

“I THINK I SHOULD BE FEELING BAD ABOUT IT”
HIV/AIDS, NARRATIVE, AND THE INSTITUTIONAL VOICES OF MEDICINE –
TOWARDS A CONCEPTUALIZATION OF MEDICAL CONSCIOUSNESS

By

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Abstract

For those living in resource rich countries such as Canada a positive HIV diagnosis no longer means an imminent death. In response to this change, numerous treatment and therapeutic institutions have arisen to assist individuals with managing their illness. Illness narratives then, the stories people tell and retell about their illness experience, are constructed by and within this multiplicity of medical frameworks that can interact in ways that are both complimentary and contradictory. Drawing on ethnographic data obtained through two months of participant observation and seven in-depth interviews at an HIV/AIDS treatment facility in Vancouver, British Columbia I discuss how illness narratives reveal the presence of and an orientation towards the powerful discourses of medicine. Some of the frameworks evident in the narratives I examine include biomedical understandings of health and disease, support group dialogues on self-empowerment, tenets of complementary and alternative medicines, clinical models of low-threshold access to health care, notions of health services as a human right, and addiction treatment concepts. In order to afford a place for the institutional discourses of medicine in my analysis, the subjective experience of illness is contextualized with reference to it's situatedness amongst the myriad of other voices that both construct and constrain narrative production. Ultimately, I seek to demonstrate how the incorporation of disparate institutional voices into a subjective story of illness reflects the development of a unique orientation to the institutions of medicine an understanding that I conceptualize as medical consciousness.

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Introduction

It is now nearly three decades into the AIDS epidemic and the etiology of HIV infection has dramatically changed for those living in resource rich countries such as Canada. While the burden of HIV continues to fall disproportionately onto the most marginalized communities, where poverty and addiction increase susceptibility to infection, a positive diagnosis no longer means a certain and imminent death. Responding to this change, numerous treatment and therapeutic institutions have arisen to assist individuals with managing their HIV positivity creating what Sargent and Johnson (1996) have termed complexes of health care resources. To illustrate, those dealing with a positive HIV diagnosis may encounter discourses on biomedical understandings of health and disease, support group dialogues on self-empowerment, tenets of complementary and alternative medicines, clinical models of low-threshold access to health care, notions of health services as a human right, and addiction treatment concepts. Adler (2002) suggests that an individual's healing system then is an attempt at rendering these disparate elements coherent. Consequently, the production of illness narratives, the stories people tell and retell about their illness experience¹, occurs within this multiplicity of institutional frameworks that can interact in ways that are both complimentary and contradictory.

Narrative increasingly forms the basis of ethnographic analysis because as Quinn (2005) observes that the things people say offer the anthropologist the fullest, most decipherable record though not the only or unproblematic. Furthermore, for individuals living with an illness, Mattingly and Garro (2000) propose that narrative becomes a fundamental human way of giving meaning to experience, a constructive process that mediates between the inner world of thought-feeling and the outer world of observable action. This expanding

interest in the use of narrative reflects what has been called a ‘narrative turn’, both theoretical and methodological, across many disciplines. As such, I draw upon a rich body of work in anthropology on illness narratives (Mattingly and Garro 2000; Becker 1997; Frank 1995; Good 1994; Hassin 1994; Kleinman 1988), as well as upon discussions in literary criticism and philosophy (Ricoeur 1981, 1984), and law and society (Merry 1990; Ewick and Silbey 1998) to inform this paper. Traditionally, narrative was examined as a “mode of discourse” (Mattingly 1994:811) and conceptualized as a means for the researcher to understand the subjective experience of an individual. A seemingly uncomplicated one-to-one relationship where the things people said equated to their experience. However, the perception that the interview process –and the discourse it produces– is an accurate reflection of experience, what Miczo terms the “fetishism of words” (2003:469), can hamper our understanding of patient voice and agency in the construction of narrative. To illustrate, privileging the subjective experience in illness narratives obscures what Good (1994:167) terms the “heterology of illness”, the multiplicity of voices and perspectives that enter into a conversation about disease and treatment, at the same time devaluing the relationship of narrative to both bodily experience and social power (Lock 1993; Kirmayer 1992). Therefore, research focusing solely on the pragmatic and experiential dimensions of narrative elevates the individual’s subjectivity thereby exaggerating the agency of the narrator who must negotiate amongst these discourses in order to construct his or her coherent narrative.²

To extend my analysis beyond subjective experience, I introduce the concept of medical consciousness to draw attention to how illness narratives reveal an individual’s orientation to the extensive discourses of medicine. In anthropological literature, consciousness is understood as a commonsense understanding of the world expressed in the way people act as well as in the content of what they say (Comaroff and Comaroff 1987).

Examining consciousness retains agency insofar as consciousness incorporates what Swidler (1986:273) calls “strategies for action”, wherein individuals draw upon a tool-kit of symbols, stories, rituals, and worldviews, which they use in varying configurations to solve different kinds of problems. Here Bourdieu’s (1977:72) concept of “habitus”, a system of transposable dispositions and a way of being that results from an organizing action, is demonstrative because the tools available to an individual are the product of the constitutive structures of a particular type of environment, which are both structured and structuring. To elaborate, consciousness develops through experience but this experience takes place inside structures [institutions] that define people’s lives, and I incorporate Saris’s (1995) definition of institutions as not simply buildings and social networks, the sites of narrative production but also structures –physical, conceptual, or both– that constrain and constitute discourse and practice. This idea is consistent with Geertz’s (1983) observation that individuals make sense of what they do by setting it within larger frames of signification, and keep those frames in place by organizing what they do in terms of them. For those living with illness, the institutions of medicine function as a particularly value-laden environment that generates and structures practices and representations. Once an individual learns a discourse it becomes part of his or her consciousness (Merry 1990) resulting in commonalities amongst the narratives of those living with HIV who have been exposed to a similar iterations of institutional voices. By incorporating consciousness into our analyses, the experiential dimension of narrative is retained however, it is contextualized with reference to its situatedness amongst the objective voices that construct and constrain narrative production. The conceptualization of medical consciousness also expands on the notion of “therapeutic emplotment” (Mattingly 1994:811), which examines narrative not as a mode of discourse but as social action, an interactional organization of therapeutic events into a coherent form organized by a plot. Examining how

narratives are emplotted recognizes that narratives emerge from a series of existential negotiations between active social actors struggling to construct (and reconstruct) the meaning of illness. Therefore, the illness narrative a person creates signifies more than lived experience denoting an acceptance or rejection of the multiplicity of medical discourses that enter into an HIV-positive person's life. At the same time, analyzing medical consciousness affords the recognition of an underlying structure to narrative, an orientation to the institutions of medicine, acknowledging that an individual does not produce a single narrative but rather frames events in response to available resources and particular contexts.

In this paper, I discuss the illness narratives of participants at an HIV/AIDS treatment facility to examine how narratives reveal a conformation to, negotiation of, and/or resistance to institutional discourses, and how the incorporation of disparate institutional voices into a subjective story of illness reflects the development of a medical consciousness. This paper is divided into six sections. In the introduction, I presented an overview of literature pertaining to the key ideas used in this paper including, illness narratives and narrative analysis, institutional discourses, and consciousness. Next, I provide a contextual background on HIV/AIDS in Vancouver with reference to the larger institutions of medicine. The third section describes the research setting and outlines the methods used. This is followed by the presentation of the interview findings organized into three case studies, which form the basis of my discussion. The fifth section discusses the implications of the findings as they relate to the relevant literature on narrative and their connection to the concept of medical consciousness. Finally, I summarize the paper's main arguments and key findings in the concluding remarks.

Background – HIV and the Discourses of Medicine

In North America, HIV prevalence is highest in urban city centres where socio-economic factors such as poverty, addiction, and ethnicity co-determine susceptibility to infection. To put this into a local perspective, as of 2005 the British Columbia Centre for Excellence in HIV/AIDS reported an incidence rate of 450 new infections per year with an upper limit of 12 300 people infected with HIV living in the province of which 7 380 reside in the greater Vancouver area (<http://www.cfenet.ubc.ca/content.php?id=18>). At present, AIDS remains a fatal infection with no known cure. However, advances in treatment have dramatically extended the lives of those living with HIV. For instance, according to British Columbia's Persons with AIDS Society (BCPWA 2004) many HIV positive individuals are now living for more than twenty years before developing AIDS, which means more people than ever are living with HIV/AIDS in the province. In British Columbia, AIDS, not HIV, is a reportable condition allowing positive individuals a degree of autonomy over status disclosure as long as their counts remain below a certain threshold. To assist this growing number of HIV-positive individuals the province has established a range of health management options, including free antiretroviral medications, income and housing assistance, alternative and complementary therapies, support groups, drop-in centres, spiritual counseling, and clinical health programs.³ As such, the institutions shaping the patient's phenomenological appreciation of medicine and contributing to the development of medical consciousness, encompasses not only the biomedical and clinical manifestations, but also medicine as a social institution, the paradigms of medical research, organizations such as hospitals and clinics, and the broad domain of complementary and alternative medicine (CAM), which includes all health systems, modalities, and practices and their accompanying theories and beliefs outside the professional

setting (Adler 2002). Consistent with the Western emphasis on individualism that advocates free will and personal responsibility, ill individuals are encouraged to become empowered patients and choose from amongst this myriad of treatment options to develop a health management strategy that works for them. For instance, the BCPWA (2004) proposes that an HIV-positive diagnosis presents a person with the opportunity to become actively involved in their healthcare decisions.

However, Foucault (1984) suggests that medicine, as a general technique even more than as a service to the sick or an art of cures, assumes an increasingly important place in the administrative system and in the machinery of power. In light of this understanding, an emphasis on taking personal ownership of one's illness only exaggerates the power of HIV-positive individuals many of whom occupy powerless and/or deviant positions in society to work within powerful biomedical discourses and clinical environments. In medically pluralistic societies, people are then paradoxically encouraged to be both active agents and passive recipients. Acknowledging the underlying power structures, Nichter (2002) suggests that discussions on therapy management invite analyses of transactions that are at once influenced by cultural values, social roles and institutions, power relations, and economic circumstances, highlighting what people can do and the reasons for their actions, but also what they cannot do and what underlies this apparent passivity, acceptance, or fatalism. In addition, analysis such as Ezzy's (2002:616) concept of the polyphonic narrative recognize the limited control individuals have over their environment by acknowledging the multiple and sometimes-contradictory plotlines overlaid upon one another. However, while his analysis addresses the structural constraints on narrative production the examination does not extend to how narrative reflects an individualized orientation to these institutional influences.

Reframing the object of inquiry as medical consciousness is particularly useful in the analysis of illness narratives because medicine is an ideology, a set of symbols subject to interpretation and manipulation and a framework through which the world is interpreted. As Good (1994:173) observes, “the core symbols of medicine may hold in tension a powerful networking of meanings, the process of synthesis is not only semiotic but social, dialogical, imaginative and political.” In their work on legal understandings, Ewick and Silbey (1998) develop types of consciousness that portray an institution as a particular configuration of capacity and constraint organized to achieve a normative ideal. Medicine then, like law, is a social structure actively and constantly produced in what people say and in what they do because as Hill (2005:159) notes, “in the sense that social actors produce discourse, they simultaneously negotiate emergent meanings and draw on shared understandings that create the very possibility for such negotiation”. If the normative discourses of medicine operate as a means of social control, medical systems can be understood not only in terms of what they do as therapeutic interventions but also in terms of what they allow people to say (Das and Das 2007:69). For instance, Anderson and Weatherburn (1999) suggest that individuals attempt to shape the clinical culture where they are involved as equal partners, and consequently many people have been able to develop their own critical perspective on treatment by viewing it from very different perspectives. Adler (2002:413) proposes the term “integrative medicine” to indicate patients’ deliberate and complex application of best options into an individualized treatment strategy.

To understand how disparate discourses influence narrative production I chose to conduct my research at an HIV/AIDS treatment facility. By working within a clinical environment and subsequently within an institutional paradigm, I hoped to draw attention to the impact of objective voices on the narratives of individuals who were attempting to, as

Goffman (1974) observes, not only make sense but create sense out of their illness. In order to highlight these objective voices I raised questions about individual understandings of health, disease, and illness, use of health care facilities, sense of entitlement to health care, satisfaction with service provision, and experiences with institutional programs. Reconceptualizing the object of study as medical consciousness, I sought to encapsulate both structure and agency by acknowledging that illness narratives both construct power and provide a way to challenge that construction, or alternately, that illness narratives are both structured by and structuring of the institutions of medicine.

Research Setting

One example of the complex of health resources available to HIV-positive individuals is the Dr. Peter Centre (DPC)⁴ a Vancouver based treatment facility where I gathered the data for this paper. The centre is named for Dr. Peter Jepson-Young a University of British Columbia trained doctor who became a public educator for HIV/AIDS. After his HIV-positive diagnosis in the mid-1980's and a subsequent decline in health, which resulted in his no longer being able to practice medicine, Dr. Peter decided to document his experiences living with AIDS. The outcome of these diaries culminated in one hundred and eleven television episodes produced with the Canadian Broadcasting Cooperation (CBC) in Vancouver. As a handsome, well-educated, and articulate individual, Dr. Peter personalized the face of HIV/AIDS for many in a time when fear and uncertainty surrounded the illness. To preserve and continue this legacy, just prior to his death the Dr. Peter AIDS Foundation was established to provide care to people with HIV/AIDS. Dr. Peter suggested, "There is no substitute for the ongoing involvement and support of caring people. Persons living with HIV and AIDS have many needs far greater than just survival." (<http://www.drpetercentre.ca>) Two years after his death, the foundation began to consult with AIDS organizations and health care providers about what services could be provided to fulfill its mission of comfort care.⁵ The result of this dialogue was the Dr. Peter Centre, which first opened in April 1997 in an old wing of St. Paul's Hospital, and in September 2003, re-opened in a completely renovated four-storey building located behind St. Paul's on Comox Street. The centre is unique in offering the only Day Health Program and Residence for people living with HIV/AIDS in British Columbia. A long-term residence for individuals requiring twenty-four hour care or end of life services comprises the top two floors of the building. The Day Health Program, which runs Monday to Friday

from 9:00am to 3:00pm, operates on the lower levels. The main floor consists of a large dining area, outside patio, and kitchen while the second floor has a variety of facilities including laundry, computers, television, nap rooms, library, showers, a gym, a nurse's station, and counseling rooms. Staff serves breakfast and lunch everyday, and scheduled activities including music, art, and complimentary therapies are available to those who wish to participate. The layout is an open concept with lots of natural light and clean lines. The centre's design reflects the low-threshold approach to health care with a balance between communal and private spaces allowing participants to gauge their level of interaction and involvement with the facility.

One of the aims of the DPC is to help those most at risk of deteriorating health from HIV infection, individuals facing multiple illnesses, disabilities, and disadvantaged life circumstances, and to assist the community and health-care system to cope with the growing AIDS crisis. While the DPC currently has over two hundred fifty registered members, the number of people and the group dynamic, varies throughout the month. In terms of the group make-up, many of the participants come from Vancouver's Downtown Eastside area and there is a disproportionate ratio of men to women despite targeted efforts to include more women. Individuals come and go from the centre often routinely according to the social assistance payment schedule, what the staff calls the ebb and flow of check day, while for others attendance is more sporadic because they return to the centre only in times of crisis. The environment reflects this shifting dynamic in that some days the atmosphere seems upbeat and positive while other days are tense and uncomfortable. According to staff, the biggest issues facing participants are systemic structural issues, such as lack of resources, the same conditions that increase susceptibility to HIV infection in the first place. These structural factors function as barriers to accessible treatment, which is often highly regulated and

restrictive. In contrast, the DPC attempts to provide health care services at whatever level the participants need. On a practical note, the staff tries to keep the entire process increasingly lower threshold. The crux of the comfort care mission is holistic health care with a commitment to acceptance so that strength and hope are possible. For instance, individuals are required to sign a community agreement outlining behavioral expectations, and to log in and out of the premises, but otherwise are free to keep their own schedules. In addition to the centre's guidelines, there appears to be informal communal rules amongst those who frequent the centre on a regular basis. For instance, participants have specific areas they routinely occupy and positions in the line for meals, while others indicate that they know who to ask, or how to ask, for things they want and who to avoid. In terms of continuing to utilize the facilities, there is no discharge process and individuals may remain at the centre indefinitely; however, the staff assure me that their goal is to assist individuals to the point that they no longer have to rely on the services provided by the centre.

Methods

Ewick and Silbey (1998) suggest that narrative can enter into research as the method, object, and/or product of study. In my paper, I chose to incorporate narrative as both the method and the object of study, basing my findings on the analysis of seven in-depth interviews with participants (5) and staff (2) of the Day Health Program and two months of participant observation from January – February 2008. Following Mattingly (1994) narrative is considered a social action, rather than an abstract object, something produced interactionally and contextually. As such, establishing rapport is an important factor in eliciting illness narratives, which can be highly personal, and the first week of my fieldwork consisted solely of participant observation. During this time, I took detailed notes the environment and the social group, interacted with participants, introduced my project and myself at the weekly community meeting, and took part in activities such as art therapy and flower delivery to the residents. Over the two months, I participated and/or observed a variety of activities in order to interact with different individuals in diverse environments. For instance, I joined one individual in the safe injection room where we were able to talk on a more intimate level and I went with another individual to an outreach centre where we collaborated on an art project. At the same time, I tried to make myself available by taking notes in communal areas and assisting participants with day-to-day needs like access to equipment or facilities. Research and researchers are a common part of the milieu at the DPC as such I found the environment to be open and accommodating. However, there were individuals and groups I felt uncomfortable approaching some of whom I eventually fostered a relationship with and others who clearly indicated that they did not want to participate in my project. I informally recruited participants, discussing my project in more detail with everyone who expressed an interest in

contributing in the research. This strategy allowed me to stay within a comfort zone where I felt like I was not imposing my project onto those who may not wish to participate. Many individuals conveyed their desire to “tell their story”, and while I initially intended to conduct ten interviews scheduling was often problematic with people unable to create the time or failing to meet at prearranged times. There was no predetermined basis for inclusion and I interviewed every person who wanted, and was able, to attend an interview.

I conducted the majority of the interviews at the centre using available office space with two held at a nearby restaurant and coffee shop. Overall, the interviews went well with the occasional disruption from people who needed access to the room where I was interviewing. An average interview lasted approximately two hours and took place over multiple sessions of between one-half and one hour. Having multiple interviews gave me the opportunity to pre-test my research questions, generate additional questions after reflecting upon the answers given, and allowed for the identification of contradictions within individual narratives (Briggs 1986). In addition, for some participants the interview session was tiring and having several short interviews allowed us to take breaks and collect our thoughts. Interviews were semi-structured to afford what Quinn (2005:9) terms “discursive privilege”, granting the control to the interviewee by encouraging them to organize the interviews their own way and to pursue their own thoughts. However, I developed a list of questions to act as prompts during the conversation and to ensure I addressed the study’s main issues. The questions include understandings of illness, treatment and therapy courses, peer and familial relations, previous encounters with illness, experiences at the DPC and other institutions, and ideas about health as a human right.⁶ To thank people for their contribution, I gave participants a twenty-dollar grocery certificate at the conclusion of our interview. I digitally

recorded interviews with consent, and I transcribed and coded the data according to the major thematic areas addressed in this paper.

Findings – Narrative Accounts of Living with HIV

In this section, I introduce the narratives of three participants at the Dr. Peter Centre.

Collectively these cases show that illness narratives do not equate to lived experience in a one to one relationship. Instead, the narratives reveal how subjective experiences are interwoven with and inseparable from the many institutional voices of medicine. The medical discourses that are evident in the narratives I present include, biomedical understandings of disease and treatment, clinical models of low-threshold access to health care, complementary and alternative therapies, support group dialogues on self-empowerment, addiction treatment concepts, and notions of health services as a human right⁷. By situating personal stories of illness within this framework of available discourses, an individual's narrative illustrates a distinctive orientation to the institutions of medicine. The unique understanding of the nature of illness that emerges from this orientation, a comprehension that foregrounds action, I take as demonstrative of the development of a medical consciousness.

Case 1: Tom

This case presents the narrative of Tom⁸, a short lean man in his mid-fifties with an ironic sense of humour and an exceptional artistic gift. I first met Tom when I noticed him sitting alone in a room upstairs and went in to introduce myself. From that day forward, we talked periodically and after a few casual conversations, I told him about my project. Tom immediately expressed an interest and told me he felt comfortable with interviews because he had previously participated in a video project at the centre. One afternoon, to a backdrop of falling snow, Tom told me the complex and often-tragic story of his life. He grew up in Eastern Canada raised by strict religious grandparents after his father's death. As an adult,

Tom moved to the British Columbia's Lower Mainland and frequented Vancouver when he felt the desire to explore the different facets of his lifestyle. Tom married and divorced twice, and fathered two, now adult, children of whom he was extremely proud. During this early period in his life, Tom experienced a number of traumatic incidents, which included the suicide of a family member, physical and psychological abuse, arrest, and struggles with addiction, events that had a profound impact on the course of his life.

It was during his stay at a drug treatment centre that Tom found out he had contracted HIV from unintentionally sharing a contaminated needle. After the news, he relocated to the city to be closer to the hospital and the other health services he anticipated that he would need to manage the illness. For Tom, someone who had already experienced a lifetime of hardships, the diagnosis was not unexpected because he had so thoroughly prepared himself to expect the worst. As such, after finding out he was HIV-positive when Tom's doctors bombarded him with guarantees that today's technology could make you live another twenty years, what the doctors intended as a positive reassurance became an emotional burden. He informed one doctor, "before I figured out I had HIV I figured I only had ten years left; now you're telling me that I've got another ten years on top of that for Christ's sake." At first I felt his attitude was somewhat fatalistic, but Tom pragmatically described it as a realist outlook; noting there was some truth to his statement because he was tired, "my stint as a human being has been fulfilled" and sometimes just wished for a timely end to his life. At the same time he conceded, "there must be a reason my god wants me here", to "stick around", and suggested that because he already endured so many hardships he now had the experience and knowledge to deal with adversity.

Tom's narrative also drew attention to the sense of personal responsibility he felt for his illness. For instance, Tom acknowledged that bad decisions got him to this point in life,

and he frequently referred to what he should be doing as opposed to the course of action he had chosen. Speaking about his reaction to the HIV diagnosis, Tom reflected, “It hasn’t made a difference...I mean I am not going ‘oh my god I’ve got to do something about my life before it’s too late’, it hasn’t done that to me and sometimes I feel guilty about that.” This tension between what he did versus what he perceived was the right or correct course of action was particularly evident in his decision to forego antiretroviral medications, avoid doctors, and not monitor the CD4 counts and viral loads what he described as things he should be doing but that kept him sick mentally. Tom knew that if he saw the doctor, she would convince him to take medications forcing him to become “the victim of AIDS research.” However, if he avoided contact with her he could “stay in the frame of mind that I don’t need them [medications], I don’t want them.” I asked how he made treatment decisions and Tom described the following rationale:

I know the disease is killing me, I know the counts are changing, but I feel that because I take care of myself I’ve got a pretty good handle on the disease. It’s as simple as this, why should I go for blood tests to see what my levels are when I feel fine. Knowing what my levels are and having them drop isn’t going to make a difference to whether I feel good or not. The day I don’t feel good enough to function normally then I’ll go to the doctors and find out what the readings are, then maybe I’ll go on medications but other than that I really don’t want to know.

Another prominent theme in Tom’s narrative was his distrust of institutional paradigms generally, and those in authoritative positions, specifically. To illustrate, Tom had a history of struggling with addiction issues and at the time of the interview had quit every substance except one, which he continued to use for the advantage that it took him “out of reality for a short period.” Despite the therapeutic benefit this did not mean Tom wanted to continue using and he had previously attempted to treat his addiction through the Narcotics Anonymous program. This turned out to be a largely negative experience for Tom who questioned the

aims of rehabilitation programs with strict codes of abstinence that were unrealistic and even harmful to those they purported to protect. He felt such programs failed to address the individual's unique situation and took away control. Despite the frustration, his involvement provided Tom with the means to regain financial stability and a set of skills applicable to other aspects of his life. Speaking about Narcotic's Anonymous, Tom informed me:

The drug and alcohol centres they taught me how to understand what my problems were, and realizing why I was the way I was and why I did the things I did and so on. They teach you to understand your problems, it's not just a drug awareness thing it's the post-traumatic stress disorder, it's the reasons why you went to drugs in the first place. So anyway, I took the information I found necessary and that was understanding.

A second incident that reinforced Tom's skepticism about institutional motivations was his experience participating in a psychiatric evaluation. During the assessment, Tom purposefully gave what he considered the "wrong answers" in order to put the evaluator "in the game." In response to her questions about having experienced negative or bad thoughts, what he assumed was a trick question, Tom turned the question back onto her and challenged the taken-for-granted assumptions she was making about him and the potential consequences of his answers. He elaborated telling me that the evaluator knew everyone had bad thoughts and due to the stressful nature of the circumstances—a pre-incarceration assessment—she had tried to trap him into saying something incriminating and committing himself. I felt his attitude indicated a desire for a degree of power over an inequitable situation and mentioned "there is something about being able to control the situation yourself" to which he responded:

That is so right. I had it all set up to get the rest of my teeth taken out, there's not many left there but every one of them got a cavity in it, and I quit going to the dentist, quit getting my teeth taken out. They don't like that at Vancouver General. "That's it, don't ask us to take any more of your teeth out, you missed your appointment." I didn't really want to say, to tell them, but you're so right, the very few teeth I have left I can chew steak with, I can still cook toast all the

way, I can still eat chips. Once they're gone all that's gone and I'm not ready to let go of that yet, it's like I'm not ready to let go of, I'm not ready to be tied to a series of pills.

While Tom indicated that he enjoyed contesting boundaries, he also implied an awareness of the constraints imposed by illness and treatment. For instance, Tom noted that having HIV meant he was tied to the health services available in the city, a dependency he was uncomfortable with; "I'm getting help here so it restricts you, limits you, to where you can go and what you can do." As an HIV positive individual he was able to access free anti-HIV medications, disability insurance, housing support, and other forms of social assistance, yet these provisions often came with conditions that were difficult to meet or the possibility that those services may be taken away if you did not adhere to the stipulations. Tom described how living with HIV meant he had good days and bad days, and observed, "When I have an off day I guarantee you if somebody phoned me and said, 'Oh by the way it's mandatory that you go see so and so or you may have your funding cut off' I would say ok thank you, bang [gunshot]." Bringing our conversation back to health services broadly, I asked Tom if the treatment and assistance he received for having HIV was something he felt all HIV-positive individuals should be entitled to. He responded, "Anything I get in the line of help for the fact that I have HIV, I personally think it is a privilege." Indicating a sense that health service provision was tenuous, when Tom took advantage of our conversation to give voice to concerns he wanted "to get out and around", such as the need for services to run seven days a week and on holidays, he repeatedly qualified that he was not complaining. Referencing the Dr. Peter Centre, Tom said he would not want to do or say anything that could ruin the privilege of being able to use the centre. His understanding that treatment and assistance was a privilege resulted in Tom's sense of obligation to give back. He iterated, "I always feel like I should be contributing back to it...I'm taking advantage of the facilities, at least that's what I'm

supposed to do, but I don't feel like I'm putting anything back into it." After our interview concluded, Tom reflected that recording our conversation was beneficial because it allowed me to edit what he said and suggested that open-ended questions enabled me to get at his "true feelings."

Tom's narrative did not centre on the HIV experience as a significant disruptive event, but situated HIV into a complex life history of traumatic events contextualizing his lived experiences within the available framework of institutional discourses. His narrative included a rejection of biomedical notions of treatment, a selective inclusion of addiction models because of their relevance to other portions of his life, and an acceptance of notions of self-empowerment; discourses that reaffirmed his notions of personal responsibility for his illness and sense of obligation to give back to the health facilities he used. In addition, Tom's narrative highlighted how the negotiation of discourses was dependent upon balancing resistance and adherence in accordance with material needs. For instance, he developed of an understanding of illness, a unique medical consciousness, which was resistant to authoritative discourses insofar as this defiance allowed retention of a degree of control over the illness course but not so far as to jeopardize service provision.

Case 2: John

This case presents the narrative of John⁹, a thoughtful genial aboriginal man in his early fifties. John was the first person I met when I arrived at the Dr. Peter Centre, and he immediately offered to show me around the building and introduce me to the other participants. His enthusiasm eased my transition into the community and I relied on his assistance a great deal over the course of my fieldwork. John was also my first project volunteer and I used the camaraderie we had developed to pre-test my interview questions. His insights challenged me

to think about my own active role in the interview process and as we talked further, I found the concept of communicating, specifically understanding, was central to John's life. He felt it was important to listen to what others were saying in order to examine their point of view and described how his personal motives were not always something he freely shared. The importance he placed on communication stemmed from early childhood experiences. John was born in a Northern aboriginal community; however, an adoptive Euro-Canadian family in British Columbia's Lower Mainland raised him. Growing up John felt he did not easily fit into this new community where he was unable to partake of the same opportunities made available to his peers. Retrospectively, he described this tension as originating from a devaluing of aboriginal peoples by the larger society. Partly due to his inability to integrate into the adopted community, John decided to leave high school and join the military at the age of seventeen. However, he soon found that he also struggled to find a place within the highly regimented lifestyle. After the military, John relocated to Vancouver's Downtown Eastside (DTES)¹⁰ a place where he found a sense of communal acceptance amongst other aboriginals and eventually, other drug users. Motivated by his desire to give back to the "have-nots" John quickly involved himself in a number of projects on addiction and aboriginal issues after which time he "was like zero to hero within a few months." However, he qualified that the community determined what needed to be addressed. At the same time, John acknowledged that the elevation of the social over the individual made him feel powerless when he wanted to "push the envelope" and be more involved but felt denied a "seat at the table."

After his relocation to Vancouver, John began using injection drugs, a habit that led to his contracting HIV from a contaminated needle. He recounted that the diagnosis was not a shock; he heard the news and thought, "I had thirty seconds to either kill myself or live for here on in, and I still wait for that thirty seconds." John told me that he based the decision to

live on the knowledge that AIDS was no longer a life-threatening disease. In terms of his treatment, John chose not take antiretrovirals for the first four or five years after diagnosis and opted instead to keep an eye on his baseline blood status. He explained that the choice was born out learning from other HIV-positive individuals, aboriginal understandings of health and illness, and involvement with the Vancouver Agreement harm reduction model.¹¹ Recently however, John experienced a drop in CD4 levels and decided to consult an HIV specialist about beginning antiretroviral therapy. In contrast to his earlier position, John reasoned that there was an obligation to go on anti-HIV medications out of respect for his family and for those who were unable to afford, or have the opportunity to take, antiretrovirals. I asked if being on medication influenced his perception of health status and he told me that while HIV was always on the backburner of his mind, it did not stop him from doing things. John believed, “The people I’m involved with have an understanding that they don’t have to feel sorry for me and that I don’t look for it, I don’t want to be a victim of my own circumstances or make somebody else want to be a victim of me.” He elaborated that this interconnectedness between the individual and the community was integral to his sense of well-being. When not “centred” in respect to his health John’s illness became a problem outside of him. In such instances, the social group was affected when he could not keep the illness contained within his own body. At the same time, members of his community functioned as examples of the limitations of his own embodied experience:

I find it difficult in that sometimes I want to go beyond my capabilities, so that’s challenging. However, I have plenty of examples of going ok I can see what happens when I go that route, when I want to go too far, there’s an example. There but for the grace of god go I, and I go I have a choice, that person had a choice; they chose to be where they are at.

One area of John's life that required established limitations was drug use, which had been and still could be a problem when he wanted it to be. John specifically credited the city's approach to addictions management because it provided the knowledge and skills to use in the safest way possible, minimizing the risk to himself and others. He told me "It may be a right that I can use but it is also a responsibility to stop using, or use with manageable concepts". In order to manage his drug use, John participated in an aboriginal treatment program for addiction where he learned a number of different therapeutic processes including aboriginal spirituality, Eastern medicinal techniques, and contemporary holistic therapies. I asked how he felt about the many therapeutic options and he suggested that the ability to choose was important, "there's huge complementary therapies and treatment models that I can call from and use. There's not just any type...there's many types and I can follow on one that I feel fits for me." Taking into consideration things like diet and personal outlook, which he adjusted according to the treatment model he had chosen, John was able to integrate and apply these different therapeutic processes to manage his illness and his addiction. Reflecting on his experience at the treatment facility, John mentioned that the knowledge gained set a precedent and a belief down the road because it provided skills applicable to other aspects of his life. In addition, consistent with the importance he placed on the social aspect of well-being, John felt a responsibility to use and pass on the skills he acquired:

I still use a lot of the therapies that were given to me there, and carry on and maintain the experience and knowledge and wisdom of the therapies that were given to me for the more they're used the more experienced and practiced the better I get and the better I am able to provide for somebody else.

John's narrative highlighted his belief that the community and the individual were mutually dependent. This perception influenced his understanding of an individual's health as connected to the health of the community and contingent upon social well-being. John's

narrative indicated an acceptance of a discourse of personal responsibility in regards to addictions management and rational choice; however, at the same time it rejected ideological notions of individualism that advocated self-interest over that which would benefit the entire community. John's narrative also revealed the tension within the notion of self-empowerment, which promoted self-care and giving those living with HIV a meaningful voice, and the constraints and conditions that both structured an individuals' susceptibility to HIV infection and limited their agency. Interestingly, John's narrative often made explicit reference to those discourses he had accepted and integrated to develop his understanding of medicine. The medical consciousness that emerged from our conversation indicated an approach to illness management that selectively drew upon a number of complementary and contradictory discourses that were consistent with his socialized understanding of illness.

Case 3: Will

This case presents the narrative of Will, a gracious sociable man in his early seventies, whom I met at the urging of an intern who introduced us with the caveat "he really likes to talk." During our subsequent conversations, Will repeatedly told me to ask what I like for he had nothing to hide. We segued into our first formal interview and he assured me that instead of picking up where we had left off we would start again at the beginning. He recollected the minutia of his past in detail, indicating a well-developed and rehearsed narrative; however, recent events gave him pause. Will was born into a military family in the United Kingdom and after the Second World War relocated overseas, where he went to boarding school with the expectation of following his father's example. However, he had other plans and ended up pursuing a variety of careers, which took him all over the world. Will married for a short period but enjoyed his independent lifestyle too much to remain settled. Eventually he re-

located to British Columbia where he worked for several years in logging and commercial fishing. Shortly after, the province went into recession and he struggled to continue to find employment. It was also at this point that Will found out, unbeknownst to him, he had lived with HIV for nearly a decade and recently developed full blown AIDS. Due to worsening health and an unstable housing situation, Will was forced to relocate to Vancouver in order to access subsidized housing and health services.

Prior to his diagnosis, Will knew little about HIV and had to educate himself about the epidemiological information such as the nature of the virus, disease progression, and statistical indicators. Initially he agreed to go on medication; however, he informed the doctor that he would only give it two months to see the state of his liver. Will opted for this limited trial because he was concerned about the imprecise nature of antiretrovirals, which felt just shot-gunned your immune system. He noted, “People with AIDS don’t normally die of AIDS; the liver gives out because of the ARV’s.” If one combination of medications did not work, he knew that the doctors would just continue to change the dosage making it more poisonous each time. In addition, Will questioned the logic of stressing over blood counts since “CD4 and viral lodes [were] just numbers.” He felt that the inexactness of treatment resulted from the fact HIV was not typed in North America meaning doctors were unable to successfully tailor medications to the specific viral strain. Reflecting on the situation, Will believed that modern medicine treated the symptoms but not the disease. He argued, “They make you feel better, but the doctor knows you’ll be back in a couple of weeks or a month.” After he learned more about the disease, and observed peers who had gone off their medications and continued to have huge viral loads but felt fine, Will made the decision to “quit all of the pills.”

For Will, the HIV diagnosis was unexpected and while it did not disrupt his expectations for the future as he preferred to live in the past, the diminished physical

capabilities that resulted from the HIV-related neuropathy¹² seriously undermined his quality of life. He described it as going “from being an active, physical, capable person, to a semi-invalid.” In regards to health status, Will did not think of himself as ill, “I don’t feel sick other than my legs, if my legs were good I’d be healthy again, just like I was.” In his current condition, he required assistance walking and eventually will need a wheelchair. In addition to the financial burden, he proposed that the transition would be particularly difficult because he did not want to depend on anything or anyone, “because then you start to rely on it and then you need it and can no longer go without it.” This inevitable dependence and lessened quality of life culminated in Will’s decision to take his life once he was unable to lead a meaningful existence; a resolution he had given a great deal of thought to. He told me, “I’m fortunate, I’m ready to die, I’ve been for some time, and I believe in reincarnation.” What motivated him to keep going was a question of “if the spirit [was] willing”, a philosophy that fit his sense of responsibility for the illness:

I’ve got a lot of aches and pains but I’ve got to live with them, I chose my lifestyle and now I’m paying for it, there’s no use in complaining. Most people are, “oh [Will] if I’d only known this when I was young” and they’re in misery, if I’m feeling bad I think about some of the great things I’ve done or some occasion, and mind over matter. You don’t get better, but when you’re going around sick you’ve got to look after your mood.

Will’s acceptance of individual accountability extended to his long-term struggle with alcoholism. He first lost control of the drinking when in order to get a portion of the limited work that was available during the recession he had “to drink with the boys.” Locals, he believed, were distrustful of outsiders and drinking functioned to build and solidify tenuous connections to potential employers. After this period, Will continued to drink despite the knowledge that alcohol was his biggest disease, “I’m not going to die from AIDS, I’m going to die from alcohol.” He accepted this outcome because it was the consequence of his own

decisions. At the same time, Will tried to self-manage, but not cure, his addiction. He entered into a detox program, which he described in retrospect as cost-prohibitive and unsuccessful, and mentioned various independent attempts at controlling his level of consumption.

Ultimately, Will tested his limitations to develop a technique for managing his alcoholism that allowed him to “sort of cruise along.” Another reason he chose to manage, not cure, his drinking was the therapeutic benefit that alcohol conferred. He believed that addicts, drug or alcohol, fared better with the illness because they had a means to take the pain away, and elaborated on his own situation, “If you’ve got a nervous infection [neuropathy] which nothing can be done about, anything that smoothes the way is a help.”

Eventually our discussion turned to health services broadly and the Dr. Peter Centre specifically. Will first went to the centre to take advantage of the meals at his doctor insistence that he put on weight to avoid contracting an opportunistic infection. After he regained strength, Will continued to come to the DPC in order to socialize and participate in acupuncture and massage therapy sessions to assist with addiction and pain control. Referring back to his conviction that illness management was mind over matter, Will noted that the centre kept him willing because it provided a place to go every day and a reason to get out of bed in the morning. Finally, when it came to end of life care, the centre offered the reassurance of a place to die with dignity. Will stated, “I definitely feel having this place as my major support is very important.” Since he had indicated a number of positive benefits from his involvement, I asked if people living with HIV should be entitled to access a place like the Dr. Peter Centre. Personally, he felt that all assistance was a privilege, and considered himself fortunate to have found subsidized housing and to utilize the services of the centre. Demonstrative of the importance he placed on personal responsibility, Will was appalled by the behaviour of those who complained about the centre and suggested that they should be

grateful for anything they received. At the same time, he indicated the material constraints that limited his own therapeutic options such as, having to purchase a wheelchair or cover a portion of his medications.

Will's narrative emphasized the importance of quality of life, over quantity of years lived. For him, the HIV diagnosis came as a shock, but it did not significantly disrupt his identity. Rather, the illness's side effects were problematic insofar as they challenged his assumptions about the boundaries to a quality life. Will's narrative was strategically oriented towards the past, focused on the positive events in his life; a temporal orientation that functioned as a motivating force, which kept his spirit willing. His narrative also foregrounded a strong sense personal responsibility and agency. Will reasoned that if he was responsible for contracting HIV, he was also responsible for the decision to continue to drink, to independently research HIV epidemiology, to question doctor's assumptions, and to end his life when he chose. The medical consciousness that emerged from Will's narrative contested biomedical notions of treatment and compliance, rejected a sense of entitlement due to his health status, while it concurrently embraced a discourse of self-empowerment that privileged free will and validated his acceptance of a shortened life.

Discussion

A central aim of this paper is to draw attention to what Biehl et al. (2007:8) have called “the human and institutional interconnectedness evident in the production of illness narratives” by extending the analysis of narrative beyond subjective experience to reflect the development of medical consciousness. Kirmayer (2000) argues that the production of narrative is a culturally mediated encounter in which active agents struggle to negotiate meaning with materials given to them by their cultural surroundings – a milieu into which they must then take any meaning they have managed to construct. The narratives individuals generate thereby have relevance in the specific terms of their broader sets of interests, needs, and circumstances (Bourdieu 1977; Sahlins 1976). What the narratives presented here demonstrate is that individuals selectively and strategically incorporate often-divergent medical discourses in the construction of a meaningful understanding of their illness experience, an awareness that informs their expectations about the management and treatment of their illness; a negotiation I term medical consciousness. To elaborate, Tom’s narrative incorporates biomedical notions of illness and treatment, addiction management concepts, evaluative models used in correctional facilities, and discourses on control and self-empowerment. John’s narrative draws upon aboriginal ways of knowing, socialized medicine, complementary and alternative therapies, discourses on self-empowerment, and drug management concepts. Finally, Will’s narrative integrates understandings of personal responsibility, biomedical notions of illness and treatment, complementary and alternative medicine, and alcohol treatment programs. Overarching all three case studies and the context of the interviews were the institutional voices of the Dr. Peter Centre, which endorses a clinical mandate that includes biomedical concepts, complementary and alternative medicine, harm reduction, and a holistic approach to health and

well-being that includes basic needs such as meals and stable housing. At the same time that individuals draw upon divergent discourses to construct their narratives they are simultaneously constrained by these same institutional voices, which function as a form of social control constructing the normative ideal of the compliant patient and expected illness outcome. The productive and restrictive power of the institutions of medicine means that while individuals create their narratives using these objective discourses they are also limited in their ability to retain and reject these same discourses. Employing an ethnographically grounded analysis, this discussion begins with an acknowledgement of the author's own situatedness as co-creator of the illness narratives presented. This is followed by a detailed examination of the prominent institutional voices evident in the case studies and an exploration of two discourses, harm reduction and health services as a human right, common to all three cases, contextualized with reference to the relevant literature. Finally, this paper's main arguments are summarized in a concluding paragraph.

Situating the Anthropologist in Narrative

Following Abu-Lughod's suggestion to retain the original voices and be "tactically humanist" (1990:157), this paper recognizes that the narratives presented here emerged "intersubjectively" (Ezzy 2002:616) through collaboration between the teller and their audience.¹³ For those who chose to participate in the research the interview may have been perceived as a forum for the authorization of their narrative because "the problems of the powerless often fail to find expression in the dominant narratives and structures" (Ewick and Silbey 1998:234). At the same time, Mattingly and Garro (2000) suggest that stories are constructed for particular audiences with particular goals in mind, and during the interviews, both Tom and John indicate an awareness of the productive capacity of their role as co-

narrators. Tom specifically, uses the conversation as an opportunity to advocate for a change in health service provision. For Tom, the telling process may be validating because he perceives the interviewer, with their clear institutional ties and interest in health care, to be in an authoritative position –at least more authoritative than him– able to get his ideas to “the right people.” Kirmayer (2000) suggests that people must fight to tell their story and to have it heard, accepted, or authorized; as such, they try to control the circumstances of its hearing and to some degree its interpretation. In his narrative, John makes it clear that his story is truncated. The interviewer may inquire about the motivations behind his decisions but that is something he may or may not choose to share. This selectivity is consistent with Becker’s (1997) position that stories are partial and people have reasons for not telling all there is to tell. Interviewees edit their stories as anthropologists edit theirs. It is also demonstrative of an actor exerting a degree of agency in an inequitable situation.

Finally, in the case of illness narratives, both anthropologist and collaborator must work within the institutional discourses that define the clinical setting of the fieldwork. By choosing to work within an clinical setting the interview may have been influenced by participants desire to reflect positively upon the centre and thereby maintain and/or secure their position within the service provision. At the same time, the interviewer’s role may have been unclear due to the interactive nature of participatory research wherein the researcher engaged in many facets of the centre’s operations and activities, which may have affected the content of the narratives presented. In a clinical environment, Mattingly (1994) suggests that the emplotment of narrative is reworked and redirected by the responses of other actors who are also actively trying to shape the lived events of the individual. In the role of interviewer, one is in the position to validate, legitimize, and/or empathize with these narratives, and at the same time, one is constrained by their own institutional connections and the necessity to act

based on their readings of the situation (Kirmayer 2000). The anthropologist's then has an active and collaborative role production as they attempt to emplot the emerging narrative. The agentive interviewer and the institutions they represent becoming part of the interviewee's consciousness and thereby generating another objective voice that the emergent narrative is oriented towards.

Locating the Institutional Voices in Narrative

Recognizing the institutional voices evident in narrative is important because actors must construct their narrative using the framework of available discourses. In the case of illness narratives, the institutions of medicine provide a multiplicity of often competing and contradictory discourses to draw upon, discourses that may be inconsistent with embodied experiences, shared cultural values, and existing worldviews. As such, Davis (2000) observes that significant variation exists about which categories fit together to match illness with therapy. However, there are limitations to the categories people are able to utilize in the production of their narratives because "people vary in the resources available to them to resist or rework the cultural meanings of illness" (Kleinman 1988:26). These constraints are particularly salient for individuals, such as those at the Dr. Peter Centre, who often face multiple disadvantaged life circumstances. The narratives presented reveal how individuals orient themselves to the institutional discourses of medicine in order to construct a meaningful illness narrative and inform their therapeutic management.

In the first case, Tom's narrative highlights a resistance to and a subscription to biomedical understandings of disease. Biomedicine as a cultural model is based upon underlying assumptions such as individualism, which conceptualize health as an "achieved status" (Scheper-Hughes and Lock 1998:218) meaning the individual is responsible for their

health and by extension their illness. The application of this idea to therapeutic management is problematic because the individualism advocated for in biomedical discourse is limited. For instance, patients have a ‘choice’ only insofar as they choose to adhere to prescribed courses of treatment. Failure to follow recommendations can result in individuals being labeled non-compliant and the discontinuation of their services, as Tom’s story about his decision to keep his remaining teeth highlighted. Becker (1997) proposes that the rhetoric of personal responsibility further restricts choice because doing nothing is also equated with a failure to take responsible action. In Tom’s narrative, it is apparent that he has accepted the notion of personal responsibility because his perceived deviation from the normative ideal becomes a source of guilt evidenced by his need to qualify decisions with “I know I should be.” Another central assumption underpinning biomedical understandings of the body is Cartesian dualism, which advocates for the naturalized separation of mind/body, seen/unseen, and real/unreal. This framework conceives of disease as acting on and being contained within the body as distinct from the self, thereby external indicators can define the boundaries between the diseased and healthy individual. However, in Tom’s case it is not the numbers –CD4 counts or viral loads– that affect how he feels, but rather his own embodied experience.¹⁴ This idea works against the Cartesian legacy, which fails to conceptualize how emotions –feelings, cognitive orientations, public morality, and cultural ideology– can link the mind and body (Scheper-Hughes and Lock 1998). Tom’s narrative incorporates a holistic conception of health, which rejects the mechanistic separation of the subjective from the objective. This understanding informs his decision to avoid medication and rely on his perceptual experiences to gauge health status.

Tom’s narrative also indicates a general distrust of institutional paradigms, the boundaries of which he tests through dark humour and irony. For instance, his resentment at

being required to undergo a mandatory psychiatric evaluation leads him to deliberately give wrong answers and turn questions back onto the evaluator. He takes these actions to put the doctor “in the game” suggesting Tom believes that there are knowable rules, which can be subverted. He observes that his attitude reflects an acceptance of “the way things are.” Tom chooses to play against the doctor-patient power differential and challenge the evaluator’s normative assumptions about the normal/pathological dichotomy; however, his narrative indicates that he feels his behaviour is perceived as somehow deviant. Here Tom’s narrative reveals an awareness of and orientation to another facet of the larger institute of medicine, the application of medical models in a correctional or disciplinary setting. In light of this understanding, the decision to work against the dominant discourses could have very real repercussions. Tom’s observation seems justified since psychoanalysts have medicalized resistance, or the failure to produce a coherent narrative, as the “reluctance of a patient to have their story redirected and/or reinterpreted” (Kirmayer 2000:173). Tom’s decision to forego medications is also indicative of a desire to work against institutional paradigms. He reasoned that avoiding ARV’s meant he would not become the “victim of AIDS research” suggesting that for Tom two separate medical institutional practices –service and research– are inextricably linked. Indeed, for HIV/AIDS patients the boundaries between treatment and research are blurred due to the complexity of the virus and the need to continuously develop combinations of medications that allow practitioners to stay ahead of the disease progression. As a result, those prescribed new medications essentially become the study population within which to test and monitor drug efficacy. For Tom, perceiving research and services as mutually reinforcing means that to retain agency over his illness he had to abstain from the prescribed treatment course.

Finally, Tom's narrative questions addiction treatment models such as Narcotics Anonymous', which he believes characterizes dependency as treatable only insofar as one complies with the program's guidelines. He dismisses NA's strict abstinence policy as unrealistic and proposes that the program destroys more lives than it saves. Tom indicates that NA fails to account for the individual and that by denying the entire group a wide range of prohibited substances, some of which they may have found therapeutic or unproblematic, the program takes away the individual's control over their own life. The overriding discourse of NA is demonstrative of Mattingly's (1994) emplotted narrative in that individual stories are overwritten or at least overshadowed by the meta-narrative of the treatment program, which seeks to create a larger shared narrative structure. At the same time, Tom's narrative indicates that he integrates the beneficial and applicable aspects of the program such as the skills to understand his own nature. For instance, Tom knows that he might succumb to the doctor's recommendations if he sees her therefore based on an assessment of his character using the skill set provided by the tenets of the NA program he feels the best course of action is avoidance. Ultimately, Tom's narrative indicates a consciousness that is resistant to authoritative biomedical frameworks, but at the same time selectively integrates the portions of these same discourses that can form the basis of his therapeutic management. His position highlights the negotiability inherent in therapeutic emplotment such that the creation of narrative can be guided but it cannot be dictated (Mattingly 1994).

In John's case, his narrative contests the individualism underpinning biomedical discourse by foregrounding a socio-centric understanding of health and illness and by defining his sense of well-being in terms of the health of the community. John's narrative reveals an understanding of illness as not confined within the boundaries of the "individual body", understood in the phenomenological sense of lived experience, but rather made meaningful in

terms of the “social body” wherein the body in sickness is an organic model of social disharmony (Scheper-Hughes and Lock 1998:209). For instance, when John is unable to keep the illness inside his own body, what he refers to as being “not centred”, this disruption affects his social network. As such, the community first perceives when his HIV has become a problem “outside of him.” One of the enduring ideologies of the relationship between individual and social health is integration, and throughout John’s narrative he conceives of the community as serving many functions including moral compass, guideline to acceptable/unacceptable behaviour, health status gauge, and source of empowerment. Kleinman and Kleinman (1991) suggest that health seeking behaviours are constrained by and responsive to the problems of negotiating mutual responsibilities between individuals in terms appropriate to their local and moral cultural world. For those who employ a socio-centric understanding of health such as John, a relevant approach to therapy would acknowledge that it his sense of social responsibility motivating him to take medications, to manage his addiction, and to be cognizant of his communal obligations. The narrative John presents is oriented to a socially relativist view of medicine within which the health and illness of the body-self is dependent upon and embedded within the context of social relationships.

Another institutional discourse evident in John’s narrative, one that exists in tension with his socio-centric views, is the inclusion of an understanding of self-empowerment. In opposition to top-down biomedical interventions which advocate patient compliance, community-based health organizations and peer-driven advocacy groups often encourage the HIV-positive individual to take personal ownership of the disease (BCPWA 2004). John’s narrative incorporates this ideology when he says that he made the decision to “not to be a victim” and he decided when to consult an HIV specialist about medication. Having a choice, or the perception of having a choice, is important for John who is grateful for the ability to

develop a health response from the multiplicity of treatment options available to him. John indicates that he ascribes to and differentiates amongst the different medical institutions including complementary and alternative treatments, Eastern medicine, biomedicine, nutrition, and aboriginal understandings of wellbeing. He feels able to retain patient agency insofar as he can integrate these healing systems in varying configurations. However, while self-empowerment is often contrasted with a more paternalistic health care system the discourse of personal choice also places the onus on the individual to maintain their health through responsible and rational choices (Peterson & Lupton 1996). The dialogue on empowerment acknowledges what Farmer (1999) calls the structural constraints that pattern illness distribution; however, there is a failure to address how these same constraints limit an individual's ability to make rational and responsible choices about their health. For instance, in his narrative John mentions his powerlessness to extend his own role within peer-driven organizations where he is denied a voice despite the fact that such groups are modeled as being community based. Moffat (1999) suggest that if models of empowerment do not benefit the individual, then advocating self-empowerment functions to shift efforts at social control to a possibly even more productive technique of eliciting compliance through self-regulation. What John's case highlights is that individuals construct illness narratives from the voices of medicine, but these voices are not necessarily coherent amongst themselves. Indeed, biomedical models and community-based health interventions are often conflicting, working at cross-purposes. As such, medical consciousness can be understood as processual and contextual with individuals drawing on specific discourses tailored to particular environments.

In Will's case, his narrative challenges the presumption that illness is a disruptive event that upsets notions of self and unsettles future expectations. For instance, Davies (1997) assumes that the central difficulty facing people with HIV/AIDS is the challenge the illness

presents to the temporal framing of their lives. As such, he proposes that one can analyze illness narratives to uncover an individual's temporal orientation such as, "living in the empty present" (1997:567), which describes those who mourn the loss of their future and live in an idealized past. However, Will's narrative problematizes such typology because as a self-described fatalist, from long prior to contracting a fatal illness, he had prepared for a shortened life and HIV did not affect his expectations for the future. The narrative he gives is oriented to the past because Will's history defines his notion of self. Much like John's narrative, the discourses Will uses to produce his narrative are often contradictory such as a fatalistic worldview and the integration of a discourse on the power of positive thinking. Becker (1997) suggests that Cartesian dualisms such as mind over matter emphasize the belief that hope and determination can change the course of an illness. This idea reflects the neo-liberal influence on health and subjectivity, which values the entrepreneurial autonomous individual who attempts to control and order illness through rational determinism (Persson and Newman 2006). An idea while inconsistent with Will's decision to live in the past fits with his belief in taking responsibility for his illness. The integration of contradictory voices calls attention to narrative as social action wherein the tension between discourses may reflect the influence of multiple social actors struggling to define and shape the emerging narrative.

The sense of personal responsibility evident in Will's narrative also extends to the understanding that he is accountable for managing the course of his illness. As mentioned earlier, biomedicine values patient agency only insofar as individuals choose from prescribed courses of action. In the beginning of his illness, Will described adhering to the doctor's recommendation and taking medications. For HIV-positive people, biomedicine's gold standard of treatment is antiretroviral drugs, which doctors and specialists present as a means to return to bodily normality. Becker (1997) proposes in such instances the moral force of

normalizing ideologies, seen through prescriptions for health, may interfere with embodied experience, and for Will the treatment did not cure his HIV and the debilitating side effects were more disruptive than the illness. This intrusion is what Persson and Newman (2006:1588) term “the productive capacity of medicine” noting for some it is not the HIV that threatens notions of self but the medications, a domain defined by indeterminacy and conflicting discourses on treatment and best practices. Will’s experience undermined his perceptions on quality of life and Persson and Newman (2006:1594) question if neo-liberalism then asks the impossible, to make rational choices about things that are not necessarily rational. In his narrative, Will indicates his skepticism over the efficacy of biomedicine and the imperative of an undetectable viral load as the normative outcome; an understanding that motivates him to develop strategies to manage those aspects of the illness that are unsettling. Alternatively, Will’s narrative was oriented towards a more abstract social institution called medicine insofar as meals, massage, and acupuncture comprised his phenomenological experience of the institutions of medicine. The narrative Will presents, reveals the conflict between the discourses he integrates including a strategic temporal orientation to the past, a subscription to the power of positive thinking, and an understanding of personal responsibility that subverts the normative biomedical ideals for illness outcome.

Shared Discourses - Harm Reduction and Health as a Human Right

The discourse of harm reduction is pervasive among both the HIV/AIDS and drug-using communities and an acceptance of the tenets of this discourse is evident in all three case studies. In North America, the medical harm reduction paradigm¹⁵ has roots in the public health response to HIV/AIDS and the search for alternatives to drug enforcement, a means of promoting health and mitigating harm to the individual (Giffen et al 1991). In Vancouver

particularly, the principles of harm reduction increasingly inform public health interventions targeted at reducing the spread of HIV and educating the drug using communities about safer practices. The medicalization of users and drug use means that harm reduction becomes another manifestation of the institutes of medicine. Pragmatic and humanistic values underpin the philosophy, which focuses on minimizing, not eliminating, the consequences of drug use. Roe (2005:246) suggests, “One of the central tenets of harm reduction is that it was a ‘bottom-up’ approach, ‘empowering’ communities to address their own problems by providing them with the knowledge and the means to do so.” The narratives presented each draw attention to how the individuals attempt to manage and justify their addictions through a dialogue on risk minimization. In this sense, Nichter (2003) argues that harm reduction practices are an expression of agency, a means to reduce one’s sense of vulnerability and enhance their sense of self-control, and a fundamental approach to preventative health used by local health cultures.

To illustrate, Tom applies the knowledge he gained from an addiction treatment program to understand the reasons why he went to drugs in the first place. In light of this understanding, it is clear that he continues to use because of the therapeutic aspect using confers; drugs offer an escape from the realities of his situation. John explicitly integrates the harm reduction model into his narrative by crediting “the city’s approach to addiction” with allowing him to minimize risk and use in the safest way possible. He therefore has an active role in controlling his addiction, one that is dependent upon the balance between a right to use and a responsibility to use with manageable concepts. For Will, who is not a drug user, the pragmatism that underlies the harm reduction model is evident in the rationale that he continues to drink because it helps to ease the complications of HIV. Since attempts at curing his alcoholism failed, these experiences motivate him to minimize the consequences of

drinking to a point where he does not get out of control but still receives the therapeutic benefit of pain management. In our burgeoning risk society, there is a decreasing optimism about science's ability to cure pressing health problems and growing pressure to assume accountability for one's health (Nichter 2003). For those who have little power to negotiate within the dominant and authoritative structure of biomedicine, broadening their understanding of the institutions of medicine may be a strategic method of regaining control over one's illness. Nichter (2008) also suggests that in cases where illness is thought to be inevitable harm reduction is both a behaviour and a mind set. A chronic illness like HIV health may be perceived of as a relative state, and in such cases, harm reduction practices like the therapeutic use of drugs and/or alcohol to manage the effects of HIV appeal to notions of individual responsibility and may function as a stopgap measure to prevent problems from worsening. The narratives of all three individuals incorporate central tenets of the harm reduction philosophy such as taking personal responsibility for one's health and risk management into their understanding of medicine.

Another discourse common to all three case studies is a rejection of understanding health services as an entitlement or a human right. Under the Universal Declaration of Human Rights, "Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services" (UDHR Article 25). Moreover, federal legislation such as the Canadian Human Rights Act and the Canadian Charter of Rights and Freedoms¹⁶, and provincial legislation such as the BC Human Rights Code¹⁷, further enshrine the protection of the HIV-positive individual. In the Federal Initiative to Address HIV/AIDS in Canada (2002), the Minister of Health reconfirmed the country's commitment to a human rights-based response to the epidemic. Despite the wealth of literature and pervasive discourse outlining the rights of

the HIV-positive individual, including the overarching clinical mandate of the DPC that also subscribes to an understanding of health as a right, the narratives indicate that each of the individuals recognize the supports they receive as privileges not entitlements.

For instance, Tom observes that anything he gets in the line of help for having HIV is a privilege. In John's case, he feels that he is to be a part of the community-driven movement that advocates for the needs of HIV-positive and drug using communities. If John does not receive an adequate level of health care, he has the privilege to make a request to the larger community but not the right to demand change. Finally, Will suggests that he is privileged to be part of the DPC and grateful for whatever level of service provision he is provided. At the same time, Will expresses his indignation at those who fail to appreciate what they are given. However, underlying the belief that health services are a privilege is the reality that due to their disadvantaged life circumstances all three individuals are reliant upon the assistance they receive and therefore may have a vested interest in preserving even a limited or tenuous connection to health care. Alluding to this dependency Tom notes that the last thing he would want to do is ruin the privilege of attending the centre, and even when voicing concerns he qualifies that he is not complaining. In the narratives presented, the understanding of health provisions as a privilege and not a human right may be illustrative of the material and structural constraints that act upon the production of illness narratives.

Conclusions

For those living with illness, the institutions of medicine provide a powerful set of symbols and network of meanings; an ideology, as the case studies highlight that once learned then becomes part of an individual's consciousness. As such, a narrator develops a unique understanding or orientation to the discourses of medicine that allows them to strategically integrate and negotiate amongst this heterology of voices in order to produce their illness narrative. However, as Foucault (1984) has observed, medicine operates both as a service to the sick and a normalizing means of social control, which affords the construction but at the same time constrains the production of illness narratives. Within the case studies considered, the individual narratives are informed by and interwoven with discourses on biomedicine's acceptance of personal responsibility for health and illness, the harm reduction model, community-based notions of the self-empowered patient, normative treatment and illness outcomes, socio-centric understandings of health, the normal/pathological dichotomy employed in psychiatry, and conceptions of health as a human right. This paper argued that earlier anthropological studies on narrative privileged the subjective experience exaggerating the narrator's agency, and that it is more useful to the construction of narrative as a dynamic process involving multiple agentive actors. Consequently, this paper seeks to problematize the essentialization of experience by challenging the institutional/individual dichotomy and re-framing the object of inquiry as medical consciousness. It is important to acknowledge the presence of institutional voices evident in narratives because the illness experience does not exist in a vacuum. The concept of medical consciousness affords recognition of the inseparability of lived experience and the institutional voices of medicine that facilitate the construction of narrative, as well as the narrator's own situated position within these same

discourses. Moving forward, this paper has proposed the idea of medical consciousness in the belief that by calling attention to the institutional voices evident in narrative the anthropologist can retain the agency of the narrator who selectively and strategically employs these discourses to shape their story for a particular audience. However, the concept of medical consciousness is also salient because it affords analyses that acknowledge how these same discourses constrain and limit the development of narrative. The stories people tell about their illness reveal the multifaceted and contradictory nature of narratives, which are constructed by and construct the institutional voices of medicine that facilitate their production.

Notes

¹This point draws upon the distinction made in medical anthropology between disease as the abnormalities in the structure and/or function of the organs, pathological states, and illness as a person's experiences and perceptions of certain socially disvalued states, including but not limited to disease (Rhodes 1996:171).

² Linde (1993:169) argues that coherence –the “interpretable wholeness” of a narrative– is not an inherent property in the discourse, but must be negotiated between interlocutor and narrator, in a process that inevitably leaves some gaps and failures of understanding.

³ The BC Centre for Excellence's Drug Treatment Program (DTP) provides anti-HIV medications at no cost to eligible HIV-infected individuals (www.cfenet.ubc.ca). According to the province of British Columbia, HIV as an episodic illness is recognized as a disability and thereby fulfills the requirements for income assistance and subsidized housing (<http://www.eia.gov.bc.ca>).

⁴ I have chosen to use the actual name of the institution, with their permission, to capture a realistic portrayal of the research environment and to accurately highlight some of the institutional frameworks that enter into an HIV-positive individual's life.

⁵ The Centre's mission is to provide Comfort Care which is guided by the following principles and values: accepting, respecting, and valuing the dignity of each individual; supporting the spiritual, psychological, social and physical needs and desires of each individual based on their own choices; transforming despair, isolation, fear, and fatigue into inclusion, support, safety, and security; and recognizing the broad determinants of health and quality of life, and providing innovative, integrated, flexible, community-based care. The Centre's clinical practice operates under six overarching concepts; Maslow's Hierarchy of Needs, Orem Model of Self-Care, Therapeutic Community Model, Restorative Justice, Theoretical Model of Change, and Harm Reduction (www.drpeter.org).

⁶ While I chose to pursue a different focus for this paper, the relative lack of discussion on health as a human right, or human rights generally, is an interesting area that I intend to explore further in a future paper.

⁷ The discourses that I have drawn out from the narratives presented is in no way meant to be an exhaustive list. Rather I have chosen to highlight those institutional dialogues that I felt emerged most prominently during the interviews and at the same time, chose dialogues that I felt were prevalent amongst individuals at the Dr. Peter Centre who faced both similar illness courses and life circumstances.

⁸ All names have been changed to preserve the confidentiality of the interview participants.

⁹ Just as the discourses I elucidated were not meant to be comprehensive, so to the frame of medical consciousness is not the only way in which these narratives could have been characterized. In John's case, his narrative reveals a strong connection to aboriginal medical systems and ways of knowing. For instance, Waldram describes aboriginal medical systems as communal, based on the principle of the world as a place in which harmony and balance exist between and among human and other entities, as such, illness is indicative of a disruption in this balance and healing entails repairing the moral fabric and normative order of society (1995).

¹⁰ Vancouver's Downtown Eastside (DTES) is branded by an entrenched and visible street drug culture that has spawned intense scrutiny from federal health institutes, drug enforcement agencies, and provincial and municipal governments. In 1997, it was declared that the neighborhood carries the highest rate of HIV/AIDS transmission in the Western world and medical authorities there described both intravenous drug use and overdose incidence as epidemics. The intense visibility of homelessness, sex work, mental illness, and open drug use in the community further solidified a public call for action. In 2000, Vancouver municipal authorities sanctioned a plan to combat the drug problem in the neighborhood through funding the 'Four-Pillars' prevention, treatment, enforcement, and harm reduction (Robertson 2006).

¹¹ The Vancouver Agreement (VA) is an urban development initiative between the governments of Canada, British Columbia, and the City of Vancouver. It is an innovative partnership between governments, community organizations, and business to make the city a healthy, safe, and sustainable place to live and work. Projects include expanded addiction treatment services and aboriginal strategies. It works within the city's Four-Pillars approach to reducing drug-related harm (<http://www.vancouveragreement.ca/TheAgreement.htm>).

¹² Neuropathy is a disorder of the peripheral nerves—the motor, sensory and autonomic nerves that connect the spinal cord to muscles, skin and internal organs. It usually affects the hands and feet, causing weakness, numbness, tingling, and pain. Peripheral neuropathy's course is variable; it can come and go, slowly progressing over many years, or it can become severe and debilitating. It has a number of causes including AIDS and HIV related neuropathy, and was once thought to be a side-effect of such illnesses (http://www.neuropathy.org/site/PageServer?pagename=About_Facts).

¹³ This point is true of all narratives that by their very nature are necessarily dialogically produced, and thereby produced in the interactional context. Telling is an interaction in which the audience actively shapes both teller and telling (Kirmayer 2000). In this sense, creating a narrative is an active and constructive process; even when an audience is not physically present the supposed expectations of the reader may cause the narrator to fashion their story around particular themes and events, blurring the distinction between text, context, narrator, and audience (Mattingly and Garro 2000).

¹⁴ The rejection of the objective in favour of the perceptual experience and mode of engagement with the world is embodiment. Embodiment as a theoretical construct challenges conceptual dualities such as mind/body, subject/object. It is an existential condition in which the body is understood as an indeterminate methodological field and the intersubjective ground of experience (Csordas 1999).

¹⁵ I use the term medical harm reduction to distinguish the tension between those who see harm reduction as a medical means of promoting health and the more activist position that envisions harm reduction as a platform for enabling the broad structural changes which could eliminate, or reduce, the inequalities that factor into the production of 'risk' and 'harm' (Roe 2005).

¹⁶ Article 15 of the Charter guarantees equality before and under law and equal protection and benefit of law. Discrimination on the grounds of disability is prohibited, and HIV is recognized as a disability (<http://laws.justice.gc.ca/en/charter/>). The purpose of the Human Rights Act is to ensure that all individuals should have an opportunity equal with other individuals to make for themselves the lives that they are able and wish to have and to have their needs accommodated, consistent with their duties and obligations as members of society, without being hindered in or prevented from doing so by discriminatory practices (<http://laws.justice.gc.ca/en/ShowFullDoc/cs/H-6>).

¹⁷ The BC Human Rights Code protects British Columbians from discrimination in areas such as employment, housing, and services and facilities customarily available to the public (http://www.qp.gov.bc.ca/statreg/stat/H/96210_01.htm).

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Appendix 1 UBC Ethics Board Certificate of Approval



The University of British Columbia
Office of Research Services
Behavioural Research Ethics Board
Suite 102, 6190 Agronomy Road,
Vancouver, B.C. V6T 1Z3

CERTIFICATE OF APPROVAL - FULL BOARD

| | | |
|---|---|---|
| PRINCIPAL INVESTIGATOR: Vinay Kamat | INSTITUTION / DEPARTMENT: UBC/Arts/Anthropology | UBC BREB NUMBER: H07-00763 |
| INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT: | | |
| Institution | | Site |
| UBC | | Vancouver (excludes UBC Hospital) |
| Other locations where the research will be conducted: Dr. Peter Centre, 1110 Comox Street Vancouver, BC V6E 1K5 | | |
| CO-INVESTIGATOR(S): Sara C. Hancock | | |
| SPONSORING AGENCIES: N/A | | |
| PROJECT TITLE: Finding Meaning in the Right to Health: Conversations with HIV-Positive Individuals at the Dr. Peter Centre in Vancouver. | | |
| REB MEETING DATE: September 27, 2007 | CERTIFICATE EXPIRY DATE: September 27, 2008 | |
| DOCUMENTS INCLUDED IN THIS APPROVAL: | | DATE APPROVED: October 15, 2007 |
| Document Name | Version | Date |
| Consent Forms: | | |
| Health and Human Rights Consent Form | Version 2 | October 4, 2007 |
| Advertisements: | | |
| Health and Human Rights Recruitment Flyer | Version 2 | October 4, 2007 |
| Other Documents: | | |
| Sample Interview Questions | N/A | October 4, 2007 |
| The application for ethical review and the document(s) listed above have been reviewed and the procedures were found to be acceptable on ethical grounds for research involving human subjects. | | |
| <p><i>Approval is issued on behalf of the Behavioural Research Ethics Board and signed electronically by one of the following:</i></p> <p>_____</p> <p>Dr. Jim Rupert, Associate Chair Dr. M. Judith Lynam, Chair Dr. Laurie Ford, Associate Chair</p> | | |