals who often demand daily observed consumption for such prescribed medicines or, alternatively, refuse to prescribe painkillers, sleeping pills, or mood stabilizers to individuals they suspect have addictions (see figure 6). Some patients do hope to get prescribed pharmaceuticals from their physicians for their market value on the street. But other local residents voiced intense frustration with doctors who would not

prescribe pain medications, especially in the hospital setting, suggesting that it was cruel and unusual punishment based on erroneous stereotypes of drug seeking behaviour.

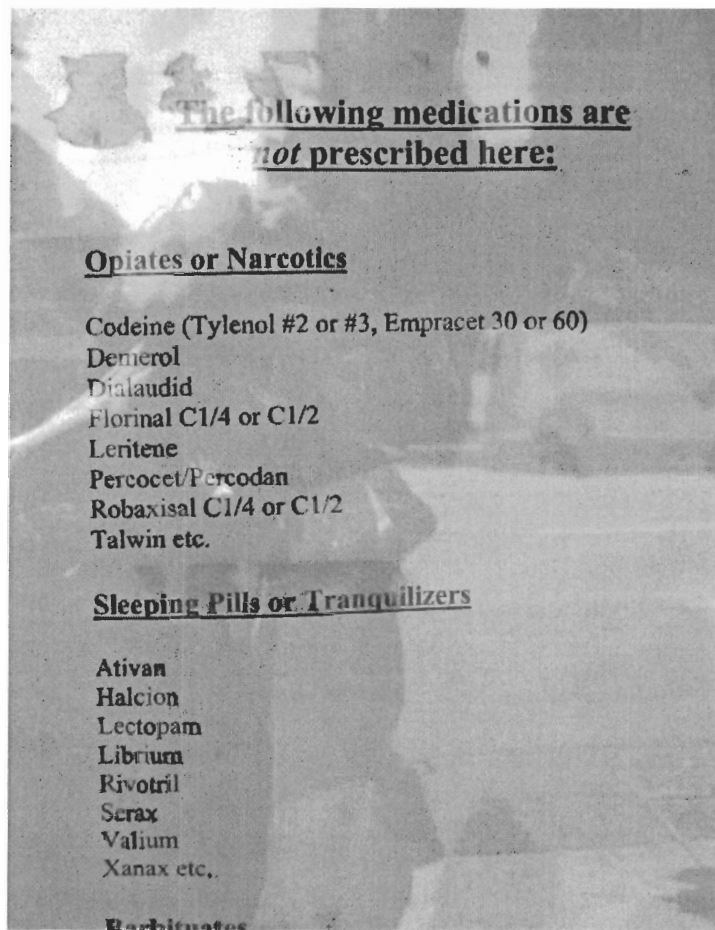


Figure 6. "Ethical" Pharmaceuticals.

One is struck by the amount of prescribed drugs that local residents are ingesting. In interviews participants would list off sleeping pills, HIV medicines, methadone, vitamins, painkillers, anti-depressants, anti-psychotics, and others. None of these medicines are known to cure any disease – including antiretroviral therapies that, while keeping people alive, are only a temporary solution. Pill trays at the DOT programs overflowed with medicines; patients were passed cups full of pills. At one time, this might have been expected – the treatment for HIV medicines alone often meant over a dozen

pills daily. But with advancements in pharmaceutical science, antiretroviral treatment often entails only 4 pills daily. In the Downtown Eastside the principles of healing, curing, or treating, are often eclipsed by the emphasis on medicines - what Petryna and Kleinman refer to as the “overfetishization of pharmaceuticals” (2006, 9). Individuals seeking health care in Vancouver’s inner city are shuffled around from one health service to another. They see lists of physicians, each one prescribing a different medicine, most of which do not aim to cure the patient, but simply hide or alleviate the symptoms. Many of these medicines are not well tolerated due to adverse reactions and in turn must be treated with other medicines. Similarly, after years of pharmaceutical treatment, long term side effects that arise may also be treated with medicines as a participant recounted to me in a story about a friend. The woman had taken AZT (also known as Zidovudine) for her HIV and now, after years of therapy, although no longer taking medicines for HIV, was ingesting over 20 medicines a day to treat long-term side effects that rose out of the AZT treatment. Physicians endlessly prescribe medications attempting to alleviate the suffering.

In this chapter I explore the interstices of pharmaceutical science, medical practice and the political economy of anti-HIV medicines in Vancouver’s impoverished Downtown Eastside. I begin by tracing out public discourses about the value of medicines and treatment for HIV in the Canadian context and consider the relationships between these discourses and the perceived value of inner city residents. I then trace out the role of the pharmaceutical industry in HIV medicine production, distribution, prescribing practices and consumption for the urban poor. Last, I turn my attention to preventive AIDS vaccine clinical trials in the Vancouver context. As a partnership

between research institutes, the state, and industry, what do these new research collaborations reveal about the new workings of the state and the value of disease?

### **The value of life, the value of medicines**

In March 2006 I met with a clinical associate on 10C (the AIDS ward) at St. Paul's Hospital to discuss how clinicians expertly negotiate treatment with "difficult-to-treat" patients. Specifically I was interested in how clinicians on the AIDS ward balanced individual patient autonomy while ensuring care to oppressed or marginalized citizens who often directly or indirectly refused to engage in treatment. I assumed that this was an ethical dilemma inherent in daily medical practice since Vancouver doctors specializing in HIV and AIDS often provided care and treatment to patients who were drug users, homeless, Aboriginal, sexual minorities, and/or impoverished -- patients who, at least in Vancouver's Downtown Eastside, are reported to be among the least likely to engage in HIV treatment, resulting in absurd rates of advanced AIDS and subsequent deaths. I wanted to know – could we realistically expect the oppressed to make "healthy," lifesaving decisions when they had been told that their lives were worth nothing? Could the subaltern speak in the powerful world of biomedicine? How did clinicians negotiate this in daily medical practice?

In response the clinical associate flatly told me that it cost between \$8,000 and \$10,000 a month to treat people living with HIV. There was no dilemma – if patients did not want treatment and if they did not adhere to the strict daily regimens of antiretroviral therapy, he saw no reason to prescribe treatment. Anti-HIV medicines were expensive and these patients would "never be functioning tax-payers," reminding me that even in a



province with universal access to antiretroviral therapy, the question of the cost of drugs is central in public health. His response also reinforced that measures of success in medicine are not based purely on the therapeutic value of medicines but also on their *economic* value. As other anthropologists have artfully demonstrated elsewhere, the global world of medicines is an unstable field where ethics, state intervention, scientific evidence, neo-liberal agendas, consumption, formal and informal economies, and suffering collide.<sup>3</sup>

The cost of medicines for HIV and drug pricing is a continual source of debate in the Canadian context but particularly so in the global context. Nations in resource-poor settings don't have the infrastructure or resources to deliver antiretrovirals to their citizens. In the North, some nations do not offer comprehensive medical coverage plans (including prescription coverage), making the cost of HIV medicines a very real concern. But in the province of British Columbia, the economic cost of HIV medicines theoretically does not impact availability or use of particular antiretroviral medicines. Representatives from the Centre for Excellence for HIV/AIDS frequently expound on the fact that in British Columbia HIV medicines are provided free to anyone eligible under the current therapeutic guidelines.

Even the most liberal estimates for the cost of providing care and treatment to people living with HIV are well-under the estimated figure provided by the clinical associate working on 10C at St. Paul's Hospital. While estimating cost of care for HIV is difficult, in the province of British Columbia a standard triple therapy combination of treatment costs about \$1200 to \$1400 on average per month.<sup>4</sup> In 1999, Hanvelt et al

estimated the direct costs (including physician billing, hospital stays, emergency room visits, counseling, lab tests, antiretrovirals and non-antiretrovirals, etc.) per HIV infected individual over the course of infection to be approximately \$145 000, with indirect costs somewhere between \$450 000 and \$560 000. One can assume with rising costs of medical care, new advancements in therapeutic technologies, and the rapid evolution of pharmaceutical science, that the actual cost in 2006 will be significantly higher. In 2004 estimates from Southern Alberta suggested the cost of care per year to range between \$8 455 and \$18 455 depending on how advanced disease progression was when the patient sought care. “Late presenters” (those seeking care with a CD4 cell count below 200 cells/ $\mu$ l and who were presumably sicker) will likely incur more complicated illnesses and thus additional costs (estimated as \$18 455 per year).<sup>5</sup> Reporting on unpublished research from the Centre, Dr. Julio Montaner estimated that the “cost of medical management” per person over a lifetime for someone living with HIV was \$250,000.<sup>6</sup> In comparison, it costs between \$1,600 and \$2,300 per month to treat Hepatitis C infection where treatment lasts between 6 and 12 months.<sup>7</sup>

In November 2005 at the semi-annual HIV Update Dr. Julio Montaner told the large crowd of health-care professionals, clinicians and fellow HIV researchers that the Centre for Excellence is witnessing “a steady increase in the cost of antiretroviral therapy” and estimated that the Drug Treatment Program would spend approximately 60 millions dollars in 2006 on antiretroviral therapy in the province of British Columbia. He explained that in part this was because clinicians were doing a better job in treating people with HIV – people deemed “hard-to-reach” or “untreatable” were now being reached and beginning treatment. But the increase in number also meant that the price of

drugs was going up, especially drugs for salvage therapy, such as Fuzeon™, and it means people who had been on therapy for a long time and had been taking scheduled treatment interruptions<sup>8</sup> from their therapy were now returning. Dr. Montaner explained in a public lecture that this “creates a big challenge for us from a fiscal standpoint. It is a very substantial, um, chunk of money and we all need to be very careful how we go forward with antiretroviral therapy. We need to treat those that need it but we do it very cautiously.”<sup>9</sup>

Pharmacare, recently renamed Health Insurance BC, is the provincial service that provides British Columbia residents with subsidies for prescription pharmaceuticals and other medical supplies – including antiretroviral therapies. Each year the Ministry of Health through Pharmacare covers the cost of the Drug Treatment Program at the BC Centre for Excellence so that antiretroviral therapy can be provided at no-cost to those requiring treatment in the province of British Columbia. HIV medicines weren’t always covered through Pharmacare. Dr. Michael O’Shaughnessy, Director of the Centre from 1992 until 2003, explains as he reflects on the history of funding at the Centre: “Yeah, that came from the Ministry of Health but the Ministry of Health was smart, at least the fella who was funding us [was]. He realised that the cost of drugs was going to get enormous so he passed the cost off to pharmacare. He took it out of his budget and said, ‘You guys really oughta be paying for this.’ I probably would have done the same thing.” Dr. O’Shaughnessy further explained that the Centre for Excellence’s role in drug distribution and auditing wasn’t simply about a centralized system of distribution but they needed to address the cost of medicines in what would clearly be a rapidly expanding market. On purchasing medicines, Dr. O’Shaughnessy explains: “Because you get no

favours from industry unless you fight them, right? They'll give you what's the list price and because they're so close to the United States, they generally try to keep it as high as possible. Generally our drugs are about twenty five percent cheaper than they are in the US. But you can even do better. You could get another ten, fifteen percent on top of that." He explained that he still had the first budget written on a piece of paper, a napkin he fondly recalled from the Deputy Minister at the time who, passing him at the airport told him the Centre would be responsible for the antiretroviral therapy delivery program. The budget for the first year? "The first year we spent a half million dollars on drugs. And I heard this year they're about fifty million."

Each year the cost has continued to rise and the province has reportedly responded by covering the request each year. There were rumours that in 2006 the province had said they were not increasing the budget for the Drug Treatment Program and that the Centre would have to make do with the same amount from 2005. When I followed up to confirm this rumour with administration at the Centre I was told that this was incorrect, that in fact the Centre was still negotiating this for 2006 (even in June 2006). Irene Day, who joined the Centre as Director of Operations in 2006, denied the report, explaining that she was part of the negotiation process with the province. Yet she also mentioned that the budget for 2006 had not been finalized since negotiations were on-going. She asked – how could they not agree to increase the amount of funds for the Drug Treatment Program when it was needed to treat patients? Her response suggests a rather simplistic view of the Drug Treatment Program, provincial politics and the cost of treatment. Most notably, her remark suggests that the cost of treatment per patient is non-negotiable, somehow set in stone. Yet some of the most controversial debates involving

the Centre in the city include weighing cost-effectiveness with treatment efficacy in comparable drugs – especially surrounding the use of Efavirenz and Nevirapine.

In British Columbia the direct costs of HIV care and treatment are shared between Vancouver Coastal Health Authority, Providence Health Care, the Centre for Excellence in HIV/AIDS, and a handful of community-based non-governmental organizations. Primary sources of funding for those institutions in the Canadian context is government funding – both provincial and federal dollars although increasingly the pharmaceutical industry appears to be adding to the pot (but very minimally still). How much money these organizations spend on HIV and AIDS care is difficult to ascertain. My requests for even ball-park estimates were rebuffed, eluded, or responded to with long-winded explanations of why such estimates were impossible. It seemed peculiar in an age so obsessed with accountability and cost-effectiveness of health-care, that I was unable to get budgets or estimates for HIV care and treatment from senior-level public health administrators. We do know that in 2006 it is estimated the Drug Treatment Program will spend approximately 60 millions dollars on antiretroviral treatment alone in the province of British Columbia for 3,475 people receiving therapy.<sup>10</sup> That amounts to a little over \$17,000 per year per patient – but this does not account for physician care, hospital or clinic stays, government funded research, pharmaceutical research, conferences on HIV/AIDS, community services, loss of income, economic support, housing, food and nutritional supplements, psycho-social support, and so on. Dr. Julio Montaner estimates that by 2008/2009 the provincial financial requirement will increase by 50% to approximately \$90,000,000 for the drug treatment program alone.<sup>11</sup> HIV/AIDS is truly a multi-billion dollar global industry which has created a fiercely competitive market of

research. Dr. Julio Montaner commented on the financial burden in March 2006 during AIDS rounds. “As the deputy minister herself has told me a number of times – *this is not sustainable*.”<sup>12</sup>

According to the UNAIDS there are an estimated 38.6 million people living with HIV, increasing each year by 10% (UNAIDS 2006). They predicted that in 2005 there would be 4 million new infections. If we are spending \$60 million on 3,475 in the province of British Columbia, it is difficult to comprehend the cost of treating HIV globally – especially since antiretroviral therapy continues to be problematic for many due to adverse effects, drug resistance, and non-adherence. Global funding for HIV in 2005 reached \$8.3 billion according to the UNAIDS (UNAIDS 2006). And yet only a fraction of those who need treatment are receiving it and approximately 2.8 million people died from AIDS last year alone.

### **Pharmaceutical Industry in the Inner City**

The presence of the pharmaceutical industry in the Downtown Eastside is rather muted paradoxically. Drugs, both ethical pharmaceuticals and illicit street drugs, are the ultimate fetish in the Downtown Eastside, with the most powerful capital as they circulate between transnational corporations, state regulatory institutions, research institutes, provincial Pharmacare, physicians, the street, and people who are sick, suffering and poor. In the Downtown Eastside the prescription and consumption of pharmaceuticals are the practices through which powerful transnational corporations become entangled with historically oppressed groups who continue to be peripheralized within the Canadian state. Yet the pharmaceutical industry seems to escape the intense gaze that falls on other

drug economies in the Downtown Eastside. On the notice boards in the clinics, posters are tacked up announcing HIV and Hepatitis C updates by local physicians and HIV specialists on a regular basis. They are held at Il Giardino restaurant, The Metropolitan Hotel, the Sutton Place Hotel, and other similar opulent and fine dining establishments – places that do not serve, or even let in, impoverished, Downtown Eastside residents, forced to scrounge for food in garbage bins, or wait in long public lines for day-old bread and pastries that are often donated by other establishments. These events are offered free to physicians, nurses, and other health care professionals working in the field of HIV and infectious diseases and provide lovely dinners while updates on HIV pharmacology, new research findings, and new drugs are discussed by a guest speaker – most likely being paid a fee of \$1500 minimally for a one hour speak.

Some drug companies donate funds to local not-for-profit agencies. For example, Abbott Laboratories Limited provides funding for Vancouver Native Health Society to offer “Sweet Information Sessions”, an Annual “Pappalooza”, music therapy and the nutritional supplement Ensure as part of their directly observed therapy program for antiretrovirals. Other drug companies provide small sums of money that allow for similar small projects or conference travel for one or two employees or volunteers to attend smaller provincial meetings on HIV or Aboriginal health like the BC Aboriginal HIV/AIDS Conference. Researchers working with the Centre are regularly given research grants from the pharmaceutical companies -- \$20,000 for a Fuzcon™ project from Roche Laboratories and \$15,000 from Pfizer as part of their community-research programs. I hear rumours among the pharmaceutical sales reps that there are hopes for a

“pharmaceutical sponsored research facility” in the Downtown Eastside. Increasingly, the community appears as a living laboratory for HIV research.

Drug companies also provide research funding for physicians and HIV specialists to carry out non-clinical trial research. For example, Roche Diagnostics recently provided \$20,000 funding to an HIV specialist to do a chart review of patients living in the Downtown Eastside that might be suitable for Fuzcon™ or T-20 – a relatively new drug on the market that is proven effective in salvage therapy or treating drug-resistant strains. Fuzcon™ is one of the more expensive drugs. Unlike most antivirals, it must be injected twice daily - proving to be particularly problematic in the Downtown Eastside, where patients with long histories of chronic intravenous drug use or those in recovery, often experience anxiety when they need to have treatments or diagnostic tests done involving needles. The Centre for Excellence identifies the challenge in treating Downtown Eastside residents as an issue of uptake and adherence, not a patient population requiring ‘salvage’ therapy – just therapy. Thus, Fuzcon™ seems an absurd treatment choice except for the very few.

Early in 2006 I hear from two different pharmaceutical sales reps, working for different pharmaceutical companies, that in the prairie cities of Winnipeg, Saskatoon and Edmonton, as well as Montreal, physicians specializing in HIV treatment complain that the reason so many patients in British Columbia are receiving Fuzcon™ is because physicians in British Columbia don’t know how to treat HIV. As one pharmaceutical medical director explained to me – the concern is when patients fail their first line of therapy, doctors in British Columbia are too aggressive with the second line of therapy.



Patients are given too many drugs that results in drug resistance and patients deemed “salvage” should they fail again. Salvage therapy is expensive, complicated, and means patients have few options left for treatment. As Dr. Julio Montaner explained during AIDS rounds, it is “nasty and very expensive.”<sup>13</sup> While Dr. Montaner thus far has been successful working with bureaucrats in British Columbia justifying the cost of medicines, the use of expensive therapeutic options like Fuzcon™ does have the effect of generating a concern about the value of therapeutic options and the value of those lives that consume (or inject as is the case with Fuzcon™). Patients, health-care professionals and medical researchers alike are cognizant of the cost of medicines.

### **The Centre for Excellence in HIV/AIDS and Big Pharma**

Prescription practices for antiretroviral therapies in the province of British Columbia are not standard as they might be for antibiotics during a visit to the family doctor. Physicians who decide to begin patients on antiretroviral therapy complete a drug request form that is sent to the Centre for Excellence’s Drug Treatment Program for approval. The form acts as a legal prescription but it also collects baseline data on patients beginning treatment – CD4, pVL, opportunistic infections, and so on. The Centre for Excellence reports that less than 1% of antiretrovirals in the province are purchased through other sources and therefore have a firm account of antiretroviral use in the province. The Drug Treatment Program statistics (updated January 2006) indicate that there are currently 3,475 individuals in the province receiving antiretroviral therapies through the BC Centre for Excellence in HIV/AIDS, 86% of which are men, 14% women.<sup>14</sup> At least 60% (over 2000) live in the Vancouver Coastal Health Authority. In March 2006 Benita Yip, statistician for the Drug Treatment Program, reported that only

301 individuals with Downtown Eastside postal codes were receiving antiretrovirals (personal correspondence). The consumption of antiretrovirals does not map onto the epidemiological profile of infection reported by the Centre. They maintain that the Downtown Eastside is the “epicenter” of the epidemic in British Columbia. In spite of needle exchange programs, supervised injection sites, an intensity of public health programs, the Centre’s researchers report that 17%, maybe 20%, of residents have HIV. In March 2007 at a public speak at the University of British Columbia Dr. Julio Montaner reported that 30% of Downtown Eastside residents had HIV – about 4,800 of the estimated 16,000 who live there.

It is no secret that Dr. Julio Montaner is an enthusiastic supporter of medicines for HIV as he explains – “Drugs save patients’ lives.”<sup>15</sup> Working in the field for over twenty years, he witnessed an era when a lack of effective treatment meant certain death. Aware that other clinicians might have a less aggressive approach to prescribing pharmaceuticals, Dr. Montaner maintains that antiretrovirals save lives when it comes to HIV. Indeed, researchers have clearly documented the success of antiretroviral therapy in prolonging life for people living with HIV. He explained to the audience at the University of British Columbia that highly active antiretroviral therapy is 100% effective – when patients adhere. As he presented in the semi-annual HIV update in June 2006 reporting on one of their cohort studies in British Columbia, antiretroviral therapy can add up to 40-50 years on the average lifespan of someone living with HIV. While the cost of medicines for the province has continued to rise, the impact has been substantial for people living with HIV. People live longer and they are often healthier. Former Director, Dr. Michael O’Shaughnessy similarly expounds on the value of medicines to save lives,

explaining that in the 1990s they witnessed a death a day from HIV but now they see only two per month.<sup>16</sup> During an interview, reflecting on pricing of HIV medicines he gives us a glimpse of the complicated relationships HIV researchers and clinicians have with industry.

But you know I'm not seeing any, any data, you know where someone says what it really costs. But I suspect this is a, HIV drugs are pretty profitable. Um, that's my suspicion. At least that is an enormous profit potential and I mean the whole business of drug pricing is, is such a quagmire. I'm not opposed though, to pharmaceutical companies, because I know too many people who are alive today, because of the action of the company, so the pricing is a separate issue. But certainly the pharmaceutical companies have done a pretty reasonable job of giving us drugs that will give... if you're thirty years old and you get HIV and I can say, you know you're probably going to live into your fifties. Well that's a whole lot better news than it used to be when you say, well, um, you've got two and a half years. So, you know, I'm not opposed to them. I just don't get their pricing structure.

Pharmaceutical science is portrayed as lifesaving, it has the ability to alleviate suffering, reduce how many die, to save and, yet, these promises seem mute in the Downtown Eastside. Suffering bodies limping down the street in the summer heat, or crumpled up in doorways during winter rains.

The Centre is involved in just about every avenue of pharmaceutical production from clinical trials involving human testing, distribution, prescription, and auditing. As Director of the Centre and an international researcher on HIV, Dr. Julio Montaner has close relationships with medicines and pharmaceutical companies and he is acutely aware of the intense scrutiny that researchers receive because of such relationships. As mentioned in a previous chapter, in February 2002 Boehringer Ingelheim announced that

they were awarding Dr. Montaner with the Boehringer Ingelheim Distinguished Researcher Award in HIV valued at 1 million Canadian dollars.<sup>17</sup> It is reported that he was also awarded a \$1.7 million award from GlaxoSmithKline that he similarly donated to the University of British Columbia for research on HIV virology. He is principle investigator and co-principle investigator on various clinical trials testing new antiretroviral therapies in Vancouver – and strives to offer the most-cutting edge and effective treatment to people living with HIV in British Columbia.<sup>18</sup> He advocates for a more rapid review process of drug approval in the Canadian context. At the Canadian Association of HIV Research in May 2005, giving plenary lecture, he complained that the regulatory practice for drug approval in Canada was “dismal” and he advocated for a move for the American regulatory body, the Food and Drug Administration (FDA), and the Canadian body, Health Canada’s Therapeutic Products Directorate (TPD), to work more closely together as a means to speed up the regulatory process in Canada. According to Jack de Silva, the Coordinator of the Ambulatory Pharmacy at St. Paul’s Hospital, antivirals continue to be released on the market in the United States first. In the past drug approval with Health Canada took about 6 months, now it is reported to take as long as 1-2 years.

In December 2005 the Centre successfully advocated for the use of two experimental drugs, TMC 114 (PI) and TMC 125 (NNRTI)<sup>19</sup>, in the treatment of four British Columbian patients. Both drugs are considered to be particularly effective in the treatment of drug resistance HIV-1 strains and therefore potentially critical treatment alternatives for patients experiencing virological failure. Dr. Montaner, although happy that four of his patients had been granted access to the experimental drugs, continued to

voice frustration with the regulatory drug process in Canada, particularly Health Canada's Special Access Program, lashing out in a letter to the Canadian Medical Association Journal (CMAJ) entitled "The Perverted Irony of Health Canada's Special Access Program." In the letter, he and Centre for Excellence medical ethicist Dr. Tim Christie expressed outrage that the Special Access Program was being used to approve silicone breast implants for women and yet denied the Centre's request for anti-HIV medicines like TMC 114 and TMC 125 (Christie and Montaner 2006)<sup>20</sup>. Co-founder and c-director of the Canadian HIV Trials Network, Dr. Montaner advocates for faster access and less regulation to new pharmaceuticals as a means to get new medicines to patients desperately in need (primarily those who are on salvage therapy who have developed drug-resistance, typically – not Downtown Eastside residents). As others argued elsewhere, because there is so much at stake financially and therapeutically with new drugs, regulation and approval of new pharmaceuticals is a particularly polemic process (Epstein 1997; Walsh and Goodman 1999).

In April 2005 Dr. Jeff Sturchio, Vice-President of External Affairs for Merck and Company, presents at the "Evidence Speaks Series" CHEOS talks at St. Paul's Hospital. His talk entitled "Making a Difference: The value of partnerships in addressing the HIV epidemic" draws a large crowd, over a hundred people listen in the Hurlburt Auditorium including high level administrators and researchers from both the Centre for Excellence and CHEOS like Martin Schechter, Mark Tyndall, Julio Montaner, Brian Harrigan, and Aslam Anis who are dressed overwhelmingly in dark suits on this day. Although he is there to report on "lessons learned from Botswana," Malawi and Estonia regarding partnerships between Merck and Co. and the United Nations (UN), Global Fund to Fight

HIV/AIDS, and the Global Alliance for Vaccines and Immunization (GAVI), one cannot help but listen and wonder what partnership Merck and Co. is proposing to the province of British Columbia or the Centre for Excellence. Sturchio, who resembles an accountant in his dark suit and red tie, paints a benign, rather humanitarian, portrait of the transnational Merck and Co., highlighting their efforts to support “initiatives that foster disease education, prevention & care, and sustainable access to medicines in less developed countries.” Partnering with the Bill and Melinda Gates Foundation and the Botswana state, Merck and Co. donates millions of dollars and HIV medicines like Efavirenz and Indinavir.

### **The politics of vaccine research**

*“They are going to be exploited.”*

*-- Comment at December 4<sup>th</sup> Public meeting on AIDS Vaccine Trials, Vancouver, BC*

A few months after Jeff Sturchio’s visit there were rumblings in the community that the Centre for Excellence is partnering with Merck-Frosst (the Canadian subsidiary of Merck and Co.) as they move forward with Phase IIb preventive HIV vaccine clinical trials research. Typically the Centre for Excellence’s involvement in clinical trials, most of which are industry-sponsored, is portrayed as part of their commitment to develop and make available leading anti-HIV treatment to Canadians but these trials represented a shift. As Kalman Applbaum explains, this optimistic portrayal of clinical trials is pitched as part of the “global evolution” of treatment, signifying a commitment to “progress towards superior medical treatment, based upon scientific advances coupled in localities with increasingly enlightened healthcare policy that recognizes and adopts medical innovations” (2006, 85).

But HIV preventive vaccine trials require trials participants to be HIV *negative*. In antiretroviral therapy trials most participants will be positive, engaged in clinical trials with hopes they will have access to novel pharmaceutical treatments not yet available on the market or, in other words, the hope of personal medical benefit. Often it is assumed that, like the four individuals pleading for access to TMC 114 and TMC 125, that clinical trials are the last avenue of hope in failing treatment.<sup>21</sup> But the need to engage “high-risk” HIV negative populations in order to measure the efficacy of the vaccine has raised concerns regarding rights to health-care, the informed consent process with impoverished communities, and false positive tests. Participation in the trials does not ensure access to treatment and the low efficacy rates offer little prevention. Current vaccine candidate efficacy rates remain low (20-30%), also raising concerns regarding a false sense of health security and increased risk behaviours. As one of the most intensely researched communities in Canada, advocates and residents of the Downtown Eastside voiced mounting frustration and wariness – specifically with medical researchers who treat community residents like “guinea pigs” in their search for drugs and profits. The rumor that the Centre for Excellence was going to be partnering with Merck-Frosst created a shock wave through the community – reminding us of the complicated relationship many of us have with pharmaceuticals. But the Merck and Co. trials were not the first preventive HIV vaccine clinical trials to be held in Vancouver. Dr. Robert Hogg, the Director of the Drug Treatment Program at the Centre for Excellence, was involved in the international VaxGen trials in 1999.

Now known as “The Step Study,” the current vaccine trials being run by the Centre for Excellence are a collaborative effort between Merck and Co., the HIV Vaccine

Trials Network (HVTN), and the Division of AIDS with the National Institutes of Health (NIH) in the United States. They are Phase IIb trials, meaning they are proof-of-concept studies as opposed to efficacy or safety trials. The proof of concept that Merck and Co. is testing is twofold: 1) to determine the impact of the vaccine candidate on the virus load once infection occurs, and 2) to prevent persistent HIV infection. Merck and Co. had been planning on ending the recruitment phase in December 2006 but needed to push through until February and March 2007 since they had not quite reached their target goal of 3000 randomized participants from all their clinical trial sites (3 continents and about 30 cities).

As of February 3, 2007 Merck and Co. reported that the Vancouver trial site had screened 66 participants and randomized 39. In one month the Vancouver clinical trials team recruited the same number of women that they recruited previously in the entire 10 months of operation (April 2006 – January 2007). In January 5, 2007 Merck and Co. recorded 33 participants screened and 18 participants randomized – the total since April 2006. They more than doubled the number of participants who were randomized (18 to 39).<sup>22</sup> Randomized refers to participants who have actually been enrolled in the study, those who will move forward and receive either the placebo or the vaccine candidate. At that stage, these participants have undergone initial pre-screening and clinical evaluations to determine if they are both clinically and behaviourally suitable for the study. Research subjects must complete a long informed consent process, behavioural surveys, HIV risk-reduction counselling, and laboratory testing for liver function, HIV infection, pregnancy, adenovirus-5 titers, and other medical issues. Clinically, participants might be turned down if they tested positive for HIV, had very poor liver



functioning tests (although Hepatitis C infection does not automatically disqualify one from the trials), had high Ad 5 titers, or had other medical issues. Behaviourally one must be considered “high-risk” to engage in the trials. It is also possible that after being initially screened, that participants decided they did not want to continue with participating in the trials. A colleague working on the same trials at the Philadelphia site reported to me that one participant continued to come in for pre-screening (each time receiving an honorarium) but would not commit to the actual vaccination. In the end, this participant declined randomization because of concerns about a false-positive test.<sup>23</sup>

How trial sites recruit research subjects is a key issue in the development and operation of the clinical trials. In Vancouver recruitment strategies for trials subjects was a concern from the get-go. At a public meeting on December 4, 2005 about 60 people came together to discuss their growing concerns about the possible implementation of AIDS vaccine trials in Vancouver. Organized as part of the Canadian National Day of Remembrance and Action of Violence against Women December 6th memorial activities (in memory of the Montreal Massacre at the École Polytechnique), Vancouver’s Rape Relief and Women’s Shelter held the public meeting at the Vancouver Library, drawing media, academics, Downtown Eastside residents, and feminist community advocates. Directors and staff from a number of women’s-centered organizations from the inner city were present representing Vancouver Area Network of Drug Users (VANDU), the Downtown Eastside Women’s Centre, and the Women’s Information Safe Haven (WISII). During the heated and politically charged discussion, advocates raised concerns that the AIDS vaccine trials were a form of “racialized harvesting” where impoverished, young, Aboriginal women would become the experimental subjects of a “corporate” drug

company. Indeed, some of The Step Study trial sites have focused exclusively on young (18 – 30 year old) “high-risk” women. Meeting minutes dated July 13, 2005 from a teleconference addressing “Community Mobilization and Retention for HRW” for The Step Study illustrate the strategies being used to specifically target young women: “Joy in Philadelphia ... wants to know how Chicago is targeting younger women because they haven’t been as successful with that in Philadelphia. Parric explained that the site is targeting women 18-30 by hitting the prostitution strolls and identifying those that look younger. This isn’t a sophisticated approach but it’s working.”<sup>24</sup> Concerns in Vancouver that the trials are targeting ethnic groups also appear substantiated according to meeting minutes from August 10, 2005 that report on specific strategies for “recruiting people of color in New York” – including hiring culturally diverse staff and displaying posters with people of colour.<sup>25</sup>

Of course, the history of clinical trial research generally has been limited to white men. Advocacy groups have demanded that women and minority groups be *included* in clinical trials. The inclusion of female subjects in randomized control trials has been an on-going contentious issue. Until the 1980s women were excluded from trial participation because of concerns about the ways in which hormones affected drug metabolism and absorption in the body and the possibility of fetal abnormalities in pregnant participants (i.e., resulting from studies of the effect of thalidomide and DES). Participation in randomized control trials today is clearly a women’s health issue as researchers have documented the need for understanding the gendered differences in drug effect, interaction, and metabolism and the exigency to generate women specific data. Today drug trials actively try to engage women yet they face serious challenges as concerns

burgeon among female trial participants, activists and communities concerning the implications of participation in clinical trials. Similarly, some might argue that the recent findings from the BiDil case also support the inclusion of ethnic minorities into randomized trials (Jones and Goodman 2005). At a recent conference in Vancouver held by the Canadian Aboriginal AIDS Network, the organizers held a session entitled “When (Guinea) Pigs Soar: Involving Aboriginal People in Clinical Trials.”<sup>26</sup> The abstract explains that the session will provide information on clinical trials, ways to make them culturally appropriate, and “ways of *promoting* the participation of Aboriginal peoples in HIV clinical trials.” However, this session addressed clinical trials generally, not focusing specifically on preventive AIDS vaccine trials that are considered particularly challenging ethically because of the need to recruit relatively *healthy* research subjects, requiring a degree of altruism on behalf of research subjects.

Advocates at the December 4<sup>th</sup> meeting in Vancouver also reported that individuals and organizations were being lured by financial incentives from the Centre for Excellence in HIV/AIDS and Merck and Co., leading those in attendance to ask how could individual impoverished women in the community be able to make truly voluntary informed decisions in light of the monetary incentive? While providing honoraria is a standardized research practice in this community as a means to acknowledge the time, skills and patience of participants involved in research projects, some suggested that the amount of the honoraria would be too powerful for impoverished women to refuse making the idea of a truly informed consent questionable. The practice of providing honorarium in the community is a practice that is generally accepted uncritically and undoubtedly does lure participants to research projects. Like our own ethnographic

practice in the inner city, clinical trials also offer an honorarium to research participants. All researchers providing honorarium in intensely impoverished communities are forced to consider the ethics of providing monetary or other incentives for research participation. As one woman from the community explained to me, regardless of the research project, if there is a promise of a financial incentive and she is using illicit drugs, she'll volunteer for the project. She continued explaining that she doesn't even read the consent form, just agrees and signs it. While this is intensely problematic for all research in the Downtown Eastside, advocates have rightly noted it is particularly so when it includes double-blind, randomized, placebo-controlled treatment where safety may not yet be firmly established.

Merck and Co. and HVTN both encourage the use of incentives as a means to entice participation in the trials. Minutes from a teleconference meeting on September 14, 2005 read, "Parric notes that money is a real motivator, and that the women look forward to their study visits because the compensation means that they can have fewer 'dates' that day. Parric also noted that women's motivation seems to change over time. While money may bring them initially, over time the women seem to really respond to the site staff." This has been similarly voiced in the local Vancouver context speaking more broadly about supporting research in the community as a viable economic alternative to sex work, drug dealing, or other underground innovative economic strategies.

Each Merck/HVTN site provides different types of incentives and they are not the same value. Depending on the site, trial participants may receive McDonalds' vouchers, movie gift certificates, small gifts (lotions, soaps, and so on), or monetary incentives (cash or cheque). The vaccine trials require a number of commitments from participants –

not only are they expected to receive an experimental vaccine (or placebo) but they also must fill out Vaccine Report Cards. Participation in the trial itself provides an honorarium, completing the Vaccine report card is also compensated (\$50 in Chicago on top of the visit compensation), and referring other individuals to the trials is also a source of compensation (called “Respondent Driven Sampling,” clinical trial coordinators pay \$5.00 for referrals to pre-screening). In Vancouver, Downtown Eastside residents have similarly reported that they have been offered nominally paid positions as community-advocates to help refer research subjects to the trials (including women who themselves are not eligible to participate in the trial because they are HIV positive). Participation in the Vancouver trial (attending the clinic for necessary appointments) is financially compensated (\$25.00), as is the completion of the Vaccine Report Card (noting such things as side effects – an additional \$25.00, due at each visit).

Downtown Eastside residents also talk about being recruited for the trials. At Merck and Co. they identify discordant couples as possible avenues for researching subjects. In Vancouver, the trial site nurse followed suit according to one HIV positive man. The nurse has a long history of working in the Downtown Eastside and was formerly employed with the Downtown Community Health Clinic’s DOT program from its initial development under the management of the Centre for Excellence. As a result, she has strong ties with many local residents. After bumping into the nurse, this fellow, excited that he had recently become involved with a woman after being single and alone for a long time, told the trials nurse how he was now dating someone. He was, in fact, on his way to try and find her. In response, she asked if his new partner was HIV negative. Indeed she was. They then spent the afternoon trying to find her, the nurse driving him

around to places where the girlfriend might be hanging out, so that she could pre-screen her and enrol her in the clinical trials. The fellow recounted this story to a number of community health-care providers in the community, explaining that he felt very uncomfortable with what had occurred. He explained to me that he felt “used” by her, that her interest in him was only about recruiting another subject for the trials.

Concerns about trial recruitment and voluntary participation was further complicated by concerns about the actual informed consent process. Although I have not viewed the local informed consent form, I assume because the trial is developed and sponsored by Merck and Co. that the informed consent forms are very similar across the various field sites – save minor changes regarding honorarium rates, contact information, and health-care services.<sup>27</sup> In the United States, there are two informed consent forms. The first for the vaccine trials themselves, and the second granting permission to Merck and Co. to keep stored samples of biological material for future research purposes. The informed consent form for the trials is 17 pages long, single-spaced, raising serious concerns regarding literacy (and scientific literacy) among inner city, often educationally disadvantaged, citizens. It addresses what the trials are testing for, how the research will be done, compensation, and what the trial participant will be expected to do (including answer questions about drug use and sexual history, have physical examinations, provide blood and urine samples, take birth control, provide medical history, and so on). As others have argued elsewhere, “the social and economic contexts make the “choice” to participate ... anything but a ‘free’ and ‘autonomous’ one” (Scheper-Hughes 2003:221).

Researchers involved with the trials attempted to highlight the positive impact an AIDS vaccine could have on global suffering, stressing altruistic principles and the exigency of pharmaceutical research for all. They contacted key community members and organizations to engage in discussions regarding the possibility of meaningful community engagement and trials that were ethically responsible to the community yet most community activists immediately refused – raising the never-ending question “who speaks for community” in communities where there is no internal cohesion?

The controversy and debate that the trials evoked in the community need to be read within the specific socio-historical context of the Downtown Eastside -- the particular requirements of vaccine clinical trials, the history of medical research in the community (and with similarly oppressed groups in the Canadian context), and a growing suspicion of industry sponsored clinical trials globally. The specific targeting of “at-risk women” in the community was seen as particularly problematic for a number of reasons. To begin, the community has gained international attention as being the home of over 69 missing women (many advocates suggest this number is far too conservative and that most likely there are over 100 missing women). A long, controversial investigation into the disappearance of these women has resulted in Canada’s most horrific and notorious criminal trial – with the arrest of Robert Pickton for the murder of 26 women who are said by police to have been known residents of the Downtown Eastside. Portrayed primarily as sex workers and drug addicts by the media and the Royal Canadian Mounted Police’s “missing person” poster, it appeared to many advocates and vulnerable women living in the community that the state was neglect in addressing their disappearance, portraying the women as “disposable” and not worthy of basic human rights granted to

other Canadian citizens. As a result, the community and advocates are particularly vigilant about protecting the rights of local women, long oppressed, exploited or ignored by state officials. Additionally, aboriginal women are over-represented in the community reminding others all too easily of the Tuskegee experiments in the United States or Canada's own history of treating Tuberculosis in Aboriginal communities where they were forcibly removed from their homes and imprisoned in TB clinics.

The trials also occur in an era when there is serious mistrust of the pharmaceutical industry – especially it seems in relation to HIV related drugs, plagued by complex ethical dilemmas where in some cases community opposition has halted clinical trials altogether (for example, the Tenofovir trials by Gillead in Cambodia and Cameroon). There are continual reports that pharmaceutical companies are engaging in unethical research practice, not disclosing unfavourable results and not following guidelines (Schulman et al 2002). Yet concomitantly clinical trials are increasingly pitched as therapeutic rather than “experimental” -- effectually masking the risks of engaging in trials developed to test the efficacy and safety of new drugs or biologics.

In Vancouver a temporal shift in community response to clinical trials for HIV vaccines is highlighted by the media response. Compare two different reports from the Vancouver Sun – both reporting on the possibility of AIDS vaccine clinical trials in the city, one from 1998 reporting on the VAXGEN trials and another from 2005 reporting on the Merck and Co. trials. In 1998 even the by-line of the report was optimistic and hopeful: “New AIDS vaccine to be tried in 2 Canadian clinics: The director of a B.C.



AIDS centre expresses hope Vancouver will be one of the cities selected for trials.”<sup>28</sup> The text of the report read,

The world's first large-scale test of an AIDS vaccine will be available to Canadians and administered out of at least two Canadian clinics, says the chairman of the American company granted permission by the U.S. Food and Drug Administration to test the vaccine. While Dr. Robert Nowinski, chairman of the San Francisco-based biotech company VaxGen, would not give the location of the two Canadian locations, the director of the B.C. Centre for Excellence in HIV/AIDS, said he's hopeful Vancouver will be one of the cities chosen. "This is good news. Let's not pre-judge whether it will work or not work, but it would be good if the West Coast was involved," said Dr. Michael O'Shaughnessy. He said a vaccine may not be the answer, but North American studies need to be done. "The sooner we can get reasonable vaccine trials on the go, the better off we will all be."

AIDSVAX B/B, a vaccine candidate produced by VaxGen Inc. out of California, enrolled 5,108 men (who have sex with men – MSM) and 309 “high risk” women from the United States, Puerto Rico, Canada and the Netherlands (Francis, Heyward, Popovic et al 2003). The trials proved that the vaccine offered no protection (the vaccine 5.7%, and the placebo offered 5.8% protection). The Vancouver site of the Merck and Co. trials was specifically targeting young, women at-risk of HIV infection whereas the VaxGen trials were conducted primarily among adult gay men. While marginalized because of their sexuality, gay men typically have not faced the same intensity of oppression that the women being targeted for the new trials do (a history of colonialism, poverty, drug addiction, and stigmatized labour). The specific activism history of gay men in HIV/AIDS also positions them uniquely in the world of pharmaceutical science. The AIDSVAX phase III trials held in Vancouver did not ignite the same local response although the trials were eventually also plagued by tensions and controversy.<sup>29</sup>

# HIV vaccine study stalled by critics

Prostitutes might think they're protected and take even more risks, opponents say

BY PAMELA FAYERMAN  
VANCOUVER SUN

A study using an experimental vaccine to prevent HIV in up to 100 Vancouver volunteers at risk of getting the disease may be in jeopardy because of concerns it would give participants working in the sex trade a false sense of security, placing them at even greater risk of contracting the virus.

Researchers at the B.C. Centre for Excellence in HIV/AIDS have been hoping to recruit male and female prostitutes and injection drug users for a Vancouver arm of an international drug trial using a Merck vaccine that is designed to prevent HIV in those at high risk.

But HIV/AIDS specialist Dr.

**"I am learning there are some people who are violently opposed to this and there are certain people who seem to be spreading a lot of misinformation around."**

Dr. Mark Tyndall  
HIV/AIDS specialist



Mark Tyndall said his initial discussions with various groups have him wondering if Vancouver will ever be a study site.

Tyndall noted that an Internet publication recently reported — erroneously, he said — that studies have found sexual risk-taking increases in vaccine trial participants and that vaccines can actu-

ally trigger an opposite effect of suppressing the immune system.

About 30 per cent of B.C.'s 12,000 HIV-positive patients are working in the sex trade and another 30 per cent are injection drug users, while the balance are mainly gay or bisexual males.

See **VACCINE STUDY** A2

**Figure 7. Local media reports of AIDS Vaccine trials.**

**Source: The Vancouver Sun, December 19, 2005.**

In contrast, the Vancouver Sun reported December 19, 2005 on its front page that the Merck and Co trials were stalled by community tensions – “HIV vaccine stalled by critics: Prostitutes might think they’re protected and take even more risks, opponents say.”<sup>30</sup> Beside the by-line the local HIV clinician running the trials is pictured in colour with a quote from him boldly highlighted: “I am learning that there are some people who are violently opposed to this and there are certain people who seem to be spreading a lot of misinformation around.” The body of the report was considerably more critical and suspicious of these trials. For instance, it read:

Kate Gibson, a spokeswoman for WISH, a drop-in centre for prostitutes on the Downtown Eastside, said she thinks a vaccine study would predispose trial participants to HIV. “My concern has to do with the fact that women could misunderstand things, that they would think that they are getting a vaccine and that they are therefore protected, so they would take greater risks. It just wouldn't be a safe thing to do. They would think they are

protected and they would end up dead," she said. Asked if she didn't believe the researchers would adequately explain to participants that in a double-blind study, some would get a placebo injection and others a still-to-be-proven vaccine, she said: "Women who work on the streets do take precautions and I just don't want that to change because, between their unstable housing and their drug use, this may not be safe for them." Representatives of Vancouver Rape Relief and Women's Shelter have also expressed concerns about the study. But Doreen Littlejohn, a nurse coordinator with the Positive Outlook Program of the Vancouver Native Health Society, supports the study. "This is drawing a lot of controversy but I think it would be a good thing. If we have a chance to protect people, then why not take it? There are a lot of intelligent [prostitutes] and they can make up their own minds," she said. "It is a maternalistic, paternalistic, old-school approach to say they can't give informed consent. We should give them more credit and give them the choice of going into something like this," said Littlejohn, noting that Tyndall has not yet even briefed sex trade workers about the trial. Caryn Duncan, spokeswoman for the Vancouver Women's Health Collective, which helps women find health care, said she "wholeheartedly" supports the critics of such a vaccine trial. "This is a money-making venture for the pharmaceutical industry. In a perfect world, a vaccine would be desirable but how we get there is the question," she said, conceding that her cynicism about the pharmaceutical industry leads her to believe there would never be enough controls in place to protect study participants.

While this report was considerably more impartial than an independent, alternative on-line news source covering the trials<sup>31</sup>, the Vancouver Sun still reports it in a manner that highlights the tensions and fuels the debate by highlighting the quotation from Dr. Mark Tyndall saying there is "violent opposition" when there, of course, was none (see figure 7.) But clearly, community groups have become more savvy and knowledgeable about the practice of pharmaceutical corporations and this increased awareness, and suspicion, is reflected in the recent media reporting. Concerns about the integrity of industry sponsored clinical trials have steadily been increasing. In 2002 the *New England Journal of Medicine* published a special report suggesting that guidelines

developed in order to ensure the integrity of clinical trial research funded by industry (the “Uniform Requirements for Manuscripts Submitted to Biomedical Journals” developed by the Committee of Medical Journal Editors) were not being followed, raising concerns regarding “design of the trials, unimpeded access to trial data, and the right to publish their findings” in addition to concerns about commitments to trial participants (Schulman et al 2002, 1339). Others have also reported on concerns that profit-driven industry sponsored trials have downplayed ill-favoured results and suppressed data (Djulbegovic et al 2000) but it is not clear that state-sponsored clinical trial research on drugs is any more “pure” than private industry sponsored trials. The idea that state agencies are less corrupt, coercive or less motivated by profit seems naïve in this neo-colonial, neo-liberal era. But perhaps more importantly, and what I have illustrated here, is that there are no longer clear boundaries between trials that are “state sponsored” and those that are “industry-sponsored”. State institutions are increasingly ensnared with industry. This speaks again to the ways in which research, treatment, surveillance and regulation are increasingly blurred as they are shared among government actors, research institutions (or disciplinary paradigms), and pharmaceutical corporations.

The World Health Organization’s new clinical trials initiative attempts to address some of these ethical considerations by setting up international guidelines and rules for drug research. Called the WHO International Clinical Trials Registry Platform, the purpose according to the World Health Organization is “to increase transparency and accountability on the part of companies and institutions that do clinical research, and, in turn, boost public trust and confidence in that research.”<sup>32</sup> Yet, recent reports suggest that the new guidelines will prevent industry from doing research and development in certain

areas “because they would not want to make sensitive information public too early – as required under the initiative – as it would become available to their competitors, and secondly, if they are unable to protect their innovations with patents” (Humphreys 2006, 513). The actual impact of the WHO guidelines is yet to be evaluated but debate and resistance among the pharmaceutical industry leads one to imagine this will be a long-going battle.

The Merck and Co. HIV vaccine trials and other HIV preventive vaccine trials occurs amidst growing concerns regarding the limitations of clinical trials more broadly (concerns about the safety of new drugs, the process of drug approval by Health Canada and, in the USA, the FDA) and as debates regarding the ethics of double-blind, randomized placebo-controlled drug trials grow. Still, it is clear that on the international and national level, there is growing pressure for communities to engage in vaccine research. Canada’s largest government funding agency for health, the Canadian Institutes for Health Research, continues to request funding proposals for HIV vaccine related research and few would disagree that an HIV vaccine would have critical implications for global health. On February 20<sup>th</sup> 2007, Prime Minister Stephen Harper announced with multi-millionaire Bill Gates that the Canadian government was supporting the Canadian HIV Vaccine Initiative by providing \$111 million dollars (see figure 8). The impetus behind AIDS vaccine research and the demand for clinical trials continues to grow.



**Figure 8. Stephen Harper and Bill Gates - AIDS Vaccine Research.**  
**Source: The Office of the Prime Minister.**

These particular vaccine trials are also interesting because they represent a shift in pharmaceutical industry practice – a move to “partner” with government and research institutes. Recall, Dr. Jeff Sturchio’s presentation at the CHEOS talk emphasized the success of public-private partnerships in addressing HIV. Irregardless of the Merck and Co. vaccine trials, it becomes clear that the Centre for Excellence is so enmeshed with pharmaceutical companies it seems almost impossible to disentangle the two. As a research centre it is marketed as an independent think-centre yet its complicated relationships with both industry and the state transforms our understanding of medical research. It complicates the social landscape of medical research and suggests debates about “industry-sponsored” research may be futile.

### **Public-private partnerships: The value of rumours**

*JSM has received consulting fees, served on paid advisory boards, or received lecture fees from Avexa Ltd, Abbott Laboratories, Boehringer Ingelheim Pharmaceuticals Inc, Borean Pharma AS, Bristol-Myers Squibb, Gilead Sciences, GlaxoSmithKline, Hoffman-La Roche, Immune Response Corporation, Janseen-Ortho Inc, Kucera Pharmaceutical*

*Company, Merck Frosst Laboratories, Pfizer Canada Inc, Shire Biochem Inc, Tibotec Pharmaceuticals Inc, and Trimeris Inc.*

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If the fictional novel *The Constant Gardener* by writer John Le Carré (2001) and subsequent film by the same name (released in 2005) is even remotely representative of the politics and deceit of the global pharmaceutical industry, you would never know it at first glance in the Downtown Eastside. And indeed if one studied HIV treatment only from the point of view of individuals who are living with HIV, it would be difficult to discern the role of the pharmaceutical industry in their treatment - besides the obvious research and development of the drugs they ingest. In a year of fieldwork, never did an HIV positive person speak to me about the role of industry in their treatment. Even at the level of program delivery and health services, the role of the pharmaceutical industry is barely discernible. Front-line workers, nurses, and most clinicians rarely mention pharmaceutical companies by name. On only one occasion did a clinician involved in direct care mention industry to me.

In September 2005 I was observing one of the clinicians in clinical practice in the Downtown Eastside. I sat on a spare chair in the tight office space. In between seeing patients the physician wrote notes into the medical record. I interrupted and asked him how he decided which drugs to prescribe to a patient starting therapy since, as I understood it, there were a number of possible combinations that one could choose from. In response, and what I assumed was to be in jest, he explained to me that it depended on which pharmaceutical company had recently paid for his travel and accommodations to conferences, how much money they had paid, what type of accommodation they had

secured for him, and so on. I assumed from his smile and the very fact that he was stating as much, that he was kidding me. No one would actually admit to this, would they? Well-known in the community for his dry sense of humour, this physician continued on in elaborate detail as I sat there rather dumbfounded and too nervous to ask if he was serious. In reflection, it is possible that he was mocking my lack of detailed knowledge about prescription practice and therapeutic guidelines that published each year and regularly revised appear to outline clear directive prescribing procedures for physicians. But if that were true, his response wasn't really fair since the therapeutic guidelines for HIV are regularly contested and negotiated, challenged by on-going clinical trials and scientific research on drug efficacy and safety. Perhaps it was simply a sarcastic commentary on the relationships between prescribing physicians and pharmaceutical companies – highlighted one month later in a report in *Nature* with the headline “Cash interests taint drug advice.”<sup>33</sup> Perhaps he was serious – as a pharmaceutical employee working in HIV suggested to me when I recounted the story, asking for insight into the relationship between prescribing practices and the lavish conference travel that medical doctors are provided with by pharmaceutical companies. Physicians specializing in HIV care request or are offered funds for conference travel and then are often paid a substantial fee to present post-conference talks when they return. In Vancouver pharmaceutical companies pay between \$1500 and \$2000 to local physicians presenting a 45 – 60 minute talk on highlights from HIV/AIDS conferences.

But the clinician's comment is interesting not for its representation of 'a truth' so much as what it alludes to – the relationship between medicines, money and men and poverty, suffering and treatment. With reflection, it appears to be a rather brave answer in



light of the continual politics and powerful rumours surrounding choice of drugs in HIV treatment in the province of British Columbia. In the small Vancouver context of HIV research rumours abound as they do just about everywhere. There are rumours about doctors who use patients as guinea pigs for antiretroviral clinical trials putting patients at risk in the name of pharmaceutical research; rumours of doctors who have trunk loads of “donated” medicines being shipped to Guatemala which are traced back to Eastside clinics unaccounted for; rumours of love affairs, break-ups, and flirtation; rumours of corrupt prescribing practices; rumours of doctors who prescribe too much methadone, out-of-date antiretroviral therapy and those who trade prescriptions for sexual favours with drug addicted patients; and rumours of professional alliances being formed, negotiated and ended. Rumours about HIV treatment in the Downtown Eastside travel through the province, across the nation as HIV researchers, pharmaceutical sales reps, and sick bodies traverse between workshops, conferences, hospitals, and communities.

There are vague rumours that in December 2004 the medical director from Bristol-Myers Squibb made allegations that the Centre for Excellence, at that time under the helm of Dr. Montaner who was acting-Director, was favouring particular drugs in their prescribing practice which appeared to have a close relationship to what company was providing them with awards, grants, and other incentives. Others report that the accusation suggested an improper use of funds among Centre administration. A formal inquiry was launched – Dr. Julio Montaner and Mr. Brian Harrigan were reportedly asked to step down while the investigation was carried out. The inquiry apparently found the allegations to be unfounded. Julio Montaner returned as Director and in response bought multiple copies of Marcia Angell’s (2004) book “The truth about the drug companies:

How they deceive us and what to do about it,” keeping a stack on his desk, handing them out to fellow researchers at the Centre<sup>34</sup>. Brian Harrigan left the Centre for Excellence in 2005 and now works for Oxford Outcomes as Chief Operating Officer. A pharmaceutical manager who works for a competing company said he hears that the allegations were true even though the Centre was cleared. It is further rumoured that the Centre for Excellence now has a lawsuit levied against Bristol-Myers Squibb. They are of course the producers of Sustiva™ - the NNRTI (non-nucleoside reverse transcriptase inhibitor) also known as Efavirenz – one of the drugs at the centre of the 2NN debate that the Centre’s guidelines restrict access to (see Chapter 6 on therapeutic guidelines).

But rumours involving drug companies, medicines and clinicians go beyond the Centre for Excellence. In the Downtown Eastside, pharmacies, medicines and scandal go hand in hand especially when it includes methadone. Local Downtown Eastside residents report an astounding turnover rate of private pharmacies in the neighbourhood. They come and go and appear unregulated. One participant complained that they weren’t “pharmacies” – only methadone distribution centres, with empty shelves except for a few bottles of Tylenol. Dr. Michael O’ Shaughnessy perceptively pointed out that, at least in the province of British Columbia, there has been no evaluation of the methadone maintenance delivery and prescribing practices, and suggested that if someone asked for an evaluation that – “Well I think if you asked for one you’d get your ass kicked out the door. Uh, that’s not going to happen.”

Historian Luise White (1994) suggests that rumours, gossip and accusations are powerful tactics which, when deployed, work to discipline social actors. An analysis of

rumour (where rumour is “evidence”) provides us with a glimpse of problematic social fields which otherwise fly under the radar in formal discourses<sup>35</sup>. In the Downtown Eastside, rumours of pharmaceutical corruption, conspiracy theories, and social injustices suggest a space (in time and context) of instabilities and negotiations, of ruptures. Methodologically, an analysis of rumours is not to suggest or even inquire whether or not they represent some form of “truth” but to explore what these rumours represent, what they tell us about the politics of HIV treatment both locally and globally. Here, these rumours attest to unease, suspicion, and growing frustration with medical research and HIV treatment.

### **Concluding Thoughts**

*I will lift up mine eyes unto the pills. Almost everyone takes them, from the humble aspirin to the multi-coloured, king-sized three deckers, which put you to sleep, wake you up, stimulate and soothe you all in one. It is an age of pills.*

-- Malcolm Muggeridge

These are rumours, things people say in passing, over coffee, over beer, at conferences, and in hallways. But they are not *just* rumours for these whispers, as informal subaltern discourses, highlight the widening gap between those who live with HIV and those who study and treat it. They remind us that there is a profit in suffering and that a profit is being made on the disease and bodies that live within Vancouver’s inner city. These rumours also speak to the complicated entanglements between the state, research institutions, pharmaceutical corporations and disease.

Dr. Julio Montaner publicly applauds the pharmaceutical industry and their research. Friends and colleagues work as pharmaceutical sales reps and see no ethical dilemma in the work they do. A clinician prescribes medicine every day, runs clinical

trials, and consumed 12 weeks of antivirals when he received a needle-stick injury, but when asked if he would enrol his daughter in clinical trials for a preventive vaccine, replies no. Others are intensely critical of clinical trials and industry sponsored research, perhaps naively assuming that state-sponsored clinical trials are themselves not imbued with unethical practice, coercion, and some concern with profit. Many of us critical of drug companies also benefit from medicines, ranging from aspirin to antibiotics to the infamous “pill” itself. Some swallow them like they are candies; others resentfully choke them down.

HIV vaccine trials are sites of negotiation and contestation involving multiple actors (participants, advocates, researchers, drug companies, states, pharmaceuticals and biologics) where questions of good science, social justice and global health intersect. In October 2006 at the Social Studies of Science conference Kaushik Sunder Rajan spoke about experimental subjects, Indian subjects who he theorized were enrolled in clinical trials and medical research for the advancement of health of Americans, no longer willing to enrol in trials. In the Downtown Eastside, the site of new vaccine trials, these disposable bodies are enrolled in trials to save Africans. In response to criticisms that the trials were taking advantage of the most “vulnerable” women in the community, young, often aboriginal, women engaged in sex work, the trial site director responded by asking – “Well, would you rather have these drugs be tested instead on poor African women?” This research site destabilizes the way social scientists think about marginality, the relationships between the North and resource-poor settings, between the metropole and the colony. This inner city community becomes the margins, the colonial laboratory, for hopeful vaccines that will save “Africa.”

## **CHAPTER 8 CONCLUSIONS: MOTIVATED TRUTHS, MEDICAL RESEARCH AND THE INNER CITY POOR**

Dr. Michael O'Shaughnessy, co-founder of the Centre for Excellence, has reported that in British Columbia in the 1990s one person a day died from HIV and AIDS; today, two people per month die from HIV. Medicines, and the research to develop and test them, save lives and thus we understand the intense value of both pharmaceuticals and medical research. Today it is fair to say that overall Downtown Eastside residents are poorer and sicker – the consequences of a system of neoliberal and late-capitalist economic restructuring. The Downtown Eastside is not a “disadvantaged” community – it is a devastated community. The 1997 declaration of a public health emergency in the community in response to the escalating rates of HIV infection and illicit drug use was a plea for action. What has unfolded in the past ten years in the Downtown Eastside in response has been the proliferation of a complex web of public health interventions, medical research, social research, and activism. Directly observed therapy programs for the delivery of antiretroviral therapies have been established and promoted. There has been an extensive accumulation of research about adherence, resistance, the efficacy of highly active antiretroviral therapy, and behaviours of injection drug users. HIV treatment has been standardized through the development of international and localized therapeutic guidelines. Vaccine research for AIDS has pushed forward in spite of social and scientific barriers. Yet, at the same time we have witnessed increased biomedical and economic inequalities.

But these practices and actions merge at a particular time and specific context to produce unintended, often contradictory, consequences. In this local context HIV treatment and medical research is co-constituted -- with implications for who has access to and who accesses medicines. I have attempted to trace the production of a dispersed-network of medico-scientific knowledge in the context of a declared public health emergency of HIV infection and illicit drug use. I have focused this dissertation on an assemblage of clinical practices, public health interventions, biomedical discourses, pharmaceuticals, and research paradigms. In the Downtown Eastside treatment and research are often indistinguishable. Local researchers and research institutions are situated within larger global social networks of research, science and medicine where authority and expertise are negotiated and contested. In part this is an ethnography of a knowledge-producing assemblage of researchers. While I have focused largely on the researchers at the British Columbia Centre for Excellence in HIV/AIDS, because they have marketed and positioned themselves as the scientific experts on HIV and AIDS in the inner city, this discussion pertains to all of us who do research in the community. It forces us to consider the contemporary landscape of research. What is a research institution? How do we ethnographically study it and its effects? Is it a nongovernmental organization, an independent think-tank, or part of the state-run Canadian university system?

The Centre for Excellence is an amalgamation of governmental, corporate, and the scientific. It is also a medical clinic, a system of pharmaceutical regulation, and the centralized site of antiretroviral distribution. The Centre markets itself (through a marketing campaign that includes its own journal, media releases, its own seminar series,

public talks, conference presentations, academic papers, a webpage, and so on) as not only the expert scientific institution on HIV, adherence, and drug-communities but as an advocates for drug-users through their collaborative work with nongovernmental organizations in the Downtown Eastside, a history of community-based research projects (with WISH, VANDU, PHS), and through politically-engaged rhetoric.

They are involved in local, national and international contestations to establish what counts as the scientific “truth” in the world of HIV/AIDS. In this way, my dissertation engages in an on-going dialogue with medical anthropology, partially informed by science and technology studies, that reconsiders the production of scientific knowledge about human subjects, disease and work artefacts. Scientific knowledge about the Downtown Eastside subject is characterized by constant battles over spaces, bodies, and diseases, resulting in scientific papers that sometimes have a paradoxical logic. I have attempted to show through out this dissertation that the scientific production of knowledge about HIV in the inner city and forms of therapeutic interventions for HIV are socially situated, informed by colonial histories and late-capitalist economies.

I have also suggested that HIV researchers in the Vancouver context have made efforts to not only establish expert authority over HIV/AIDS (things) and drug users (people) but over social behaviours, or morality, over public chaos (spaces), and as a result increasingly the objective scientific evidence is imbued with moral imperatives. Scientific authority rests on the construction of specialized therapeutic subjects – the inner city, HIV positive, drug-using, probably homeless, most-likely Aboriginal, definitely impoverished, patient. And as I illustrated in Chapter 5, the modern

non-compliant patient is uncannily reminiscent of colonial unruly subjects. She or he is counted, surveyed, mapped, traced, studied, and analyzed but never cured or healed. Local and international research about adherence names non-compliance as a problem. The very naming of the Downtown Eastside resident as non-adherent produces a non-compliant patient (Hacking 1999). In the Foucauldian sense of subject-making but also more concretely because the intense focus on adherence has the unintended consequence of non-compliance. Patients, scared of developing drug resistant viral strains, simply stop taking medicines or refuse to start. Other patients, exhausted and weary from constant observation and surveillance, refuse treatment. Perhaps not fully reflecting on why – they tell epidemiologists and researchers that they’ve ‘forgotten.’ Clinicians, concerned that patients will run out of therapeutic options if they are non-adherent, hesitantly prescribe antiretrovirals. Other doctors refuse to prescribe to patients deemed “too chaotic” – perhaps sometimes understanding that it is difficult to think about taking medicines every morning when you are living on the street with only a shopping cart to carry your life’s belongings around. And yet others suggest the very expensive cost of antiretrovirals means that they should cautiously be prescribed to only those deemed “ready.” In the end, the results are the same – very few of the urban poor are taking antiretroviral therapy. Recall, the Centre suggests that 30% of the residents (approximately 4,800) are infected with HIV yet in 2006 only about 350 people from the neighbourhood were taking antiretrovirals.

I have also suggested that claims to expertise and scientific authority rest on the generation and regeneration of particular facts. *Highly active antiretroviral therapy effectively treats HIV. HIV can be effectively treated with 100% adherence. Non-*



*compliance creates resistance. Drug users, due to forgetfulness, cognitive impairments, homelessness, and other factors, are more likely to be non-adherence. Adherence can be improved with “supportive” interventions like DOT.* Medical researchers generate their facts through multiple research projects, statistical/mathematical modeling, epidemiologic cohorts, vaccine clinical trials, and ethnography. The facts are not neutral, objective findings – or “ideology” free – but they are imbued from their very making with values, ideas, and judgments about drugs, subjects, and spaces. Facts about adherence, efficacy of DOT programs, and therapeutic guidelines are morally inflected with ideas about value (of life and medicines), morality, and citizenship. The power of the “fact” in part comes from its alleged neutrality. The Centre for Excellence claims authority over HIV science, whether its resistance, adherence, or DOT, based on the evidence that they produce – and Dr. Julio Montaner positions this evidence in contrast to the ideologically driven motives of federal politicians. Part of the authority of being an expert comes from being able to claim a (false) neutrality in your science. It is as Peter Redfield has suggested of Médecins San Frontières (MSF), “the knowledge it produces and circulates is always undeniably motivated and built out of facts assembled directly in the service of humane values” (2006, 17). Clearly if the evidence or the facts are socially produced in particular settings reflecting specific historical, political, and economic contexts, then so are the recommendations that result from that evidence. The delivery of anti-HIV medicines in the BC context is presumed to be a straight forward action but it is very complicated process informed by the contemporary social landscape and involving multiple implicated actors (both human and non-human): therapeutic guidelines that balance subjective measures of patient’s readiness with immunologic and virologic

measures, theories of resistance and adherence that are constantly shifting in the rapidly-evolving landscape of HIV science, and discourses about brains, rationality, and disorder. It alerts us to the exploitative potential of post-(neo)colonial science especially since it is presented with such authority and simultaneously such objectivity.

While these research projects employ a wide range of methods in their data collection, ethnography is increasingly a method of choice in health research. Yet, there is a serious discrepancy between the ethnographic practices of anthropologists and the “drive-by” or “drive through” ethnographies of contemporary health research<sup>1</sup>. Such discrepancies alert us to the ways in which ethnography is sometimes misappropriated as a tool and remind us how important it is for us to critically reflect regularly on our own ethnographic practices. But it forces us to consider what the future of ethnographic practice might look like and light of such an intense assemblage of therapeutic practices, surveillance, and biomedical research?

Because research and treatment is so intertwined, co-constituting in the Vancouver context, and because they are two very powerful economies, I suggest there is a “motivated truth” in the scientific knowledge produced (Redfield 2006). By this, drawing on Redfield, I suggest that this assemblage of research and therapeutic interventions in the Downtown Eastside results in “an overtly motivated form of scientific research” (2006, 17). This is not to say that the researchers are not good intentioned, attempting to address serious inequities in health and social justice. This result is not reflective of individuals, or even institutions, rather it speaks to the new ways

in which biomedicine, the state, and the private world of pharmaceuticals merge in the 21<sup>st</sup> century. The lines between the state, industry and humanitarian aid is blurred.

In part, I suggest that this motivated truth is directly connected to the question of value. Nikolas Rose's assertion that vitality of life constitutes a source of biovalue resonates in the inner city (2006). Yet, as I have illustrated – it is the lack of vitality, rather the virus itself, which is the source of biovalue among the urban poor. It is not the capacity to grow or live – but the tendency to grow ill, to wither, to die that constitutes value here. Researchers count infection, viral loads, and mortality. In the Downtown Eastside we see the intense commodification of dispossessed bodies, of disease, and of lives. As Lesley Sharp explains, “this burgeoning commercialization of body commodities has had an extraordinary effect on the thrust of current medical research and demands for resource extraction” (2002, 373). There is profit in disease and suffering for pharmaceutical companies as they create global markets for drugs and vaccines. Whether it is a global demand for research subjects for vaccine clinical trials or informed consent forms requesting permission to do future research on blood samples (raising concerns about biopiracy), we witness the powerful ways in which value circulates globally through the world of HIV/AIDS research. But biovalue speaks to much more – it speaks to the productive force of the virus as a “new emergent medical commodity” (2002, 373). In part, the force to create an intense assemblage of research and therapeutic interventions that specifically targets the non-compliant patient. The virus and its interaction with pharmaceuticals demands surveillance – epidemiological cohorts track it, laboratory testing examines resistant mutations, and DOT programs provide supervision of swallowing.

Directly observed therapy programs embody concerns about drug resistance, therapeutic fidelity, and social behaviours. I have also tried to illustrate here that the Centre for Excellence takes a new role in ordering public spaces through their demands for directly observed therapy for antiretroviral therapy and by aggressively advocating for public health interventions that reduce “public disorder” and “chaos.” DOT programs effectually contain the disease and diseased bodies within a community. It is a biomedical technique that works to control, monitor, and regulate the urban poor and thus work as spatializing biomedical practices and technologies. Eastside residents are held captive by their poverty, but also by directly observed therapy of methadone, antiretrovirals, illicit drug consumption, and other prescribed medications, forced to rely on research for economic incentives.<sup>2</sup>

Although there are on-going debates regarding the deployment of a Foucauldian framework for understanding relations in a world characterized by millennial capitalism and neoliberal governance, I suggest that Foucault’s microphysics of power allows us to understand the complicated relationships between circulating capital, restructuring welfare states, disciplinary power, and the micro-practices of clinical care. As well, his theoretical analysis of bio-power and his empirical work focusing on the medical gaze and surveillance have shaped the way anthropologists have come to understand medicine as an apparatus of normalization that regulates and disciplines bodies. This dissertation has highlighted the ways in which disciplinary power operates through the deployment of surveys, numbers, the process of counting in public health and epidemiology, and ethnography. But in many ways the Downtown Eastside appears to be a space where the forms of disciplinary power that Foucault described later in his career, the techniques of

self-government in particular, have failed to take hold. In the neo-liberal state where health is increasingly a personal “responsibility,” residents in the Downtown Eastside escape the disciplinary powers which teach us to monitor our health through exercise, diets, and self-esteem building. As a result, in an attempt to manage the unruliness of the inner city, to discipline the ungovernable, the state employs a range of techniques of power to monitor, regulate, and control – counting, researching, observing are all central in this governance strategy, but sovereign forms of power occur synchronously with these disciplinary techniques. Police brutality, coercion, and containment, sovereign forms of power that work upon the body in often brutal ways, not only survive in the community but appear to be burgeoning. In the Downtown Eastside, disciplinary power co-exists with sovereign power raising important questions to be further explored – are we moving away from disciplinary power into something new altogether or returning to old brutal forms of domination for those considered unworthy?

Gilles Deleuze (1995) has suggested that disciplinary power is being replaced by a new formation – a move towards control societies. Foucault highlighted the ways in which power operated through clinics, schools, and disciplines. And indeed, in the inner city, we see how the clinics and disciplinary knowledge shape and regulate individual lives and bodies. But the depth and intensity of power appears to be reaching farther, growing stronger. The current configuration of medical research and therapeutic programs, whether drug treatment, harm reduction, or DOT, results in a system where surveillance has gone mad. It is no longer simply subjects that are governed, but the new emphasis on the cellular and molecular, on pharmaceuticals, on viruses, on genetics,

produces an apparatus of biomedical and biosocial technologies that monitor and regulate behaviour, cognition, and (both ethical and “unethical”) pharmaceutical selves.

In a community where surveillance and monitoring of all sorts is so intense, where residents report research exhaustion, how can we justify ethnographic practice? What can we say about doing critical ethnographic research in light of my critique of medical surveillance? Working in such a community forced me to consider the problems of situating my own research project in an intensely researched and intensely monitored community. Since we are speaking about women and men who are already overly monitored, regulated and surveyed by police, welfare services, and other state bureaucracies – the decision to do additional research in the neighbourhood is difficult. Our research becoming another layer of surveillance, not only in our everyday practices as researchers, mapping their days/nights, with our cameras documenting their lives, but also as we write about their lives. Furthermore, social researchers are also increasingly invested with scientific authoritative knowledge over the social, political, economic and health of the urban poor. These are pressing issues faced by social researchers and community activists – or “do-good academics” – working with marginalized “exotics at home” as Michaela di Leonardo refers to us (di Leonardo 1998). As an ethnographer in the community clearly this critique has implications for my own work and forces us to consider the possibilities for future *ethical* ethnographic research. As Veena Das and Arthur Kleinman remind us, “Photographs, documents, or numbers through which the real is authorized may circulate in many contradictory contexts and become the subject of micro-exchanges, which bear traces of the apparatuses of state” (2000:5). The boundaries between the state, government actors, industry, knowledge-generating institutions and

nongovernmental organizations are blurred – forcing us to reconsider not only the ethics of particular forms of medical research but of the ethics of ethnography.

## NOTES

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### Chapter 1

<sup>1</sup> I use the terms “Centre,” “Centre for Excellence,” and the “British Columbia Centre for Excellence in HIV/AIDS” interchangeably throughout this dissertation.

<sup>2</sup> “Board Declares HIV Epidemic Public Health Emergency,” Final Edition, *Vancouver Sun*, 26 September 1997, A. 11.

<sup>3</sup> The Vancouver Agreement is an intergovernmental partnership between the federal government, the provincial government of British Columbia, the municipal government of Vancouver, and private businesses and communities. Initiated in 2000 for five years, and then renewed until 2010, the Vancouver Agreement is an urban development initiative primarily focused on inner-city revitalization, or urban renewal. One of the strategies that developed from the agreement is “A Framework for Action: A Four-Pillar Approach” – a plan to tackle the “drug problems” of Vancouver’s Downtown Eastside by addressing prevention, treatment, policing, and harm reduction (Vancouver 2000). Many have suggested that the focus has been on enforcement (and perhaps harm reduction), while prevention and treatment have been ignored. <http://www.vancouveragreement.ca/TheAgreement.htm>, accessed 1 March 2007.

<sup>4</sup> At the CASCA conference in May 2006 in Montreal, QC.

<sup>5</sup> See, for example, Culhane Speck (1987) and Kelm (2001).

<sup>6</sup> See Woolford (2001) for an analysis of media depictions of HIV/AIDS and injection drug users in the Downtown Eastside and the ways in which these depictions contribute to the stigmatization of the community and people living with HIV.

<sup>7</sup> Recently, in their advocacy for a safer smoking facility, health researchers at the BC Centre for Excellence have highlighted the prevalence of crack inhalation as the drug ingestion method of choice. Whether depicted as injection drug users or crack smokers, the end result of these representations is similarly pathologizing and stigmatizing.

<sup>8</sup> Personal correspondence with Dr. Mark Tyndall regarding the ARV-OP Project, May 2005.

<sup>9</sup> Effective April 2007, this rate is being raised to \$610, the first increase since 1992.

<sup>10</sup> Effective April 2007, the amount afforded for housing is being raised from \$325 to \$375 for a person with a disability.

<sup>11</sup> See Biehl (2005) and Agamben (1998) on abandonment and the state.

<sup>12</sup> The exception to this occurs in Chapter 8, where I widen my discussion to consider preventive AIDS vaccines.

<sup>13</sup> See his “AIDS Relief in Côte-D’Ivoire and Concern about the Emergence of a Military Therapeutic Complex,” paper presented at the American Anthropological Association Annual Conference, 17 November 2006.

<sup>14</sup> <http://www.msflhr.org/sub-media-backgrounders.htm>, accessed February 5, 2007.

<sup>15</sup> <http://www.cihir-irsc.gc.ca/e/22953.html>, accessed February 6, 2007.



<sup>16</sup> MRSA stands for methicillin-resistant staphylococcus aureus and is extraordinarily common in hospitals like St. Paul's Hospital.

<sup>17</sup> By this I suggest that families, unable to cope with their own poverty, illness, or social situations, perhaps influenced by state-actors or state practices like colonialism, may simply be unable to deal with the illness of family members. They may simply be inadequately prepared to deal with HIV, resulting in the unintended abandonment of family members.

<sup>18</sup> It is difficult to know the extent to which honoraria for research contributes to individual incomes in the community. This is partially due to the punitive nature of income assistance in the Province of British Columbia, where residents might be hesitant to formally report income received from research.

<sup>19</sup> For an interesting discussion of medical research and the perspective of patients on treatment and "stealing blood," see Fairhead, Leach, and Small (2006) and White (2000).

<sup>20</sup> Even though the "data" may be stripped of identifying factors, the research findings and publications being produced from it are based, at least in part, on the individuals living in the Downtown Eastside.

<sup>21</sup> This is similar, on one level, to the situation described by Melissa Wright (2001; 2004), in which Mexican women working in the maquiladora industry are instrumental in the factories' productivity, yet end up representing poverty and lack of development during an era of economic restructuring (which involves a movement from unskilled female workers to educated, male high-tech employees).

<sup>22</sup> At least 300 of the 350 people taking medicines in the community were doing so through one of the DOT programs.

<sup>23</sup> The Society for Cultural Anthropology session "Radical Biopolitics and Iatrogenic Violence," organized by Laurence McFalls and Maria Pandolfi and held at the AAA Annual Conference in San Jose, CA, in November 2006, provided an important framework that helped me work through some of these ideas. Laurence McFalls's paper, "Structures, Agents and Institutions of Therapeutic Domination," was particularly helpful.

<sup>24</sup> It should be noted, however, that many contemporary anthropologists are situating themselves in a "space between a Gramscian and a Foucauldian position on power, government and authority," seeking to lessen the traditional tension between Marxist and Foucauldian approaches (Hansen and Stepputat 2001:3) and find this unproblematic.

<sup>25</sup> It appears that, for Foucault, "discourse" replaces "ideology." However, discourse is still quite clearly distinguishable from ideology in that there is no "innate" human instinct before discourse (as some would infer from understandings of ideology).

<sup>26</sup> In *The Birth of the Clinic* (1989 [1973]), Foucault outlines an epistemic shift that illustrates how a reorganization of space and social relationships in the clinic instigated a change in the ways of seeing. The 'clinical gaze' is a central concept in understanding the way power operates through medicine.

<sup>27</sup> See also Timmermans and Berg (1997) on "standardization" and "universality" in health practice.

<sup>28</sup> I think this television series has changed considerably since it was first aired. My analogy refers to season one of the show.

<sup>29</sup> See <http://www.cfenet.ubc.ca/>, accessed 18 January 2007.

<sup>30</sup> Providence Health Care, registered under the Society Act and formed in 1997, includes St. Paul's Hospital, Mount Saint Joseph Hospital, Saint Vincent's Hospital, and a number of other long-term residential care facilities.

<sup>31</sup> The "gold standard" for epidemiologic research is the randomized controlled trial (RCT), but cohort studies, an observational research method that follows participants, are increasingly considered a valued method, especially with the use of very large datasets. The obvious limitations of cohort studies, especially those in the Downtown Eastside, is that the participants are not randomly selected but sampled according to convenience, thus limiting the generalizability of the conclusions.

<sup>32</sup> See, for example, Petryna (2002) (why resettled Ukrainians move back to homes that are contaminated or drink milk that is contaminated rather than use filtering devices); or Bourgois (2000) (why IVD users elect to use dirty needles when harm reduction programs have made clean ones them available).

<sup>33</sup> For other studies exploring "compliance," see Ferzacca (2004), Kaljee and Beardsley (1992), Lerner (1997), and Trostle (1988).

<sup>34</sup> Or, as Petryna (2002) illustrates, to *disprove* scientific knowledge.

## Chapter 2

<sup>1</sup> See Bob Ross, "City Considers Hiring Archaeologist to Map Human Waste," *Vancouver Courier*, 15 May 2005, 8; "Putting a Lid on Stench of Homelessness: Lanes Used as Loos," *Province*, 10 June 2005, A19.

<sup>2</sup> See also the work of Heath (1998) and Martin (1994).

<sup>3</sup> The practice of providing honoraria is based on a per interview basis, but how do we compensate participants who share with us their experiences and practices of therapy and health services? For the most part, I sought individual solutions to this problem. This included, when possible, lending my services or skills (e.g., giving rides to participants, purchasing food, acting as an advocate). I also volunteered at one of the clinics as a grant writer.

<sup>4</sup> "Evidence Demonstrates Conservatives Should Keep Supporting Insite," editorial, *Vancouver Sun*, 20 May 2006, C3.

<sup>5</sup> See, for example, Small (2007).

<sup>6</sup> For a cautious critique of the implementation of harm reduction strategies in Vancouver, see Roe (2005).

<sup>7</sup> At the International Harm Reduction Conference in Vancouver in May 2006, an NGO senior administrator and health researcher, wearing a black hood, stood behind a local clinician who, in an interview with the media, was criticizing the site.

<sup>8</sup> See, for example, Small (2007).

<sup>9</sup> See Fabian's (2001) *Anthropology with an Attitude*.

<sup>10</sup> Scheper-Hughes' (2004) most recent article raises important questions about the practice of engaging in "undercover" research among illicit and underground economies, and it will undoubtedly cause more debates. She raises a number of issues that are problematic, including her collaboration with journalists; her sharing of ethnographic data with the US Food and Drug Administration, the FBI, and other national enforcements offices; and her "engaged and enraged" methodological approach.

### Chapter 3

<sup>1</sup> *Forecast: Journal of the BC Centre for Excellence in HIV/AIDS*, 13, 2 (2005): 2.

<sup>2</sup> <http://www.iapac.org/home.asp?pid=7973>, accessed 5 March 2007.

<sup>3</sup> See *Promise* 4(2), Fall 2006, Burnaby, BC: Canada Wide.

<sup>4</sup> Picard, Andre, "Political leaders accused of AIDS genocide," *The Globe and Mail*, August 18, 2006, <http://www.theglobeandmail.com/servlet/story/RTGAM.20060818.aids-leaders18/BNStory/AIDSCon/home>, accessed March 1, 2007.

<sup>5</sup> See <http://www.cfenet.ubc.ca/content.php?id=20>, accessed January 18, 2007.

<sup>6</sup> Rumours suggest that, while this might be the institutional management model, in reality Montaner only reports to Carl Roy.

<sup>7</sup> These findings were published in 1998. See Montaner et al. (1998).

<sup>8</sup> See [http://www.hc-sc.gc.ca/ahc-asc/media/nr-cp/2003/2003\\_72\\_e.html](http://www.hc-sc.gc.ca/ahc-asc/media/nr-cp/2003/2003_72_e.html), accessed January 4, 2007.

<sup>9</sup> According to the CIHR Funding Database, in 1995 the Maka project received \$198,780 under an HIV/AIDS community-based research stream operating grant and then, in 2006, an additional \$124,090 under a CIHR Reducing Health Disparities and Promoting Equity for Vulnerable Populations call for proposals.

<sup>10</sup> For example, see Small, Rhodes, Wood, and Kerr (2007). Dr. Robert Hogg did his undergraduate and master's degree in anthropology, and the Centre currently has a number of graduate students (including a postdoctoral fellow) who are trained in anthropology.

<sup>11</sup> <http://www.cfenet.ubc.ca/content.php?id=21>, accessed 28 February 2007. For example, see Gross et al. 2006.

<sup>12</sup> *Forecast: Journal of the BC Centre for Excellence in HIV/AIDS* 13, 2 (2005): 12.

<sup>13</sup> HAART Observational Medical Evaluation and Research study.

<sup>14</sup> For an example of such debates with regard to tuberculosis treatment, see Farmer and Nardell (1998).

<sup>15</sup> Atripla was the first pill to be approved (July 2006) by the US Food and Drug Administration (FDA) that includes one of the most common combination therapies (Sustiva, Viread, and Emtriva) within a single tablet. See <http://www.fda.gov/bbs/topics/NEWS/2006/NEW01408.html>.

<sup>16</sup> <http://cfenet.ubc.ca/content.php?id=26>, accessed 3 March 2007.

<sup>17</sup> Thomas Kerr kindly provided me with a copy of the ASEM survey.

<sup>18</sup> *Forecast: Journal of the BC Centre for Excellence in HIV/AIDS* 13, 2 (2005): 4.

<sup>19</sup> *Forecast: Journal of the BC Centre for Excellence in HIV/AIDS* 13, 2 (2005): 4.

<sup>20</sup> David Moore, personal correspondence, 17 May 2005.

<sup>21</sup> See "Simplifying antiretroviral therapy for 'marginalized' populations," AIDS rounds, St. Paul's Hospital, Vancouver, BC, April 2006, Dr. Mark Tyndall, <http://cfenet.ubc.ca/video.php?id=23&sid=33&cat=1>.

<sup>22</sup> Tom Sandborn, "Fraction of HIV Residents Getting Treatment in Downtown Eastside," *Tyee*, 8 May 2006, <http://thetyee.ca/News/2006/05/08/FractionTreatmentEastside>, accessed 18 May 2006.

<sup>23</sup> Matthew Ramsey, "HIV Patients May Be Paid to Take Drugs," *Province*, 27 November 2005, A4.

<sup>24</sup> <http://vancouver.indymedia.org/?q=node/2999>; accessed 4 January 2007.

<sup>25</sup> For a historical review and critical discussion of "objectivity" in science, see Daston (1992). For a similar discussion of the making of a fact, see Latour and Woolgar's (1986) discussion in *Laboratory Life*.

<sup>26</sup> For example, the WHO (2003) argues that adherence rates in developing countries are even lower than their estimates of 50 percent in the developed world, yet Edward Mills and colleagues (2006) suggest that rates of adherence in Africa have been sorely over-estimated and that, in fact, compliance does not appear to be a challenge in sub-Saharan nations.

<sup>27</sup> For an ethnographic exploration of compliance and the treatment of epilepsy, see Trostle, Hauser, and Susser (1981).

<sup>28</sup> See Haynes, Taylor, and Sackett (1979) for one of the earliest edited collections to address compliance in medicine. Lerner also suggests that the work by Haynes and Sackett was essentially the prelude to the now powerful "evidence-based medicine" paradigm (see Evidence-Based Medicine Working Group 1992). The links between adherence research, clinical compliance, and evidence-based medicine, especially in the context of the Downtown Eastside, requires additional analysis – perhaps a future research project.

<sup>29</sup> "Readiness" is highlighted in the International Therapeutic Guidelines recommended by the guidelines committee for the IAS (upon which Montaner sits). In Chapter 6, I examine the ways in which these theories of adherence, resistance, and drug users influence international guidelines and the prescription trends in the clinic.

<sup>30</sup> This has become known as the 2NN debate (see Chapter 6).

<sup>31</sup> Personal correspondence, August 2006.

<sup>32</sup> Of course, the evidence overwhelmingly suggests that taking antiretroviral therapy saves lives. It is predicted that 50 percent adherence to antiretrovirals is better than none, particularly if resistant strains are most likely to develop between 80 percent and 90 percent adherence. There is simply not enough evidence on the long-term clinical outcomes of varying rates of adherence and drug resistance (partially due to the inadequate measures of adherence).

## Chapter 4

<sup>1</sup> For more detailed histories of the development of DOT, see Bayer and Wilkinson (1995) and Raviglione and Pio (2002).

<sup>2</sup> Despite debates regarding the effectiveness of DOT, it continues to be adopted in the therapeutic management of both TB and HIV. The differences between HIV and TB have led others to question the feasibility of adopting DOT for HIV, especially since there is considerable debate regarding the efficacy of DOT programs. Epidemiological research indicates a high success rate (measured by scientific standards) for DOT for TB programs: compliance is either equal to or better than those not enrolled in DOT programs (for example, see Fitzgerald 2000). Likewise, epidemiological research has indicated a relatively good success rate for HIV treatment when used with MAT, noting improved CD4 counts and an overall increase in general health (Reynolds

2003). But others have questioned these outcome measurements, suggesting that self-administered therapy programs have the same outcomes (Garner 1998; Volmink, Matchaba, and Garner 2000). Garner insists that these measurement models fail to identify which *part* of the DOT programs are aiding in therapy compliance, suggesting that the “supervised swallowing” component may in fact play a very small role.

<sup>3</sup> <http://www.who.int/tb/strategy/en/>, accessed 5 March 2007.

<sup>4</sup> Exceptions include Kelm (2001) and Lux (2001).

<sup>5</sup> For example, see Adelson et al. (2006); AIDS Alert (2005); Bangsberg, Mundy, and Tulsy (2001); Clarke et al. (2002); Garland et al. (2006); Mitty et al. (2006); Wohl et al. (2003).

<sup>6</sup> Most recently referred to as a “comprehensive support program.”

<sup>7</sup> See, for example, Garland et al. (2006), where participants received “monthly incentives valued at \$25 and weekly incentives valued at \$5” (US dollars).

<sup>8</sup> *Treatment of Tuberculosis: Guidelines for National Programmes*, 2nd ed. (Geneva: WHO/TB/97.220, 1997).

<sup>9</sup> See, for example, Mitty et al. (2006); Garland et al. (2006); Wohl et al. (2003); and Tyndall et al. (2006).

<sup>10</sup> Tom Sandborn, “Fraction of HIV Residents Getting Treatment in Downtown Eastside,” *Tyee*, 8 May 2006, <http://thetyee.ca/News/2006/05/08/FractionTreatmentEastside>, accessed 18 May 2006.

<sup>11</sup> Heather Hay, *Living +*, January/February 2000, 8.

<sup>12</sup> This program currently has thirteen registered patients, six of which are receiving DOT through the clinic. TB treatment may be daily or only twice a week, depending on co-infections. Patients who have TB and HIV with a CD4 cell count less than 200 receive daily medicines. But others, in part due to the long-acting nature of TB meds, may only receive treatment twice a week.

<sup>13</sup> See Conway et al. (2004), and see Chapter 7 for a more detailed discussion of the Gastown Pharmacy.

<sup>14</sup> This program is untitled. For more information see [http://www.multidx.com/articles/Canadian-Nurse\\_article\\_1.htm](http://www.multidx.com/articles/Canadian-Nurse_article_1.htm).

<sup>15</sup> See Chapter 7 on the political economy of HIV medicines for a more detailed description of the pharmacy industry in the Downtown Eastside.

<sup>16</sup> For more information on the research findings, see Shannon et al. (2005). As a research project *and* a DOT program, participants are doubly monitored.

<sup>17</sup> See Chapter 7 on the political economy of HIV medicine distribution in British Columbia.

<sup>18</sup> See Sollitto et al. (2001).

<sup>19</sup> *Forecast*, “MAT/DOT Making an Impact on Downtown Eastside,” 8, 1 (2000): 3.

<sup>20</sup> VIDUS, Vancouver Injection Drug Users Study, is one of the BC Centre for Excellence’s cohort studies in the Downtown Eastside.

<sup>21</sup> According to the outreach pharmacist at the Centre for Excellence in December 2005, there were approximately 308 people in the Downtown Eastside taking antiretroviral therapy – 45 at Pender Clinic, 80 at MAT, 80 at POP, 70 at Garlane’s pharmacy (which distributes them to places like the Portland Hotel Society, Lookout, Triage, and May’s Place), and 33 to Garlane’s pharmacy (20 to the nurses, 6 to individuals who pick up their medicines daily with their

methadone, and 6 who receive a monthly supply). These are approximate numbers as they change almost daily.

<sup>22</sup> ARVs – POP/MAT presentation by Dr. Mark W. Tyndall, 23 January 2006, at the MAT/DOT Advisory Committee meeting, Vancouver, BC.

<sup>23</sup> See: [http://www.multidx.com/articles/Canadian-Nurse\\_article\\_1.htm](http://www.multidx.com/articles/Canadian-Nurse_article_1.htm).

<sup>24</sup> Dr. Stacy Pigg pointed this out during the DOT session at the American Anthropology Association in San Jose, CA, in November 2006.

## Chapter 5

<sup>1</sup> Jack, one of the regular front desk workers, explained that, while they often threaten to withhold funds, they never actually do so.

<sup>2</sup> Matthew Ramsey, “HIV Patients May Be Paid to Take Drugs,” *Province*, 27 November 2005, A4.

<sup>3</sup> In contrast to the Portland Hotel, the Dr. Peter Centre has strict rules and policies regarding the behaviour of participants, especially when it comes to their interactions with staff. If participants are disrespectful or rude to staff are “held at the door”; that is, they are banned from the Day Program. Behavioural “outbursts” witnessed at the Portland Hotel Society and frequently at the Positive Outlook Program would most definitely result in banning at the Dr. Peter Centre. By having a no-banning policy, the Portland Hotel Society and the Positive Outlook Program are able to continue to keep intensely marginalized populations engaged in some sort of health care on some level.

<sup>4</sup> See <http://www.drgabormate.com>.

<sup>5</sup> This particular nurse was transferred from the program when it was revealed that she was involved in an intimate relationship with one of the male participants who attended the program. Although married with children and living in a privileged neighbourhood on the west side of Vancouver, she was spending time with a young Aboriginal HIV/HCV positive man who was homeless and had an acute addiction to crack cocaine. Clearly, by some interpretations, her decision to engage in such a relationship might be understood as “irrational.” Yet, no one appeared to be recommending that her choices for treatment be limited.

<sup>6</sup> I’d be trying to find parking while rushing to meet someone, only a minute or two late, and they would call me on my cell phone and ask if I was coming.

<sup>7</sup> See, for example, Morgan et al. (2005).

<sup>8</sup> See Tait (2003) for a critical discussion of FASD diagnosis, especially among Aboriginal peoples in Canada.

<sup>9</sup> Exceptions include Culhane (2003).

<sup>10</sup> See Razack (2002) for a discussion on racialized spaces.

<sup>11</sup> See, for example, Lux (2001) and Kelm (2001).

<sup>12</sup> See also Culhane (1998), for the way in which the courts relied on discourses of “disorder” and “chaos” to construct Aboriginal peoples as closer to nature and therefore less “civilized” than non-Aboriginal peoples (specifically, in the case of British Columbia).

<sup>13</sup> See Leshner (1997).

## Chapter 6

<sup>1</sup> See Carpenter et al. (1996, 1997, 1998, 2000); Yeni et al. (2002, 2004); Hammer et al. (2006).

<sup>2</sup> When queried about the use of “injection” drug use over illicit drug use via other forms of ingestion (e.g., snorting, smoking), Harrigan remarked that these were the categories with which he was provided by the statisticians and epidemiologists. He neither predetermined nor defined them.

<sup>3</sup> See Wood et al. (2003).

<sup>4</sup> Quoted in Maggie Fox, “Early Treatment Always Better for HIV, Study Finds.” *Health and Science Correspondent* (Denver), 7 February 2006. <http://www.alternet.org/printable.htm?url=/thenews/newsdesk/N07219478.htm>, Accessed 9 February 2006.

<sup>5</sup> The HIV RNA assay measures between 50 and 100,000 copies/ml. Counts greater than 100,000 simply read as >100,000.

<sup>6</sup> See [http://www.csc-sec.gc.ca/text/facilit/institutprofiles/matsqui\\_e.shtml](http://www.csc-sec.gc.ca/text/facilit/institutprofiles/matsqui_e.shtml).

<sup>7</sup> These counts come from an ESIS letter sent to Dr. John Farley.

<sup>8</sup> The October 2006 version of the BC Centre for Excellence’s Therapeutic Guidelines does not include “readiness to adhere” in its evaluation of when to start treatment. Instead, it reads: “Within this range, treatment decisions should be individualized, taking into account clinical and laboratory parameters (including CD4 percentage, viral load and possibly rate of CD4 decline) as well as the patient’s preference.”

<sup>9</sup> The ASEM tool is not published, but, at my request, Thomas Kerr kindly forwarded me an electronic copy on 27 February 2006.

<sup>10</sup> See [http://www.cfenet.ubc.ca/webuploads/files/TherapeuticGuidelines\\_1006.pdf](http://www.cfenet.ubc.ca/webuploads/files/TherapeuticGuidelines_1006.pdf).

<sup>11</sup> See <http://cfenet.ubc.ca/content.php?id=12>.

<sup>12</sup> See British Columbia Centre for Excellence in HIV/AIDS (1999).

<sup>13</sup> See Montaner et al. (1997); Woolf et al. (1999).

<sup>14</sup> See, for example, Alberts, Bennett, and Woolf (2002); and Choudhry, Stelfox, and Detsky (2002).

<sup>15</sup> “Simplifying antiretroviral therapy for ‘marginalized’ populations,” AIDS rounds, St. Paul’s Hospital, Vancouver, BC, April 2006, Dr. Mark W. Tyndall, <http://cfenet.ubc.ca/video.php?id=23&sid=33&cat=1>.

## Chapter 7

<sup>1</sup> Sandborn, Tom, “Fraction of HIV Residents Getting Treatment in Downtown Eastside,” *The Tyee*, May 8, 2006, <http://thetyee.ca/News/2006/05/08/FractionTreatmentEastside>, accessed May 18, 2006.

<sup>2</sup> Methamphetamine hydrochloride.

<sup>3</sup> See, for example, the collection by Petryna, Lakoff and Kleinman 2006; Ecks 2005; and Dodier 2005 – among many others.

<sup>4</sup> This figure was provided by the outreach pharmacist for Providence Health Care, located in St. Paul's Hospital, through personal correspondence. This figure would include "standard triple combo with either an nrti or pi" (non-nucleoside RT inhibitors or protease inhibitors). Treatment costs would most likely be substantially more for those involved in "salvage" therapy. These estimates correspond to those provided by Krentz et al 2003 and 2005.

<sup>5</sup> Although Hanvelt et al 1999 suggested that both indirect and direct costs for HIV care was less among IDUs because they were less likely to engage in health-care and treatment as a result of their marginalization.

<sup>6</sup> See "Re-evaluating the cost-effectiveness of HAART," AIDS Rounds, St. Paul's Hospital, March 23, 2006, Dr. Julio Montaner, <http://cfenet.ubc.ca/video.php?id=23&sid=33&cat=1>.

<sup>7</sup> A combination treatment including ribavirin/interferon alfa-2b can cost up to \$30,000 per course of treatment for someone living with Hepatitis C.

<sup>8</sup> Referred to as STIs in the world of HIV treatment.

<sup>9</sup> "Re-evaluating the cost-effectiveness of HAART," AIDS Rounds, St. Paul's Hospital, March 23, 2006, Dr. Julio Montaner, <http://cfenet.ubc.ca/video.php?id=23&sid=33&cat=1>.

<sup>10</sup> See "Antiretroviral Therapy for HIV Infected Adults," Antiretroviral Update, St. Paul's Hospital, June 1, 2006, Dr. Julio Montaner, <http://cfenet.ubc.ca/video.php?id=23&sid=33&cat=46>.

<sup>11</sup> "Re-evaluating the cost-effectiveness of HAART," AIDS Rounds, St. Paul's Hospital, March 23, 2006, Dr. Julio Montaner, <http://cfenet.ubc.ca/video.php?id=23&sid=33&cat=1>.

<sup>12</sup> He is referring to Deputy Minister of Health Dr. Penny Ballem. "Re-evaluating the cost-effectiveness of HAART," AIDS Rounds, St. Paul's Hospital, March 23, 2006, Dr. Julio Montaner, <http://cfenet.ubc.ca/video.php?id=23&sid=33&cat=1>.

<sup>13</sup> "Re-evaluating the cost-effectiveness of HAART," AIDS Rounds, St. Paul's Hospital, March 23, 2006, Dr. Julio Montaner, <http://cfenet.ubc.ca/video.php?id=23&sid=33&cat=1>.

<sup>14</sup> See [http://www.cfenet.ubc.ca/webuploads/files/DTPstats\\_2006v2.pdf](http://www.cfenet.ubc.ca/webuploads/files/DTPstats_2006v2.pdf) for the Drug Treatment Program statistics.

<sup>15</sup> "The evolving challenge of managing experienced patients," Mark A. Wainberg Lecture, CAHR Annual Meetings, May 15, 2005, Vancouver, British Columbia.

<sup>16</sup> "The origin and evolution of the BC Centre for Excellence in HIV/AIDS," Dr. Michael O'Shaughnessy, Keynote speaker, CAHR conference, Vancouver, BC, May 12 2005.

<sup>17</sup> For the announcement see, <http://www.boehringer-ingenheim.com/hiv/news/ndetail.asp?ID=212>.

<sup>18</sup> See [clinicaltrials.org](http://clinicaltrials.org) for a list of trials that Dr. Montaner and the Centre for Excellence is associated with. Also see Wigod, Rebecca, "AIDS: Vancouver at hub of trial treatments," Series: Living with AIDS, Vancouver Sun, April 28, 1992, B5.

<sup>19</sup> Produced by the drug company Tibotec.

<sup>20</sup> The four patients were not granted access under the Health Canada Special Access Programs but under a "compassionate use protocol." See <http://cfenet.ubc.ca/viewMediaRelease.php?id=29&sid=36&nid=20&year=2006>.

<sup>21</sup> The initial request was for 6 patients but one died waiting and the other was refused.



<sup>22</sup> In comparison, the Montreal trials site which started enrolling the same month as Vancouver (April 2006) has screened a total of 12 individuals and randomized 7. Miami started enrolling in 2004 and yet have similar final results to that of Vancouver: 67 screened, 45 randomized. [Ihttp://www.stepstudies.com/private/enrollment/index.html](http://www.stepstudies.com/private/enrollment/index.html), accessed March 1, 2007.

<sup>23</sup> Preventive vaccines cause a false-positive test with standard diagnostic technologies. At the International Vaccine Conference in Amsterdam in September 2006, the search for an assay that distinguishes clearly between a false positive and an actual infection was highlighted as a priority for vaccinologists and immunologists working in the field of HIV.

<sup>24</sup> [Http://www.stepstudies.com/private/calls/StepMobiliz\\_HRW\\_RecruitonEdge\\_13July05.pdf](http://www.stepstudies.com/private/calls/StepMobiliz_HRW_RecruitonEdge_13July05.pdf), accessed January 5, 2007.

<sup>25</sup> [Http://www.stepstudies.com/private/calls/StepMobiliz\\_MSM\\_RecruitPeopleofColor\\_10Aug05.pdf](http://www.stepstudies.com/private/calls/StepMobiliz_MSM_RecruitPeopleofColor_10Aug05.pdf), accessed March 2, 2007.

<sup>26</sup> Walking a Path to Wise Practices: 1<sup>st</sup> CAAN HIV/AIDS Community-based Research Capacity Building Conference, February 13-16, 2007, Vancouver, British Columbia.

<sup>27</sup> I did request a copy of the informed consent from the investigator of the Vancouver site but my request was refused. The investigator for the Philadelphia site, on the other hand, forwarded their consent forms to me – explaining that since trial participants received a copy to take home with them, the forms were public.

<sup>28</sup> Holt, Jim with P. Fong, “New AIDS vaccine to be tried in 2 Canadian clinics: The director of a B.C. AIDS centre expresses hope Vancouver will be one of the cities selected for trials,” Vancouver Sun, June 25, 1998, A8.

<sup>29</sup> From what I can discern, the Centre for Excellence was not formally partnered with VAXGEN in the recruitment of trials subjects in any of the three Canadian sites (Vancouver, Montreal and Toronto), however, Dr. Robert Hogg, Director of the Drug Treatment Program, and a number of other Centre researchers were involved in feasibility studies for the trials. Dr. Robert Hogg held a Canadian Institutes of Health Research grant Publications resulting from those studies were co-authored with researchers (Popovic) from VAXGEN. See Lampinen et al 2005.

<sup>30</sup> Fayerman, Pamela, “HIV Vaccine study stalled by critics,” Vancouver Sun, December 19 2006, A1.

<sup>31</sup> Egan, Danielle, “HIV Vaccine Testers Recruit Vancouver Women,” The Tyee, December, 8, 2005. <http://thetyee.ca/News/2005/12/08/HIVCureVancouver/>

<sup>32</sup> See [http://www.who.int/bulletin/volumes/84/1/who\\_news.pdf](http://www.who.int/bulletin/volumes/84/1/who_news.pdf), accessed July 2, 2006. “WHO Clinical Trials Initiative to Protect the Public,” WHO News, Bulletin of the World Health Organization, January, 84(1), 2006, P 10-11.

<sup>33</sup> Rosie Taylor and Jim Giles, 2005, “Cash Interests taint drug advice,” Nature 437 (October 20): 1070-1071.

<sup>34</sup> Marcia Angell was the former Executive Editor of the New England Journal of Medicine. This book is a scathing report on the pharmaceutical industry, informed by her years working for the NEJM. She is now senior lecturer in the Department of Social Medicine at Harvard Medical School.

<sup>35</sup> See Coombe 1997, Das 1998, and Erb 1991 for ethnographic examples where rumor is an analytical tool in cultural analysis.

## Chapter 8

<sup>1</sup> I borrow this wonderful phrase from Dara Culhane.

<sup>2</sup> For a discussion of the ethics of doing ethnographic research on Aboriginal peoples in the Canadian prison system, see James Waldram (1998). For a similar discussion within biomedicine, and the ethics of informed consent with prison inmates, see Lawrence Gostin 2007.

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