**LIVING WITH HIV/AIDS:**

*A GAY MAN’S AUTOETHNOGRAPHY*

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*A GAY MAN’S AUTOETHNOGRAPHY*

**By Brick Wallace, BA, BSW**

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**Abstract**

In Canada, queer men (or ‘men who have sex with men’) continue to be disproportionately affected by HIV/AIDS, representing at least 50% of all people living with HIV/AIDS (Public Health Agency of Canada, 2012).Every year, thousands of new infections significantly increase the toll that HIV/AIDS takes on queer men and their communities. With this epidemiological reality as context, I set out to explore how my subjectivity (as a gay, HIV-positive man) *was* and *is* shaped, specifically with respect to the following HIV/AIDS-related, socio-cultural phenomena: activism, community service, ‘safer’ sex, diagnosis and criminalization. These five phenomena provide focal points (or themes) for the presentation and analysis of my experience of living with HIV/AIDS, both before and after becoming infected. Through insider knowledge, my research examines three decades of personal stories, using critical reflexivity to increase my awareness (as well as my reader’s) of the myriad challenges and complexities of living one’s life in the midst of the ongoing pandemic.

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**Introduction**

If writing beyond recognition is the price we must pay for working at the limits of self-knowledge and mastery, of piecing together radically incomplete accounts as they are performed in the crucible of social relations, let it be you who reads with feeling and solidarity. Let it be you who takes what experience tells and makes it into something you can use, something yours.

— Jones, 2011, p. 333

*Living with HIV/AIDS* is an autoethnographic bridge, connecting aspects of my experience of the HIV/AIDS pandemic to my social location as a gay man. As phenomenological research, it strives to illuminate the meanings of my experience of living with HIV/AIDS, incorporating both literary evocation and cultural analysis in order to disrupt silences and to open possibilities for research, social action and policy on HIV/AIDS, particularly with respect to five, key themes: *activism*, *community service*, *‘safer’ sex*, *diagnosis* and *criminalization*. The shifting and contingent aspects (e.g. human rights) of my experience of living with HIV/AIDS, in an increasingly neo-liberal world, compel me to express my voice(s) through both an adaptive, cultural narrative and an embodied, political analysis.

I begin with a critical review of the literature, explicating four, epistemological concerns with respect to existing studies on living with HIV/AIDS: *being vs. becoming positive*, *medicalizing HIV*, *disembodying the researcher* and *depoliticizing research*. Next, I highlight key concepts with respect to the theoretical underpinnings of my research, including *critical*, *narrative*, *post-structural*, *queer*[[2]](#footnote-2) and *critical* *disability* perspectives. Third, I explain my use of autoethnography as methodology, illustrating the purposes and methods of my research, as well as its ethical exigencies. Fourth, I consider methodological tensions that arise in conducting my research, focusing on reflexivity, analysis and emotional labour. In conclusion, I briefly suggest how my research is worthwhile.

**Literature Review**

Arising out of my review of the literature, four interrelated concerns (Jones *et al*, 2013, pp. 25/26) inform my choice of autoethnography as a methodological approach: an awareness of the limits of positivist, quantifiable data in representing the socio-cultural experiences of persons living with HIV/AIDS (PHAs), coupled with my curiosity about the potential of inter-subjective, artistic methods (e.g. dramatic dialogue) to explore and document my/our experiences; ethical and political concerns about conducting research withPHAs; a passion and appreciation for the possibilities of story, emotion and the body in research; and the enduring significance of sexual politics and community in my life, particularly with respect to how I perceive my experience as a queer PHA.

***Being vs. becoming positive***

Existing social research on HIV/AIDS typically assumes an objective (vs. subjective) stance, where the PHA is the object of the researcher’s gaze, an existential entity whose experiences (e.g. ‘safer’ sexual acts) refer primarily to the person him/herself rather than to the dynamic social context in which he/she lives (Wright, 1998, p. 11). Such research resides primarily in a positivist sphere, representing modernist, explanatory proclivities and assumptions about PHAs. Yet, living with HIV/AIDS is highly unpredictable, involving a constant restructuring of life and being (Kylma *et al*, 2001, p. 771), as well as identity. Positivist methodology is challenged by such subjective flux and complexity (Ezzy, 2000, p. 616; Ion & Mwalwanda, 2013, slide 2), gathering and analyzing ‘objective’ data rather than conscious experience. In turn, these data largely yield causal explanations of measurable, socio-cultural realities (such as HIV/AIDS stigma) rather than being thickly descriptive of the relational, non-linear, subjective experiences of those realities.

Positioning a PHA, at a distance, as an objectified ‘other’ (i.e. as the site of an external inquiry) has ethical implications, particularly when the research involves groups (e.g. indigenous people, queer men, etc.) that have been historically disenfranchised and misrepresented through “pre-existing modes of research production around disabled people’s experience. [What is required] is the move from research *on* disabled people to research *with* disabled people” (Tregaskis & Goodley, 2005, p. 364). Without phenomenological approaches, research *on* PHAs fails to conceptualize HIV as both a virus *and* a discursive, relational ‘object’ that orients the body-self vis-à-vis its socio-cultural context.

***Medicalizing HIV***

As I know first-hand, “life with HIV does not have solely negative consequences” (Lamendola & Newman 1994, Schwartzberg 1994, Stevens & Doerr 1997, cited in Kylma *et al*, p. 765). Social research on PHAs, however, frequently aligns with problematizing, biomedical discourses (i.e. oriented heuristically toward a health/illness paradigm), interpreting data through an institutional sphere of knowledge/power that invokes medical constructs (e.g. stress models and health-related quality of life indicators) to study social problems such as stigma (Emlet *et al*, 2013) and housing insecurity (Greene *et al*, 2010). As Greene *et al* illustrate, “as part of our mixed method data collection strategy, in-depth, semi-structured interviews were conducted with 50 PHAs across Ontario to provide a deeper understanding of the impact that housing instability has on their mental and physical health” (p. 223). While unquestionably relevant, the methods of biomedically-aligned studies (e.g. randomized control trials) can be limited to the extent that PHAs are constructed as ‘patients’ in care as a condition of their participation in the research (Emlet *et al*, p. 1137).

The biomedical hegemony in research on living with HIV/AIDS allows scant critical space to explore the myriad, empowering ways in which PHAs experience life and health. In addition, the knowledge generated from such research can become inaccessible except to a privileged few, confined to academic or institutional spaces, where it yields tenuous (if any) social actions and questionable benefits to the people and communities who served as participants (Greene, 2013; Ion & Mwalwanda; Powell & Takayoshi, 2003; Horsfall & Titchen, 2009). “The question of whose interests are served is central. And, of course, there is an unambiguous relationship between control and benefit” (Schnarch, 2004, p. 83). Even when biomedical research incorporates community-based or participatory elements, reciprocity is not always a clear and indisputable outcome (Greene; Ion & Mwalwanda, slide 13). When involving PHAs in the design and delivery of methodology, researchers must still consider, for example, an “additional element of inquiry into the ethical tensions [e.g. distribution of benefits] that emerge when researchers heavily rely on the lived experience of members of the PHA community as a key function of [their] role [in research]” (Greene, p. 142).

“The medicalization of HIV-infected bodies, the surveillance and governance of HIV-positive bodies, and the systematic distortions to self-care that result from the internalization of tropes of toxic bodies” requires vigilant, ethical consideration in designing research with PHAs (Willis, 2013, p. 259). One of the criticisms leveled against the biomedical hegemony in HIV/AIDS research is that it falls short in illuminating subjective, qualitative aspects (i.e. feasibility, transferability, practical constraints and cultural adaptation) of interventions such as ‘safer’ sex (Elford *et al*, 2002, p. 352). For example, the ‘social desirability’ pressure on gay men to report consistent practice of ‘safer’ sex in the context of any biomedically-aligned study would undoubtedly be high (Lasala, 2003, p. 15). This points to the importance of reflexivity in research, which biomedical methodologies tend to overlook, if not neglect altogether. Undoubtedly, this lack of reflexivity intensifies the numerous barriers to the involvement of PHAs in studies about their own experiences: “HIV-related stigma, health-related challenges, other issues taking priority in their lives, lack of research capacity, ‘credentialism’ and mistrusting researchers” (Travers *et al*, 2008, p. 619).

***Disembodying the researcher***

Most studies on living with HIV/AIDS tend not to directly give voice (or embody) the narratives of PHAs whose experiences are the subject of inquiry, including PHAs who are involved as researchers. Greene (2013) critically observes, with respect to her role as an HIV/AIDS researcher, that “I am acutely aware that through this process of reflection, and in sharing [the] stories [of PHA research assistants], I am telling and interpreting the stories of others” (p. 144). As Greene perhaps suggests, the reified narratives of HIV/AIDS research can be recounted by investigators whose ‘outsider’ locations and epistemological frameworks inform (if not control) the narration of living with HIV/AIDS, including how PHAs are represented. “The challenge, [then], is to identify that lived experience that resides in the space between subject and object, [between researcher and participant]. To increase the integrity and trustworthiness of qualitative research, researchers need to evaluate how inter-subjective elements influence data collection and analysis” (Finlay, 2002, p. 533/531).

“By not insisting on some sort of personal accountability, our academic publications reinforce the third-person, dis-embodied voice as the standard, which gives more weight to abstract and categorical knowledge than to the direct testimony of personal narrative and the first-person voice” (Ellis & Bochner, 2000, p. 735). Positivist research on living with HIV/AIDS lacks embodied, reflexive narrators to integrate measures of the wisdom and vulnerability of lived experience in ways that illuminate the complex, intersectional nature of socio-cultural phenomena such as stigma and HIV criminalization[[3]](#footnote-3). The categorical ‘evidence’ that is generated by social studies (Emlet *et al*, 2013; Adam *et al*, 2008), while unquestionably important to understanding the experiences of PHAs, generally serves the purposes or interests of academics, organizations and institutions more directly than those of PHAs.

With objectivist and interpretivist methodologies, HIV/AIDS evidence resides predominantly at fixed points outside the researcher (e.g. in academic journals), where it has power and utility primarily vis-à-vis other ‘truth’ claims. With such methodology, evidence manifests as disembodied knowledge rather than being something whose ‘truth’ becomes known in the evidencing itself (Sokoloski, 2000, pp. 160/161). In other words, evidence gets constructed objectively as a noun (i.e. knowledge), rather than subjectively as a verb (i.e. knowing). What I believe is lacking in studies on living with HIV/AIDS are more approaches to knowing and knowledge that are grounded in lived experience, methodologies that assume such acts as the (re)presentation of the HIV-positive self and the narration of embodied, personal experience, methodologies that not only gather evidence from PHAs and their stories but multiplies it through them as a strategy for reciprocity and empowerment (Maiter *et al*, 2008, p. 320).

***Depoliticizing research***

Because the HIV status of the disembodied researcher is not typically disclosed or taken up as part of methodology, it is difficult (if not impossible) to assess the extent to which the researcher is an ‘insider’ (i.e. with respect to living with HIV/AIDS), indicating a lack of theoretical attention to “the relational nature of disablement, empowerment and interdependence in research” (Tregaski & Goodley, 2005, p. 365). This, in turn, poses implications with respect to issues of ethics and representation, particularly in the historical context of oppressive research practices *on* groups who are disproportionately affected by HIV/AIDS (e.g. indigenous people, queer men, etc.). A hegemony of ‘outsider’ methodologies discourages (if not prohibits) the inclusion of the personal experiences of disabled researchers (Barnes, 1997).

As a result, disabled people run the risk of losing the opportunity to actively celebrate their expertise … We need to move to a position in [HIV/AIDS] studies where it is acceptable to draw upon our personal experiences to analyze research practice and to celebrate [PHAs’] relatively powerful position in this respect. (Tregaskis & Goodley, p. 368)

When PHAs are involved in research, engaged through our political identities (e.g. queer), the results “[include] higher quality prevention and care programming, enhanced policy development, reduced stigma and isolation for [PHAs], increased feelings of personal empowerment, self-worth and enhanced credibility of AIDS service organizations (ASO)” (Travers *et al*, p. 216; Ion & Mwalwanda, slide 10). By distancing or concealing the identities and experiences of researchers who are living with HIV/AIDS (disclosure issues notwithstanding), methodology can become unhinged from the political, which is reflective perhaps of other disabling practices and discourses (e.g. medical labeling) embedded in dominant, socio-cultural contexts of contemporary HIV/AIDS research (e.g. government agencies, universities, hospitals, AIDS service organizations, etc.).

My review of the literature turned up extensive research on the topic of HIV disclosure, ‘safer’ sex practices, and how the two are related. However, there was a lack of information regarding the impacts of HIV criminalization on PHAs, on HIV prevention work, and on public health policy more broadly (i.e. with respect to disclosure counseling, HIV testing, etc.) (Adam *et al*, 2008, p. 150). Studies on living with HIV/AIDS seem to reinforce the neo-liberal ‘responsibilization’ of the individual by “sending researchers into the field in search of new impairments and pathologies” to explain the behaviours (e.g. barebacking) of PHAs, engaging medical and legal discourses to represent PHAs as depoliticized ‘consumers’ who should behave rationally and self-determine through responsible, moral/economic choices (Adam, 2005, p. 334). Integral to neo-liberal inclinations in HIV/AIDS research is an assumption that privileges a linear methodology with a simple plot oriented toward economic goals such as epidemiological control and the reduction of HIV-related health care costs (Ezzy, p. 616). Such inclinations, however, afford inadequate critical space for addressing the complex, socio-cultural dynamics that perpetuate the pandemic, including neo-liberalism itself.

**Theoretical Underpinnings: *key concepts for my research***

***Critical***

The purpose of my research, in part, is to interrogate a social dis-order (i.e. the burgeoning HIV pandemic) in such a way that it becomes itself a catalyst, which contributes to the transformation of that disorder (Fay, 1987, cited in Kreuger & Neuman, 2006, p.83). An essential step in ending the pandemic requires critical analysis of how existing power relations and structures are created and supported within it (Fook, 2002a, p. 54). For me, this includes reflecting on systemic inequities such as heterosexism and ableism. As such, both the analytic and evocative dimensions of my research “revolve around intentions to understand and make visible relations of power/oppression, value the realm of experience, interrogate the status quo and engender social change” (Webber, 2008, p 40/41), specifically with respect to exploring my subjectivity as a queer PHA.

***Narrative***

I rely heavily on relational subjectivity, both as the author and the primary participant of my research, constructing an ‘I’ that is contingent on my relationships with others, and a self who finds voice through stories that involve those relationships. When I narrate, however, I am narrating only *my* self, versions of me, trying on identities; Brick Wallace, narrating who and how I am becoming a subject through my research process. In doing so, I draw attention to the constructedness of my voice and the performance of my self-narrative. This performativity highlights the contingencies of identity, subjectivity and discourse through which I, and others, might hear my story of living with HIV/AIDS. And perhaps re-tell it.

“Telling stories of illness is the attempt, instigated by the body’s disease, to give voice to an experience that medicine cannot describe” (Frank, 1995, p.18). My stories provide socio-cultural (con)texts through which readers (as ‘secondary participants’ in my research) might relate to one another (e.g. in community) and to themselves (e.g. as PHAs). Greene (2013) suggests that HIV/AIDS researchers might expand methodological rigour “to include moral, political and ideological value commitments in the research process vis-à-vis the telling of stories” (p. 149). In addition to the critical merit inherent in reflexive storytelling, accountability is bolstered as I make my stories explicit and more available for the benefit of external consideration. In doing so, I hope to illuminate how my subjectivity is constituted and represented through the storytelling process of my research (Kondrat, 1999, p. 459).

***Post-structural***

I conduct my research with the assumption that my individual, cultural norms and practices (e.g. ‘safer’ sex) and cultural identity (e.g. PHA) are the outcomes of situated and inter-subjective, social discourses that constantly evolve, both inside and outside my experience of living with HIV/AIDS. I am a subject/researcher constituted in language. As such, my notion of *individual* culture does not imply that culture is merely about my psychology or my personal world; rather, it refers to *my* individual versions, my stories, of the social discourses that are formed, circulated, retained, altered and sometimes discarded as cultural artifacts (Chang, 2008, p. 17). In drawing on post-structuraltheory for a discursive analysis of my subjectivity, I “simultaneously draw on previous theoretical ideas and experiences, develop and construct new theoretical ideas and re-create [myself] in the process, [embracing] the idea that research practice [is] an emotional, personal journey” (Hubbard *et al*, 2001, p. 124).

Post-structuralism enables me “to experiment within the confines of [my] pre-theoretical commitments – incorporating a reflexivity that accounts for multiplicity without making it singular and that acknowledges the unknowable without making it familiar” (Pillow, 2003, p. 181). My research engages my changing subjectivity in self-reflexive analysis — a focus on who I think I am and how I feel affects my data collection and analysis — “that is, an acceptance that *how* knowledge is acquired, organized, and interpreted is relevant to *what* the claims are” (Altheide & Johnson, 1998, cited in Pillow, p. 176). Thus, I narrate primarily for process rather than for outcome, specifically for the process of constructing and deconstructing a self who is living with HIV/AIDS. A relational, vulnerable, multiple self. But a self that is also indisputably situated, inside my body and my research, demanding a voice.

The distinction I make between ‘self’ and ‘subjectivity’ draws attention to the constructedness of the voice inside any text, including those that are written in the first person grammatical voice. The self that I lay claim to with “I” or “me” gives the impression of a stable, coherent and bounded humanist individual; however, the poststructurally-inflected term “subjectivity” draws attention to the contingencies of identity and multiplicity of discourses through which we come to recognize ourselves as particular beings. (Gannon, 2013, p. 228)

***Queer***

My queer, sexual body is oriented vis-à-vis ‘objects’ in my socio-cultural context by way of heteronormative lines of direction (e.g. beliefs about anal sex, values about monogamy, etc.) that shape and signify aspects of my subjectivity (Ahmed, 2006), particularly with respect to living with HIV/AIDS. Orienting queer bodies by way of responsibilizing lines of direction, such as ‘safer’ sex, is congruent with the governance ideals of neo-liberal, social policies (Adam, 2005). In my research, I invoke a constructivist, fluid notion of sexuality, understanding my queer identity as a means of linking my body to a range of epistemological and political concepts such as morality, education, community, public health and the law (Foucault, 1990). Thus, I invoke queer theory not to define my identity, but to unsettle my ‘sexual orientation’ and to foster multiplicity in the representation and analysis of my experience of living with HIV/AIDS as a gay man.

***Disability***

From critical disability theory, I borrow the premise that my HIV infection is “a form of social exclusion and not a product of impairment per se” (Thomas, 1997, p. 623). Throughout my research, I invoke a disability (vs. health/illness) paradigm to explore how certain HIV-related phenomena (e.g. diagnosis, criminalization, etc.) produce disabling (or colonizing) effects on my body and identity. In doing so, I pose the following questions. In what sense (or how) am I disabled by HIV? Is my queer identity shaped by the disabling of my body? In short, my research strives to contribute, more broadly, to an understanding that “the problem [of living with HIV/AIDS] is disability: the barriers which socially exclude” (*ibid*, p. 632).

**Autoethnography: *why and how***

***Research purpose***

“One characteristic that binds all autoethnographies is the use of personal experience [e.g. living with HIV/AIDS] to examine and/or critique cultural experience [e.g. HIV criminalization]” (Jones *et al*, p.22). To achieve this purpose, my methodology relies directly on my experience as a PHA for both data collection and analysis. Using an *evocative*, *analytic* autoethnography, I explore 30 years of formative, personal experience, encompassing events, activities and relationships before, during and after I became infected with HIV. Rather than setting out to provide answers to a specific research question, I “reflect on the nuances of [my] experience, write to show how aspects of [my] experience illuminate more general cultural phenomena and [examine] how [that] experience works to diminish, silence or deny certain people and stories” (*ibid*, p. 23).

A definitive feature of my autoethnography is the personal and political purpose of not only ‘truthfully’ rendering my experience of living with HIV/AIDS, but also transcending it through broader social connections (Anderson, 2006, p. 388) such as community relationships and cultural recollection. “At the heart of calls for reciprocity in methodology is the recognition that research involves building relationships among humans” (Powell & Takayoshi, p. 399). Thus, my autoethnography strives to provide a way for my reader and I to be present to one another, a space to create a relationship embodied in the performance of writing and reading that is reflective, communicative, emotional and political (Jones *et al*, p.19). My objective is to write accessible stories about living with HIV/AIDS that might merge into the flow of discussion around topics of interest to PHAs, caregivers, activists, researchers and others.

My narratives aim to disrupt ‘silence’ (i.e. my subjugated voice as a PHA) and, in doing so, to open possibilities with respect to greater social justice for other PHAs and me. The following characteristics distinguish my research from other types of personal/subjective work such as confessional autobiography or fiction: “purposefully commenting on/critiquing of culture and cultural practices; making contributions to existing research, [which distinguishes it as scholarship]; embracing vulnerability with purpose; and creating a reciprocal relationship with audiences in order to compel a response” (Jones *et al*, p. 22). It is important to note, however, that my methodology does not claim to produce more reliable, generalizable or relevant findings than other types of research, but instead provides another approach for studying cultural experience (*ibid*, p. 33), a trustworthy approach that, I believe, can complement the existing body of research on living with HIV/AIDS.

***Research methods***

In conducting my research, I position myself, as the researcher, in a multi-temporal, non-linear process of critical inquiry that is constituted in relation to other human subjects, community spaces and political expressions, including the acts of protest, writing and sex. As such, my re-search begins having already commenced, with a merging of past, present and (possible) future experience informing my approach (Schrag, 1997). I shift fluidly between voices; constructing a past ‘I’ in an evocative, present dimension, while conjugating a present ‘self’ in a more distant, analytical past. In my self-narrative, I write and re-write myself into inter-subjective positions. In doing so, I call others into relation (i.e. as ‘tertiary participants’) in somewhat unpredictable ways.

The ‘tertiary participants’ of my study are those people who are represented and/or directly implicated in my self-narrative vis-à-vis their relationship to me as the primary (or main) participant. Tertiary participants (or ‘familiar others’[[4]](#footnote-4)) provide me with relational templates for self-narration, drawing out my socio-cultural context of living with HIV/AIDS. Rather than providing data *per se*, my tertiary participants take part indirectly (or by implication) vis-à-vis their appearance in my research. The key, common characteristic of my tertiary participants is that they are people who are (or were) known to me, and who figure(d) importantly in my story of living with HIV/AIDS, including, for example, intimate partners or doctors. I do not engage directly with my participants about my study’s contents with the exception of *potentially identifiable* tertiary participants (e.g. my current partner), with whom I engage in a member-checking process regarding the sections of my self-narrative in which they appear (*see appendix A*).

In ‘recruiting’ tertiary participants who are potentially identifiable (*see appendix B*), I employ a type of purposive, highly selective sampling in an effort to yield thick, relational data. As a result, the ethical complexities and demands of my study are not unlike other types of research involving human subjects. The combination of my authorial power and my personal involvement with the participants in my stories means that my responsibility to do no harm is, arguably, even greater (Adams, 2008; Ellis, 2007). Thus, in employing my methods, I exercise strict ethical standards (i.e. using non-identifying information, creating pseudonyms and composite ‘characters’, seeking voluntary, informed consent from potentially identifiable participants, etc.) regarding all ‘tertiary participants’ who appear or are directly implicated in my self-narrative (Chang, p. 54). Ultimately, I treat all persons mentioned or directly implicated in my research as potentially vulnerable to adverse consequences (e.g. stigma), either now or at some point the future, including me as primary participant (Muncey, 2010, p. 129; Tolich, 2010, p. 1605). Since I have not disclosed my HIV status to many family members, friends or co-workers (and do not, currently, wish to do so), I use a pen name in conjunction with this thesis, particularly since this study is readily accessible via the Internet. As an autoethnographer, I consider a balanced and cautious narration (both for self and others) to be the ethical foundation of my methodology.

In an attempt to structure and organize my data collection and analysis, I examine my experience as a PHA in three life stages that are intended to be more temporal than chronological in nature: *pre-infection*, *infection* and *post-infection*. My methodology ranges from examining my experience through an otherwise traditional thematic analysis to the presentation of aesthetic projects: poetry, prose and other literary forms. The primary focus of my data collection is on internal information (i.e. my thoughts, memories, feelings, reflections, etc.). Excerpts from my journals, poetry and fiction, and my recollections of interactions with familiar others (e.g. my partner, friends, family members, co-workers, doctors, etc.) also serve as sources of internal data, representing discursive, cultural artifacts. I gather personal memory data through an ongoing, self-reflective writing process, ultimately crafting my self-narrative from these data. However fallible (as an empirical method), I also use my memories to construct and analyze storied data. In seeking out complementary, external data, I turn to inter-personal and cultural sources such as my letters/emails, videos/films, media articles and my medical lab reports.

As an autoethnographer, my goal is to present and reflect on my subjective experiences with respect to living with HIV/AIDS, to express meaning, not ‘truth’. I begin with the premise of a unifiable subject, Brick Wallace, inscribed in language. Ultimately, the objective of my analysis is “to arrive at themes that illuminate the content and hold within or across stories” (Ellis, 2004, 196). In order to preserve the evocative importance of emotion in my epistemological approach, I typically separate the aesthetic narratives (e.g. poetry and short fiction) from my thematic analysis. In doing so, I attempt to add another layer of analysis by stepping back from the text and critiquing it through a critical, post-structural, narrative, queer and/or disability lens, invoking other theoretical perspectives as needed (e.g. chaos theory, feminism, etc.). From an analytic perspective, I also include narratives (e.g. academic writing) that incorporate analysis directly in my storied data. “Much of that work focuses on telling [stories] that clearly locate the personal in the field, in the writing and in the political contexts of the research” (Jones *et al*, p. 19). In both the *evocative* and *analytic* methods of my autoethnography, I refer to the literature extensively in order to situate my self-narrative.

My autoethnography employs the following *evocative* methods (Ellis, p. 30):

● I write in the first-person style, making myself the subject/object of research.

● The focus of any generalization usually pertains to my personal experience over time rather than to multiple subjective experiences.

● My writing imitates autobiographical fiction in the sense that it is presented as my story with a narrator, characters and plot.

● My narratives intentionally disclose details of my personal life and highlight emotional experience.

● My relationship to HIV/AIDS is dramatized as connected episodes unfolding over time rather than as fixed representations.

● My experience of living with HIV/AIDS is studied reflexively in connection to the lives of ‘familiar others’ (e.g. my partner, family members, friends, parents, community members, my doctor, etc.).

● The accessibility of my writing positions the reader as an involved participant in the research, rather than as a passive receiver.

The following *analytic* features (Anderson, 2006) inform my methods:

● I am an ‘insider’ with respect to the experience of living with HIV/AIDS.

● I engage in self-reflexivity, demonstrating an awareness of the reciprocal influence between me, my setting and my ‘familiar others’.

● I am visible in my narratives.

● I engage in critical dialogue with others with respect to my research process and findings.

● I demonstrate a commitment to theoretical analysis, not just to capturing what occurs in my personal experience or my socio-cultural environment.

**Methodological tensions**

***Reflexivity***

In autoethnography, tensions can result from “an excessive focus on self in isolation from others” (Chang, 2008, p. 54). My form of research highlights issues of representation, objectivity, data quality, legitimacy, and ethics (Wall, 2008, p. 39). For example, “what does reflexivity mean for researchers who study themselves? Is the practice of self-reflexivity different when it is performed by an ‘insider’?” (Pillow, p. 182). These questions illuminate tensions that arise in my research related to dominant norms of research practice and representation. Putting my ‘self’ in the research and questioning my ways of knowing does not resolve the tension with respect to representation (*ibid*, p. 183). In addition, being an ‘insider’ with respect to HIV/AIDS does not automatically yield my research egalitarian or representative with respect to other PHAs (e.g. indigenous woman living with HIV/AIDS). As an autoethnographer, interrogating the social relations of power that are embedded in these questions increases the internal tension with respect to developing my self-reflexivity as “a continuing mode of self-analysis and political awareness” (Callaway, 1992, cited in Pillow, p. 178).

***Analysis***

Tensions arise, perhaps, to the extent that my methodology emphasizes narration over analysis and cultural interpretation (Chang, p. 54). In order to decrease the tension between these two approaches — storytelling and analysis — I position myself in my research by telling my stories, then move to analyzing external discourses (i.e. personal and cultural), which (in turn) connects back to my stories. I also (con)textualize my analysis through reference to the literature, raising questions about that literature and generating new research questions (Pace, 2012, p. 8). “Incorporating analysis into an autoethnographic study may require the researcher to write in an authoritative voice about the patterns that she/he discovers, which could detract from the stories being presented” (Ellis & Bochner, p. 758). By adopting a more constructivist, contingent approach, I mitigate the authoritative tensions that arise in analyzing and presenting my data. I use thematic analysis as a flexible, heuristic strategy rather than as a formulaic set of outcomes-oriented procedures (Pace, p. 9/10).

***Emotional labour***

“What kind of tale will I choose to tell, and in what voice? How do [I]

inscribe difference without bursting into a series of euphoric, narcissistic accounts of [my]self and [my] own kind? Without indulging in a marketable romanticism or in a naïve whining about [my] condition?” (Razack, 1993, p. 67). Undoubtedly, some might criticize my research as being self-indulgent or narcissistic, “though such critiques often ignore the dialogic relationship of self and culture — the *I* and *we* — that autoethnographers emphasize when making themselves vulnerable by making personal experiences available for consideration” (Jones *et al*, p. 24). Since autoethnography requires disclosure and performance of the self, as well as an in-depth emotional engagement in/with one’s own experience, I face emotional and representational tensions with respect to the telling of my story of living with HIV/AIDS.

Perhaps the greatest challenge facing researchers is not about [successfully managing emotional labour], but about recognizing that emotions have epistemological significance. Being emotional is a way of knowing about, and acting in, the social world and is just as significant for how we make sense of our experiences as our cognitive skills. By acknowledging the role of emotionally-sensed knowledge in our research, we may be able to further our understandings of the social world. (Hubbard *et al*, p. 135)

**Implications of my research**

I hope that narrating my experience of living with HIV/AIDS, through this research process, might be useful in illuminating some of the socio-cultural changes, challenges and complexities of living with HIV/AIDS, including shifting social discourses and relations. As the researcher-as-subject, the possibility of transformative justice (Freire, 2000), the chance to understand my experience more critically and to re-search what was and who/how I was with respect to HIV/AIDS, in contrast to what is and who/how I am now, is one of the empowering, possible implications of my study. For the benefit of other PHAs, queer or not, I also hope that my study helps to discursively engage our cultural and social rights (e.g. freedom from HIV stigma) and to amplify possibilities for reimagining social action and social justice with respect to living with HIV/AIDS.

#

**Section I: Pre-infection**

**1**

**Decolonizing Me:**

***ACTing UP against AIDS***

Sooner or later, everyone is a wounded storyteller. In postmodern times, that identity is our promise and responsibility, our calamity and dignity.

— Frank, 1995, p. xiii

**1987**

Long before I became infected with HIV, during my early twenties, I was already living with AIDS. Before coming out as gay, I believed naively in a yellow brick road of self-determination and freedom that would lead me proudly and unequivocally out of the closet. Finally, I would be unencumbered, happy, whole and able to live my life authentically. When I came out, however, I turned one set of challenges to discover another, a different set of stigmas, the door to another, more insidious closet…. With each (dis)orienting turn, I came out, and went back in, my closet equipped with a reflective, revolving door, the infinite spin of self-images that came out, went back. In. AIDS pulling me out, pushing me back. In.

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Now Jamie has KS[[5]](#footnote-5). The cancer is spreading to his rectum. Another larger, purple lesion is flowering on his back. Jamie is my boyfriend. He is 23, and he is dying (although we choose to say he is *living*). He can barely sit from the post-radiation soreness when I pick him up at the Montreal General in my black, freshly-waxed Bug, shining like an eight-ball in the late morning sun. Behind the wheel, my body is anxious and vigilant, and I have no clear idea where we are going, Jamie and I, except that the place, our lives, will undoubtedly be colonized by HIV. In loving Jamie, I begin to understand that AIDS represents an even darker, more claustrophobic closet inside my queer closet, and that, for me, emerging from the latter necessarily involves emerging from the former.

 “How’d the test go?” I ask, speeding onto the highway.

 “Fine,” Jamie replies in typical denial fashion, rolling down the window for some fresh air. The station wagon in the next lane is packed with pillows, suitcases, hysterical kids waving. One makes fish lips at us against the glass. “The doctor said I’m fine. Forget sex for a while. But I’m fine.”

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Since the beginning of the North American pandemic in the early 1980s, socio-cultural responses to HIV/AIDS have been mired in stigma, prejudice and discrimination, particularly with respect to gay men (Cain, 2002, p. 94). These responses are significantly intensified in the context of marginalization; HIV/AIDS magnifies the effect of oppressive social relations such as heterosexism. Thus, the deepest meaning of Jamie’s AIDS, his dis-ease, is not medical but socio-cultural (Stiker, 1999, p. 152). “Bodies marked as deviant [e.g. HIV-positive] provide an opportunity to solidify other social actors’ beliefs in their own moral goodness and proximity to normative ideals” (Mitchell & Snyder, 2006, p. 38).

**~**

One morning after ‘safer’, unsuccessful sex, Jamie says wistfully to me, “You can’t have everything in a relationship, Brick.” It is becoming clear that he is dissatisfied with our sex life. Since I am HIV-negative, sex with me, the possibilities for connection and pleasure, are limited for Jamie. Indeed, for both of us; our sex acts require constraint, caution and condoms.

With my closest, gay friend, Martin, I disclose, after too much wine, that, increasingly, Jamie wants to fuck me without a condom. I confess that it has already happened.

“He’s getting tired of condoms,” I explain, defending him. “Wouldn’t you? He’s been infected since he was 17.” Martin, who is working to establish an ACT UP chapter in Montreal, is sympathetic, yet somehow deftly manages to lecture me about ‘safer’ sex, all the while casting Jamie’s sexual desires as unrealistic and selfish, if not on the verge of being abusive.

“Just use condoms,” Martin tells me. “Please. You’re flirting with death.”

Whatever the sexual risks, dilemmas and discordances, three months after meeting Jamie, we decide to live together. I love him; besides, he needs someone to take care of him, completely estranged from anyone that he once called family.

Jamie and I are both students at McGill with a lot of debt and very little income. Our voices echo through our newly rented, empty apartment above the fish market on St. Lawrence Boulevard. The landlord was right — it has potential, a lot of potential, but not much else. It’s a roach-infested dive, but Jamie is insistent on fixing it up. “Projects keep my mind off things,” he explains. *Things*: AIDS, sickness, our pain, his death. He has already thoroughly scraped the thick coat of black paint off the bathroom window. Now he wants to strip the wooden toilet seat, its floral wallpaper stained by years of splashing use.

“A wooden toilet seat,” he insists, “will give the place a rustic feel.” He stands beside the toilet in the cramped bathroom, shirtless, sweating profusely. Every day, I try not to lament the gradual withering away of Jamie’s gorgeous, youthful body.

 “You’ll do all that work just to find some kind of cheap, fake wood. Look at this place, Jamie. It was hardly built with an appreciation for quality,” I argue, attempting in vain (as always) to convince him, taking a seat on the edge of the claw-footed tub. I dare not ask, “Besides, are you well enough to be doing this?” I watch the muscles in his swimmer’s back, finely-tuned machinery in motion, shifting and tighten beneath his pale, troubled skin. “Why don’t you join ACT UP if you want to take your mind off things?” I suggest gently. “Martin says they’re looking for members.”

 “Great. I’ll be the Rosa Parks of AIDS. And then my life will finally be worth something.” It’s been nearly a month since we moved in; my patience to deal with another mess, especially in the bathroom is beginning to evade me. Fuzzy, dried glue sticks to the toilet seat as Jamie carefully peels away the first shred of wallpaper. “Disgusting,” he says dramatically, holding it up for an imaginary audience. Is he worried about what the doctor said? He’s *not* fine, and we both know it.

He’s dying. *Living*. With silence, with AIDS. He’s living. “If [he’s] dying from anything, [he’s] dying from the fact that not enough rich, white, heterosexual men have gotten AIDS for anybody to give a shit” (Russo, 1989).

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In 1987 — six long years into the AIDS crisis and with thousands of people already dead, mainly gay men — American President Ronald Reagan finally acknowledged the toll that HIV/AIDS was taking on the U.S.A. and other nations, crafting his speech to morally condemn those who were sick, dying and incurable, which included Jamie: “After all,” Reagan declared, “when it comes to preventing AIDS, don’t medicine and morality teach the same lessons?” (ACT UP NY website). “There are moments in social time when people will respond on a gut level” (Kramer, 2007), and 1987 was one of them. In March of that year, the **A**IDS **C**oalition **T**o **U**nleash **P**ower (ACT UP) emerged as a popular action initiative in New York City. It eventually became a major force in influencing social program and policy responses to HIV/AIDS, not just in the United States, but in Canada and parts of Europe also.

ACT UP, from its grassroots beginnings, successfully changed the course of the HIV/AIDS pandemic. It was also very important to me as a gay man with respect to the development of my gay identity, particularly with respect to my queer, political sensibility and community connections. Alinksy’s *Rules for Radicals* (1971) illuminates how ACT UP’s popular action strategies engendered my personal development as a queer man, as well as social change with respect to HIV/AIDS. In this chapter of my autoethnography, I turn directly to Alinsky in order to:

* describe the historical and socio-cultural context in which ACT UP emerged as a community-based organization in 1987.
* explore the purpose of ACT UP, including descriptions of its membership and civil disobedience tactics.
* illustrate how ACT UP was important from a social perspective and from my perspective as a gay man.

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I am on a ladder in the dining room of our apartment, hanging a chandelier, another of Jamie’s antique store discoveries, when he enters the room and turns on the TV, flipping the channels, looking for the news. A scandalous secret exposed; Liberace has died of AIDS. “Ah damn, I won’t be the biggest queen to die from this thing, after all,” Jamie laments, mocking his own showy proclivities. “I guess there’s nothing left to live for. Except you, my dawwwling lover. Or ACT UP maybe? Of course, you were right,” he interjects. “There’s no grain in the toilet seat. Looks like pressed wood.” I shoot him the told-you-so look, and he instantly channels Liberace, throwing an imaginary fur boa over his neck as he exits the stage in one, grand stride, the piano strings still quivering in his wake.

The grandest exit. Death. Waiting in the wings.

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On October 11, 1987, I travelled to Washington D.C. to participate in the first ever national march for gay and lesbian rights. Nearly one million people flooded the American capital. In loud, proud visibility, queer people (and our supporters) from around the world marched to demonstrate against homophobia and heterosexism, as well as to celebrate sexual differences and freedoms.

Cultural discourse envelops me: rainbow flags appearing on windows, t-shirts and body parts; dance beats pumping loudly in ways that stress celebration; and parade goers yelling provocatively and flirtatiously to scantily dressed and dancing go-go boys on floats for nightclubs, or with stirring applause for Parents, Family and Friends of Lesbians and Gays (PFLAG), or with jeers and laughs at drag queens dressed as rightwing Republicans. (Berry, 2013, p. 215)

We also marched to demonstrate our outrage at the horrific impacts of HIV/AIDS on queer communities and to give political voice to people living with HIV/AIDS (PHAs). For me (and many others), the political rally was a significant event for many reasons, not the least of which was the inaugural showing of the *Names Project* or, as it is more commonly known, the AIDS Memorial quilt. It was also my introduction to ACT UP in the flesh. “ACT UP! FIGHT BACK! STOP AIDS!” Thousands of fearless, pissed-off gay men, up-in-muscular-arms, something I had never experienced before, so unlike the lonely, silent secret of Jamie’s AIDS: their politicization so sexy and alluring, so inspiring and empowering.

As I participate in these activities — helping craft the “intrinsic products” in Gay Pride poiesis — I experiment with cultural practices and meanings and begin appropriating some of them into my life. Over time these experiences allow for related ways of performing as a gay man. I come to understand myself as living with celebratory, frustrated, appreciative, scared, and political selves—complex and reflexive “extrinsic results” of poiesis. (Berry, 2013, p. 215)

After marching through the American capital, I paused for a moment of reflection beneath the Washington monument, where the AIDS Memorial quilt was solemnly on display. Death = Silence. By October in 1987, Jamie was dead. Silenced. Several close friends, young queer men in their early 20s, were frighteningly ill and dying. A heavy, raw grief hung over the quilt, a collective fog that absorbed my own multiplying shock and loss.

Thousands of loved ones had gathered, holding vigil in the cold, light rain. The discernable emptiness of that enormous tragedy reverberated from our hearts. Most people were staring down at the ground without words, strangers standing arm-in-arm, sharing umbrellas, offering a Kleenex for another person’s tears. A community deeply shaped by the tragedy that was still unfolding at our feet, a story of unrelenting, multiple loss that had no defined beginning or end. It was, for me, an inevitable story, where I sadly but proudly belonged as one who would remember and recount it.

The hundreds of sections of the quilt were laid out in rows on the wet ground: Eric, Kalpesh, Ken, Mark, Bernie, Steve…. Sacred, unearthed treasures from a mythical time before HIV colonized vulnerable bodies, each section carefully assembled by loved ones, representing another story of traumatic loss. Another life prematurely extinguished. Jamie’s story was there amongst them, but still un-narrated inside my pit of grief. Here, assembled together, their stories represented the cultural images and memories through which I would construct the meanings of my life a gay man living with HIV/AIDS.

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In the middle of the night, Jamie’s dream awakens both of us, his tortured crying out for help, a shark devouring him, his mouth gasping at the thick, humid air in our apartment, unable to breathe, our cat startled and pacing as trucks resume their busy commerce on St. Lawrence Boulevard — the delivery of apples, orchids, fish — against what is increasingly borrowed time.

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“Just as political and economic colonialism took over geographic areas, modernist medicine claimed the body of its [HIV-positive] patient as its territory” (Frank, 1995, p. 10). In response, ACT UP deployed empowering discourses with respect to how PHAs (as well as their communities) could respond to the medicalization of HIV-infected bodies by encouraging a focus on living vs. dying, stressing activism vs. victimization, fostering the identity of angry citizen vs. ‘patient’, promoting responsible sex vs. abstinence and creating solidarity vs. self-isolation. Such discursive practices helped to decolonize the bodies and identities of PHAs and, in doing so, disrupted the oppression precipitated by HIV/AIDS phobia (both inside and outside queer communities). ACT UP fostered critically reflexive and, ultimately, productive discourses that, amongst other benefits, increased community awareness of “[PHAs] as unjustly mired within their own dehumanizing, subjective and aesthetic classifications” (Mitchell & Snyder, 2002, p. 83), internalized from the broader socio-cultural context of heterosexism, racism, sexism and other forms of oppression. It demonstrated, for me, that being part of community activism empowers people to reject classifications such as ‘promiscuous homosexual’, which is what Jamie’s father had once called him, and to replace them with self-determined, resilient identities (Lee, p. 80).

ACT UP understood that without access to representations of HIV-positive bodies as variable and vulnerable, as well as equal and powerful, the AIDS crisis would continue to “obscure the necessary demand that communities can and do accommodate multiplicity in the body politic” (Mitchell & Snyder, 2006, p. 38). ACT UP expended tremendous energy in dealing with the cultural trauma surrounding HIV/AIDS, including rampant discrimination and multiple losses, where “no aspect of life or identity was unaffected…. There was a loss of community, and there was no safe haven” (Marion, 1996, pp 65/6). Without ACT UP, early socio-cultural responses to HIV/AIDS might have shifted, even further, “from a relatively benign formula, the interdependency of human lives in one’s immediate community, to one of moral and community judgment” (Mitchell & Snyder, pp. 35/36).

“Community life, thus, reflects and is partly shaped by the energy expended from dealing with the trauma that it has experienced” (Lee, 2011, p. 78). To address this trauma, a group of gay men living with HIV/AIDS in New York City urgently established ACT UP: “a diverse, nonpartisan group of individuals united in anger and committed to direct action to end the AIDS crisis” (ACT UP NY website). ACT UP’s primary purpose was to end the AIDS crisis, recognizing that civil disobedience was required to overcome government indifference as well as to challenge the stigmatizing media representations of PHAs. Over the next several years, queer communities established ACT UP chapters in numerous, North American cities, including Montreal, where I was a member from 1988 to 1990 when I needed activism to honour Jamie’s life. His death. My own living body where his never had the power. ACTing UP against AIDS.

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Jamie lies beside me on a futon on the floor of our sparsely furnished apartment. Wide awake again, both of us. The version of awake that feeds his fear and trembling. The smell of yesterday’s fish rotting in the market below us. A wedge of street light from St. Lawrence Boulevard falls across Jamie’s body, curled up and naked against me, breath warm and peaceful. A transport truck rumbles by in the street, and the whole apartment shakes. Jamie opens his eyes, releases a startled sound from his body. Moving his hand into the light.

“I’m bleeding,” he says. “Be careful.” He arches, bent against a planet’s gravity, his blood semiotic, a re-inscripted DNA unraveling, its long twisted strands encoding the infinite syllables of our calamity.

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ACT UP “stressed problems of mobilization, the manufacture of discontent and tactical choices” (McCarthy & Zald, 1997, p. 1212). In its inception, it was almost exclusively a gay, youth organization, with significant ties to LGBTQ communities. This community focus, coupled with an emphasis on identity politics (Cain, p. 97), reflected the recommendation that activists “not go outside the experience of [their] people” (Alinsky, 1971). ACT UP “brought a queer sensibility, a certain sartorial splendor, to every action it did. In doing so, [it] transformed the way activism was conducted” (Shepard & Haydak, 2002, p. 12). ACT UP was a protest movement with a penchant for drama, actualized through the aspirations and courage of the people who were most affected by HIV/AIDS, namely young, urban, gay men in their 20s and 30s. For Jamie, after the experience of his horrific death, I became one of them. In joining ACT UP, I sought to replace fear and ignorance with peer support and education, advancing the struggle for queer rights through an organized resistance to the HIV/AIDS pandemic.

For queer men, for Jamie, homophobic silence, in a real, visceral sense, *did* equal death. By 1987, the lives of thousands of gay men in North America had already been lost, at least partially due to government indifferences and public health incompetencies. ACT UP brilliantly conveyed the urgency for effective, social responses through a widespread distribution of its iconic slogan, *Silence = Death*. In its political semantics, this slogan was culturally resonant and extremely persuasive, linking ACT UP to struggles against other ‘silences’ that perpetuated grave, historical transgressions of human rights (e.g. Nazi holocaust, South African apartheid, etc). As a symbol of queer resistance, wearing an ACT UP t-shirt, with *Silence = Death* emblazoned across the front, those words superimposed over a proud, pink triangle, “became a direct link to social or individual action” (Denton, 1980, p. 10). But what did *Silence = Death* mean in terms of social injustice?

In 1987, AIDS medical research was still severely under-funded. A drastic lack of funding continued throughout the years of Ronald Reagan’s administration, sacrificing valuable time with respect to the research and development of HIV anti-retrovirals. In selecting Reagan as the focus of its virulent attacks, ACT UP was able to “pick the target, then freeze it; make it personal and polarized” (Alinsky, 1971). ACT UP understood that it is far less effective to attack abstract corporations or bureaucracies. Instead, it identified the American President as its ‘target’ and avoided protests that shifted or spread the blame. In case Reagan were to say, *Okay ACT UP, tell me what to do*, its members were prepared; ACT UP had “an alternative in mind in case the target [came to it]” (Alinsky, 1971), namely the establishment of an ‘AIDS czar’ in the federal government, an idea that was eventually adopted in 1993 as a result of ACT UP’s persistent, damaging focus on the American President.

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Jamie has not said a word since we got into the car, and neither have I. Silence again. We are speeding fast for the hospital; he is bleeding badly from his ass. I pull up behind an ambulance at the emergency entrance, and my tears start rolling. I turn off the lights but keep the motor running. We sit there for a long, unreal moment. “Well, are we going in?” he asks sarcastically. “Don’t you realize that bleeding to death is the slowest, most excruciating way to die?”

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ACT UP empowered its members through bold, civil disobedience tactics, understanding that “power isn’t what you have, but what the other side thinks you have” (Alinsky, 1971). Since ACT UP was (originally) a small, grassroots organization, its power was directly proportional to how great a social disruption it could create, how much it could get noticed. By selecting key targets, ACT UP’s power increased enormously with each disruption of a powerful, institutional sphere. The Catholic Church. Wall Street. The White House. On several occasions, the organization conducted mass *sit-in*s, where several hundred people occupied Wall Street, blocking traffic for hours in order to protest the high cost of HIV/AIDS drugs, as well as the lack of corporate and government investment in HIV-related pharmaceutical research.

 In *Rules for Radicals*, Alinsky (1971) encourages activists to “go outside the experience of the target whenever possible”. ACT UP did so, brilliantly, in 1989 when they staged a mass *die-in* at St. Patrick’s Cathedral (deemed ‘Stop the Church’) in order to protest the anti-gay, anti-condom teachings of (then) Cardinal O’Connor, understanding that “ridicule is potent” (Alinsky, 1971). ‘Stop the Church’ effectively ridiculed a powerful, religious figure, which garnered enormous media coverage for ACT UP. In addition, the protest “force[d] the target [i.e. Cardinal O’Connor] to live by [his] own rules” (Alinsky, 1971) with respect to Catholic values and beliefs regarding compassion and human, redemptive suffering. The pervasive legacy of homophobia in organized religion only served to magnify the legitimacy of ACT UP’s demand for compassionate responses to queer men living with HIV/AIDS. Yet, to characterize ACT UP as primarily anti-Catholic or anti-religious confuses its central purpose; ACT UP activists were, first and foremost, seeking to protect exceedingly vulnerable bodies from the pervasive stigma and discrimination that continue, to this day, to fuel the HIV/AIDS pandemic.

In its most influential years (from 1987 to 1991), ACT UP deployed a range of actions to “keep applying pressure” for the development of effective HIV treatments (if not a cure), recognizing that “a good tactic is enjoyable, and one that drags on is not good” (Alinsky, 1971). In 1991, at the height of the Gulf War, several ACT UP protesters infiltrated CBS television studios and disrupted the live, evening news, chanting “Fight AIDS, not Arabs” as millions of North Americans watched. ACT UP also frequently organized festive, party-like protests that disrupted large, public spaces such as Grand Central Station in New York City, where members once released thousands of pink balloons and created a deafening raucous with horns and whistles. Jamie would have relished it. Such outrageous actions brought immediate, public attention to both ACT UP’s cause, as well as the strength and magnitude of its numbers, both living and dead.

In its tactics, ACT UP was resourceful, innovative and versatile. It was in-touch with its time, engaging controversial issues (e.g. the Gulf War) and media savvy to create the threat of a greater disruption and civil unrest. ACT UP understood that “a threat is worse than the actual experience” (Alinsky, 1971). Accordingly, its members tapped into an anxiety in the body politic about the potential threats posed by a burgeoning HIV/AIDS pandemic, including more death and suffering both inside and outside queer communities. ACT UP frequently threatened to occupy the offices of the Federal Drug Administration to protest its mis-handling of HIV-related pharmaceutical matters. Indeed, the American government (and other governments) eventually responded to ACT UP’s threats because its members were increasingly perceived as dangerous radicals who were willing to get arrested to advance their cause.

The legacy of ACT UP was to show that queer people, including PHAs, could have significant power and influence when we organize and act collectively. “The period from 1987 to 1991 was one of the great peak moments in gay history of togetherness, power, achievement, and ability to work together, men *and* women” (Kramer, 2007). Amongst its many, significant accomplishments, ACT UP advanced the notion that health care is (or ought to be) a universal, human right. Its actions increased progress with respect to the development of effective treatments, which were finally introduced in 1995, transforming HIV from a ‘death sentence’ to a ‘chronic manageable illness’. ACT UP was also highly successful at changing how HIV/AIDS was represented in the North American media: how it was discussed, how it was constructed, how it was reported (Crimp, 1990). The result was a positive, socio-cultural shift in the representation of PHAs toward a more empowering, community-oriented identity, which ultimately benefited me as a gay man. Unfortunately, that shift occurred after the time of Jamie’s illness and death, at a time when HIV-positive bodies and identities could be decolonized through activism. Moreover, the shift was neither permanent nor incontestable, as is witnessed by the contemporary labeling of PHAs with criminal identities, a topic which I will address further in chapter 5 of this autoethnography.

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At night, a nurse raises the bars on Jamie’s hospital bed, which is where he dies after two, excruciating weeks in hospital. He never joins ACT UP. He never comes back to our stifling, empty apartment above the fish market. His projects remain unfinished. His voice no longer echoes.

His family places a cross in Jamie’s right hand, and it is rested solemnly across his heart. My atheist, left-handed, queer boyfriend, perfectly made up by a mortician for heavenly gates. Such delicious irony. It is my first AIDS funeral, although key indicators are never actually uttered in any meaningful way, let alone in a way that might bring respect or dignity for Jamie: *gay*, *stigma*, *AIDS*, *a test of our times*…. Just paper-thin, moralistic words from ancient, Biblical scriptures. Jamie’s religious parents chose to make it a private, “family only” funeral, partially (I suspect) as a strategy to maintain the secrecy surrounding Jamie’s AIDS, and as a way to exclude his queer friends. I am the sole, invited exception, but only because they “feel bad” that I was the one who had to clean their son’s ass in his final days.

A stylish woman in spiked heels — Jamie’s third cousin from Kingston, I overhear — wipes away her quiet tears. “James looks so peaceful now,” she whispers to me. In the lounge area, seemingly bored, male relatives in long, skinny ties argue over bitter coffee about the latest hockey scores and complain about the high cost of living. Several, blue-tinged aunts huddle together near the coffin, counting the numerous, mundane, floral arrangements: carnations, mums, the sad, unopened roses. Jamie’s aunts speculate about which relative might have sent the arrangement with the spectacular, tropical flowers. They are birds of paradise, and they are from me.

When I can take no more, I lean into the coffin and kiss his silent, powdered lips. James. Jamie. Gone. To a different paradise.

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What caused ACT UP to lose its power and momentum after 1991? (Today, only a few ACT UP chapters residually exist, mainly in American cities such as New York and San Francisco, where there are large, highly visible, queer communities.) In the 1990s, as ACT UP began to address the structural inequities that intersect with HIV/AIDS, its mission became more complex and unmanageable; meanwhile, its most active members were experiencing activist burnout (Crimp, 2011). Systemic oppression (such as poverty and racism) was not as easy to target and attack as a homophobic American President. Moreover, the advent of highly active anti-retroviral therapy in 1996 effectively undermined the urgency of HIV treatment activism.

Ultimately, a major weakness in ACT UP’s capacity to sustain queer activism was that it tended to “view each problem of the community (i.e. HIV/AIDS) as if it were independent of all other problems” (Alinsky, 1941, p. 747), particularly poverty and racism. In the 1980s, ACT UP’s members could more easily suspend critical analysis regarding the structural problems associated with HIV/AIDS and think myopically (or strategically) about what PHAs were confronting with respect to life-and-death matters such as the drug approval process for new treatments, or the fact that Reagan had not yet publicly uttered the word ‘AIDS’. Reagan’s omission was not only a mistake of discourse, however. It represented a government’s gross underestimation (or neglect) of the structural conditions that converged to fuel the pandemic. Nevertheless, to “use others’ mistakes for your benefit” (Alinsky, 1971), to attack Reagan’s obvious, ill-fated omission, was easier for ACT UP to execute than to take on the complex, structural injustices of a relatively new, burgeoning pandemic.

In its Alinsky-esque tactics, ACT UP worked extremely well for approximately five years, but its political energy was eventually unsustainable. Nevertheless, one of its many significant achievements was the *queering* of politics (Crimp, 1990), which was instrumental to the later pursuit of LGBT human and civil rights such as same-sex marriage. ACT UP illustrated how “new technologies (e.g. the mass media), together with new political identities (e.g. queer), created new methods of organizing (e.g. die-in), and new populations (e.g. PHAs) demanding freedom” (Rofes, 2002, p. xii). In this regard, ACT UP’s legacy reflects a central theme in Alinsky’s work, highlighting “political participation and the goal of broadening community participation in system-wide decision making” (Reitzes & Reitzes, 1980). The success of ACT UP illuminates the importance (particularly in the context of hegemonic neo-liberalism) of an organizing approach aimed at building community through the restoration of political identities: restoring a practice of community activism in which identity matters, and in which the construction of new identities (e.g. PHAs) builds rather than divides queer communities.

The resolve, self-esteem and hope that I gained from being a member of ACT UP were invaluable to my well-being as a gay man, including the maintenance of my sero-negativity and my mental health, particularly in the years after Jamie died. Even for gay men (such as me) who were not infected during the 1980s, it was life-affirming to protest in solidarity and to challenge the stigma and discrimination that exacerbated the toll of HIV/AIDS. There was an excitement to participating in ACT UP’s demonstrations, a sense of catharsis, belonging, relief, collective strength and pride, a *coming-into* being queer at a social time that remains profoundly meaningful to me, especially now that I am HIV-positive.

Rather than being exclusively oppressive, certain social discourses on HIV/AIDS (e.g. Reagan’s public blaming) fostered empowered queer subjectivities because they played “a tactical role in a transformation into discourse, a technology of power and a will to knowledge” (Foucault, 1990, p. 12). Institutional discourses represented, for ACT UP, a grand mechanism of reducing the rights and freedoms of PHAs, literally a collective ‘no’ to their lives and bodies as equal citizens. At the same time, such discourses also engendered personal transformations that politically subverted that ‘no’. For me, protesting with ACT UP engendered a ‘transformative justice’ (Friere, 2000), from which I could hear my voice as a gay man, alongside Jamie’s (although he was dead), powerfully in articulation of our experiences of living with HIV/AIDS. Above all, the experience of ACTing UP, in my life, provided an enduring political awareness through which I could link my voice to my body.

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For months after Jamie dies, I blame him for what happened to him. To us. Death is not proud. I imagine the virus escaping a stranger’s body, someone he casually fucked at a bathhouse, slithering quietly into his vulnerable blood, and into our lives forever as gay men, searching for a new host to colonize. Even as a baby, his parents called him James, but he preferred Jamie because, he said, it kept him young. Was he afraid of death? We both were, especially if it meant dying alone. In a bed with bars. With nothing to follow this kangaroo court we called *living*.

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I lean over the bars to kiss him again as he slips into the night, waves lapping at the hospital bed that transports his colonized body. On a distant shore, a boy splashes naked through the waves, the moon sliding down his back. Radiant: borne of a sea that draws its depth from the infinite, surrounding star. He calls, but Jamie doesn’t go. Instead, my boyfriend’s body rests in the sturdy dingy at the water’s edge, waiting for the tide to go. Out.

**2**

**(Un)balancing on a Tightrope:**

***falling from HIV/AIDS community service***

Not that I wasn’t grateful for the journey, energized even, but this was the trip that would always bear an asterisk, proof that I couldn’t leave AIDS behind.

— Monette, 1994, p. 184

**2002**

Conflict seems to permeate much of the work of AIDS organizations across the country. Internal conflicts often appear in similar patterns: the removal and resignation of board members, labor-management strife leading to the unionization of staff members, and antagonism between men and women, staff members and volunteers, HIV-positive and HIV-negative members, and gay and non-gay workers. Staff and board members may not trust each other. Staff complain that board members are out of touch with the realities of their work or that board members interfere. For their part, board members complain that staff lack the skills, interest, maturity or background they require to complete the jobs for which they were hired. Support and education workers fight among themselves, complaining that others do not understand their jobs and the pressures they face. Many groups experience a frequent turnover of staff, volunteers and board members, and recurring periods of crisis and instability, which are due, in part, to the angry organizational climate. (Cain, 2002, p. 94)

In 2002, desperate to escape such an environment, I jumped off a tightrope, quitting my job at the local AIDS service organization (ASO), exhausted and demoralized, the tensions of HIV/AIDS community service whirling forever behind me, or so I thought, as if I could ever really fall away. In body, at least, I could choose to fall because there was finally less at stake; I still identified, proudly, as HIV-negative, and the pandemic seemed increasingly under control. People were actually now *living* with HIV. Jamie, along with numerous friends, were buried peacefully in my memory. After a decade of progressive management experience in ASOs, I would land nimbly on my feet. At least, in falling, there existed the promise of some ground beneath me, however uncertain, a different place that might not be (as) colonized by HIV. And so I jumped…. A contingent freedom, but no longer that constant pressure between the tightrope and my aching, blistered feet, my sense of purpose as a gay man in fast, free-falling abandon.

**~**

On the last day of my work in ASOs, at one o’clock in the morning, unable to sleep, I watch Rayne glide through the water, back and forth, from one end of my pool to the other, the moon’s light shimmering in his wake.

 “How many lengths?” I ask as he gets out of the pool, stretching out his long, muscular arms, which remind me of Jamie’s.

 “I lost count,” he replies. “It’s those stupid pills. My brain gets distracted.”

 “Beautiful night for a swim,” I say, scanning the clear, star-littered sky, half the moon’s face beaming.

 “It’s too quiet,” Rayne observes. Lately, whenever he can’t sleep, he jumps the fence between his mother’s yard and mine to go for a swim in my pool. Since submitting my resignation, I have been dogged by self-doubt and a feral insomnia. Rayne is sexy, welcome company.

 “Would you like a towel?” I ask.

 Rayne looks me straight in the eye and doesn’t move for a moment. A startled animal in a cage. “Will it hurt my body?” By now, I am accustomed to Rayne’s unpredictable, unusual questions. I hold his gaze, as close and disarming as it is, hundreds of nocturnal lilies permeating my backyard with the acrid punch of citrus.

 “No, it won’t. You’re shivering a little, Rayne. Just thought you might want to dry off.”

 “Are you inviting me in, Mr. Fix-It?”

 At first, I hesitate. Rayne has never called me that before. *Mr. Fix-It*?

 “It would be my pleasure,” I answer. “Although I do have to work in the morning. My last day as Executive Director. Hard to believe.” That is our routine. I ask Rayne if he would like a towel, and Rayne asks to be invited in. The rest unfolds on my living room sofa.

**~**

“Worker fatigue or burnout is an all too common experience in all forms of social helping or solidarity work” (Lee, 2011, p. 266). After ten years of navigating the neo-liberal fog that was engulfing ASOs, I realized how perilously high and unstable my tightrope was, and how much that fog had invisibly penetrated not only my sense of community service but also my subjectivity as a gay man. Balancing on the ASO tightrope, for as long as I ‘managed’ to do so, represented intense oppositional identity work (Aronson & Smith, 2011), a mutually reinforcing interplay of social justice aspirations and resistant behaviours (Carey & Foster, 2011): of reflexive and practical opposition. From 1992 to 2002, I worked in ASOs, managing a range of programs that included volunteer resources, support services and education/prevention projects. In this work, balancing the longer-term work of social justice with the delivery of services to people in dire need was a constant, structured tension (Cain, 2002, p. 108). Eventually, blisters notwithstanding, my purposeful and steady feet led me to an Executive Director (ED) position on the tightrope, a spot where the tension of the tightrope was at its greatest, and where the new managerial winds blew most fiercely.

At that time, with heightened cost control efforts in health care and the cutback of hospital and homecare services (Gustafson, 2000), PHAs (and their caregivers) were scrambling to find services. As ED, I struggled with how to take the need, anger and diversity of marginalized people most affected by HIV/AIDS (i.e. queer men, indigenous people, injection drug users, etc.) and shape them into ‘effective’ services (Cain, 2002, p. 111). Neo-liberalism translated ‘effective’ as *efficiency*, *accountability* and *measurable outcomes*: obtuse, foreign words that rolled reluctantly off my former, activist tongue. In my struggle to implement ‘effective’, oppositional identity work was central to my anti-bureaucratic, social justice stance. In such a stance, I could still articulate community goals, establish alternative, organizational structures, politicize PHAs, and the like (*ibid*, p. 108).

Over the course of ten years, my work in ASOs led me from the frontlines of support and education work to a performative, managerial position, where my political voice was muted (if not irrelevant) and ‘accountability’ referred more to government funders (and, by extension, taxpayers) than to Jamie or any of the other people colonized by HIV/AIDS. The identity politics that were central in developing ASOs (as well as my own work therein) became increasingly problematic as I attempted to articulate neo-liberal goals such as ‘accountability’ and ‘quality’ of service, Lurching and swaying on the tightrope, I finally released my body. And fell. Jumped.

 I am narrating my (un)balance on that tightrope, connecting it with my story about Rayne, in order to illustrate the importance of identity politics to my personal and professional trajectories, ideally so that my story might illuminate broader forces of social marginalization and privilege that constitute not only the (un)balancing act of ‘managing’ an ASO, but “the dangers of contradictory positioning and strained performances of self” (Aronson & Smith, p. 446) with respect to how one falls. First, I explain the political reasons and organizational context of my tightrope fall. Next, I re-search my steps across the tightrope in order to “explicate the ruling relations” (Campbell & Gregor, 2002, p. 60) underlying them. In doing so, I attempt to make visible, for analysis, my “struggle with [my] divided identities in pursuit of progressive goals” (Aronson & Smith, p. 446), a queer, discursive resistance that, today, both divides and joins together my subjectivities as a gay man, a PHA, a social worker, a manager….

Specifically, I explore how neo-liberalism transformed ASOs from grassroots, community-based organizations to largely de-politicized social service agencies (Cain, 1997, p. 342). Throughout my exploration, I consider whose interests were served, whose were subordinated, and in what ways the tightrope limited the way forward for ASOs. I conclude by suggesting how my story of (un)balancing on the tightrope is relevant with respect to understanding current management challenges in ASOs. I also consider how my eventual fall from HIV/AIDS community service illuminates a need for models of practice in ASOs that can ‘effectively’ engage new managerialism while maintaining social justice pursuits.

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Nancy, Rayne’s mother, drinks alone in the evenings and needs someone to talk to, a confidant.

 “You’re such a good listener, Brick” she tells me. “Must be because you work with AIDS patients.” During one of our Saturday morning chats across the fence that divides our backyards, she cautions me about Rayne. Apparently, he is becoming aggressive and “talking nonsense” a lot. Last week, he was expelled from university for throwing a textbook at his professor, whose nose and glasses were broken as a result. “I’m just not sure what to do,” Nancy says. “I feel helpless.” She is raising Rayne as a single mother. “I’m becoming afraid of my own son. Or his condition, I should say.” That is all that she could bear to call it: his *condition*. Schizophrenia sounded threatening and permanent. Stigmatizing too, like AIDS.

I fear that Nancy might discover what is going on and accuse me of taking advantage of her 20 year-old, mentally unstable son. How could I? It seems possible that the stress of resigning my position at the ASO, accompanied by my dizzying fall into career uncertainty, is producing my own insanity. Five years after Jamie died, I finally said farewell to our apartment above the fish market in Montreal and landed here, far away in this small city in southern Ontario, where my work at the local ASO would provide an uncomplicated, meaningful life, complete with a pool and a garden of wildflowers. And then the organization imploded, and Rayne started jumping my fence.

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**Part I: Political reasons & Organizational context**

Political reasons

Long before I became infected with HIV, I was *living* with HIV/AIDS. HIV has shaped (and is still shaping) my identities as both queer and social worker, giving increased significance to political imperatives such as social justice and human rights. In the mid-80s, I came out amidst a storm of hysteria, prejudice and fear regarding a deadly, new plague. *GRID*. **G**ay **R**elated **I**mmune **D**eficiency syndrome, the name first used. Already, the storm was justifying new hooks for institutional scrutiny (e.g. ‘risk’ discourse) in matters of queer sexuality. Homophobia, whipped up by a highly stigmatized virus, reinforced stereotypical, institutional perspectives of gay men as ‘sick’, ‘promiscuous’ or ‘deviant’. Years later, Jamie and many other, queer friends would be dead from that lethal combination of heterosexism and viral infection. Eric, Kalpesh, Ken, Mark, Bernie, Steve… All the while, my vulnerable body braced against the gathering hurricane, fearing for my own precarious ‘safety’.

My interests in community HIV/AIDS work developed in tandem with my experience of coming to understand *who* and *how* I am as a gay man, a process which continues through the construction of this self-narrative. Before infection, I embodied HIV, but not in its viral state. Not yet. The virus lurked inside me, but in the contagious manifestations of stigma: fear, anxiety, shame, self-disdain and silence. This contagion of stigma eventually politicized me to become involved with community groups (e.g. ACT UP) and organizations (e.g. ASOs), where the work would be rewardingly central to my queer body, to my sense of purpose and empowerment as a gay man, including living with the lingering ‘hurt’ of HIV.

From an epistemological perspective, my knowledge of HIV/AIDS was partially acquired through discursive, professional practices (e.g. work, service, management, etc.) that disciplined my queer body and identity, designed strategically so that I might survive *and* thrive on the razor edge of an epidemiological abyss. Such practices represented the internal (e.g. individual responsibility) and external (e.g. public accountability) forms of power that shaped my experience of HIV/AIDS community service. As a HIV-negative, ASO manager, I survived (and thrived) by modifying and self-regulating my body, behaviors and thoughts in a constant, vigilant dance around the abyss. In doing so, however, I unwittingly internalized many of the neo-liberal, organizational impulses of control and regulation. Nonetheless, my queer body and identity remained sites of resistance and subversion. For me, being queer was an (un)balancing, community act, a political process “in which [sexual] colonization and liberation, subversion and collaboration are all embedded” (Aronson & Smith, p. 435). Queering my stance on the tightrope fostered a kind of ‘transformative justice’ (Freire, 2000), positioning me strategically in control of my body and identity, which, in turn, allowed me to balance with ‘competency’ and ‘effectiveness’ as an ED.

Organizational context

Canadian ASOs started appearing in the mid-1980s as a result of grassroots activism and organizing, primarily amongst members of queer communities, who stressed the need to involve those most directly affected by HIV/AIDS in policy and program development (Cain, 2002, p. 94). Linking organizational operations and management with key stakeholders through meaningful volunteer opportunities, for example, brought relevant human capital into ASOs. As with other social justice organizations, it also developed a community base of political support (Barnoff *et al*, 2006). ASOs were empowered through both human rights (e.g. queer liberation) and consumer rights (e.g. access to treatment) discourses (Cain, 1997; Cain, 2002). In the 1980s, at the height of the epidemiological tsunami, ASOs’ guiding principles were steadfastly oriented toward social justice, primarily (but not exclusively) with respect to queer communities, including an emphasis on values such as collaboration, mutual support, integrity, education, personal privacy, autonomy and compassion. ASOs provided an important community base for resisting traditional medical authority and for promoting models of empowerment that encouraged PHAs to be active, well-informed ‘patients’ (Bresalier *et al*, 2002).

From 1995 to 2002, the picture of the HIV/AIDS pandemic changed dramatically, including (finally) a decline in the number of people who were dying. With the advent of life-saving, anti-retroviral medications, the ‘death sentence’ of HIV could be re-narrated as a ‘chronic manageable illness’. However, decreased mortality rates coupled with new infections significantly increased the HIV prevalence in Ontario (Remis, 2001). The pandemic continued to disproportionately affect marginalized groups with tenuous connections to the health care system. This was especially true with respect to injection drug users, indigenous people and immigrants/refugees from areas where HIV is endemic (e.g. sub-Saharan African countries). More than any other group, HIV/AIDS also continued to disproportionately take a toll on queer men.

**~**

After his swim, in my living room, Rayne is pacing in a circle, absently tapping his water-logged lips. The damp towel is draped around his waist, molding his generous endowment with a thick, cotton skin. Admittedly, it isn’t the first time that I am staring in awe, in lust. He stops pacing for a moment to examine my framed photos on the mantle.

 “Is that you?” Rayne asks incredulously, holding the photo of me marching, buff and shirtless with ACT UP Montreal.

 “Yes, many years ago. At a political demonstration.”

 “You had hair back then.”

 Laughing, I add, “Yes, and a lot more energy.”

 “What were you protesting?”

 “AIDS. Friends dying.” I am seated on the sofa, naked under my bathrobe, pouring chamomile tea from a china teapot, steam billowing. “But that’s a story for another time. After a good, long swim and this chamomile tea, you should be able to sleep no problem.” Some nights, Rayne had gone days without ejaculating. “And I should get to bed soon too.”

**~**

By 2002, HIV/AIDS was clearly not just a “chronic manageable illness”; it was part of a raging, social storm: homelessness, poverty, racism, mental illness, addictions, homophobia…. Concomitantly, there was a lack of effective, targeted community engagement strategies, ultimately leading to less support (e.g. fundraising revenues) from key stakeholders (e.g. queer men) and a proliferation of negative media attention, particularly in the context of HIV criminalization. Across the province, ASOs were struggling to meet the growing need for HIV/AIDS-related services, in addition to managing an increasingly complex epidemiological and legal context. To make matters worse, funding for ASOs was becoming increasingly tenuous (Cain, 2002, p. 105). These rapid changes culminated in an organizational identity crisis for many ASOs, already struggling with the moral ambiguity (Teram, 2010) of needing to ‘hyper-adapt’ to the neo-liberal re-writing of values such as quality and accountability, particularly in reference to queer bodies and sexuality.

Lacking adequate management capacity (as a small, relatively new, non-profit organization), the ASO in which I worked was unable to simultaneously weather its organizational crisis *and* maintain the relevance of its programs and services, particularly with respect to PHAs and queer communities, for whom the organization was originally established. Formal program management, reflecting priorities such as planning, budgeting, performance appraisals and service audits, was non-existent. Vital support services (e.g. support groups, counseling, etc.) and education projects (e.g. HIV prevention initiatives for queer men) had withered away. From 1995 to 2000, neo-liberalism penetrated far into the ASO where I worked, straining the viability of its operations, as well as compromising its public image and community partnerships. The net result was an organizational implosion.

**~**

Gathering surveillance

Fog

Engulf my craft, my body

Inside a constant panopticon

Adrift, organizationally

Yet bound to navigate the perfect

Storm, a nauseating

Surge of governance visibility. I de-

Compensate, de-

Construct management

Practice. A critical compass frame-

Work to resist/engage the inevitable gaze

Of a new managerial star

Fierce market winds

Rip my sail

My practice required

To re-birth more efficient incarnations:

Probation. Registered.

The virus (mis)guided by evidence-

Based routes of

My body’s migration

Equity values

(In)competent to survive

The accountable swell of risk

Reduction, cost

Containing the ‘moral’

Sustainable salt

That critical switch for profit-

Making adaptation

Divided, my self reveals

A long, ambiguous search

For shores of post-

Structural apples

Rotting but edible, my body transformed

By a lightening, transcendent

Identity

Waves crash as performance

Anxiety. Responsibility. Sanctioned.

Now, audited

By the storm’s raining eye

Drifting but instrumentally guided

To measureable quality outcomes

To re-construct space(s) between

Social

Justice

As charting the boundaries

The unsinkable lines

Of this only thinkable context

I steer this skiff, my body

To marketable

Buoyancy, a perilous journey

Yet,

Still navigating the (im)possibilities

Of a cold, consumer

Sea

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**Part II: Explicating the ruling relations**

Organizational implosion culminated in the departure of the Board of Directors and, ultimately, the Executive Director (i.e. my immediate predecessor) at the ASO where I worked. This managerial collapse presented real and perceived risks (Green, 2007) with respect to both clients and workers, triggering an immediate organizational review by its government funders. The review primarily consisted of a service audit (Munro, 2004) with the aim of increasing the organization’s attention to measurable outputs and service standards. At the end of the review process, at which time I was just stepping into my position on the tightrope as the ‘new’ ED, the organization was given six months to implement numerous, agency-wide recommendations as a condition of continued funding. In effect, these ‘recommendations’ represented “a mask to disguise coercion and a series of explicit strategies to reorganize the workplace … in the language of efficiency, productivity and accountability” (Rees, 1999, p. 197).

**~**

“Who’s this?” Rayne is pointing at the photo of Jamie on the mantle, the one I took at the frozen beach in Provincetown. January, 1987. Six months before he died. Jamie was laying on a chaise-lounge beneath an umbrella, wearing a toque and parka, a stiff, sweet smile across his face. “Your lover?” Rayne asks. “My mother said he had AIDS.” I didn’t anticipate that Nancy might share our private discussions at the fence with her son.

 “His name was James. Jamie,” I say after a moment. “And your mother was right.” I brought the tea cup to my lips, blowing across the steaming surface. “Why do you ask?”

 Rayne looks up at the ceiling, one hand wringing the other.

 “Do *you* have it, Mr. Fix-It? Are *you* clean?”

 “No,” I say, “I don’t have it. I mean, you have nothing to worry about, Rayne” I add, in a surprised but reassuring voice. “Fortunately, I’m fine. I’m totally healthy, if that’s what you mean. HIV-negative.”

 “That’s not what I’m concerned about,” he clarifies. “I’m already infected.” Already infected? I suspect that he is testing me, or “talking ‘nonsense”.

 “What do you mean *infected*?” I ask gingerly.

 “With HIV. I’ve got it. It’s been inside me since Dr. Lovelips put me in that fucking hospital in Toronto. It’s what’s making me crazy.”

 “Why don’t you get rid of that wet towel and come over here,” I suggest, attempting to change the channel, so to speak, and it works; Rayne drops the towel and walks toward me, finally naked.

**~**

By 2002, neo-liberal ‘accountability’ in social services was already well-established, bringing significantly “altered governance relations — often described as a shift from ‘collegial’ to ‘managerial’ modes of regulation” (Ghorayshi, 2007, p. 222/3; Delhi, 2010, p. 95) — both within ASOs and between those organizations and external political-economic agencies (e.g. government funders). ASOs (as well as their community partner organizations) were significantly down a path toward neo-liberal reformation through the penetration of lean, social policies, “dedicated to reducing the size and scope of the human services and to managing them in a highly regulated and controlled fashion” (McKenzie & Wharf, 2010, p. xv). As with other human service organizations, operating in the survival mode of neo-liberal restructuring resulted in a weakening of ASOs’ community partnerships in a climate of competition for ‘scarce’ public resources (Barnoff *et al*, 2006; Cain, 2002). This managerial re-orientation of professional practice instilled an economic rationality in my (un)balance on the tightrope — “a way of thinking and knowing that shapes the terms and scope of the political — and the operations and effects of its techniques” (Delhi, p. 85).

The neo-liberal reform of ASOs limited their progressive, political nature (or, at least, differently politicized them) by weakening their community ties to objectives such as queer liberation (Cain, 1997, p. 342). Neo-liberal reform, however, was not just an insidious, economic enterprise — a re-arrangement of relations between ASOs and their government funders. It was also an agenda of cultural and institutional change, extending through every arena of social life (Connell *et al*, 2009, p. 333), including (where ASOs were concerned) phenomena such as sexuality, the law and health. For example, a neo-liberal inscription of ‘safer’ sex shifted the focus of risk/dis-ease management from human, social relationships to the human body, defining the kinds of acts that were permissible and impermissible, responsible and irresponsible, and eventually legal or criminal. This discursive shift allowed HIV to permeate society at a far deeper, cultural level, all the while masking the responsibilization of queer bodies, especially the ‘deviant’ bodies of PHAs.

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“Did you like Jamie’s as much as mine, Mr. Fix-It?” The fact that Rayne keeps calling me that, Mr. Fix-It, during fellatio especially, is unsettling. That and his eyes, which are blinking at an erratic pace. “Was his as big as mine?”

 “Hard to compete with this,” I concede, admittedly gagging on it.

 “You should have seen me. I was a big, fucking porn star in the hospital. A regular, Hollywood celebrity. I like doing porn, man. Hot. Last time I was in the hospital, I was in the shower and who shows up but my buddy Tim. From the swim team. Do you know Tim?” I shake my head, unable to talk, my mouth full of his nonsensical manhood. “Really hot guy. Great ass. Anyways, Tim and I were taking a shower together, soaping up each other’s bods until we were both ready to blow. Then we did it. Right there in the shower. We fucked. And I’m glad we did because after I fucked him, Tim confessed. He was working for Dr. Lovelips. My bastard shrink was watching me bang Tim behind a one-way mirror. Can you believe that? My buddy Tim, my closest buddy on the team, was working for Dr. Lovelips. Can you fucking believe it?! I didn’t know that, of course, when I was giving it to him raw. Next day in the hospital, Dr. Lovelips tells me that that I have HIV. Tim infected me. It was part of an experiment.”

 After a long, uncomfortable moment, I ask delicately, “An experiment?”

 “They’re testing my intelligence. To see if I can figure out how to get rid of the virus.”

Rayne looks around the room before he sits down on the couch. He sits there and stares into space. He is close enough that I can smell the chlorine on his pale, freckled skin. I sense that the ‘nonsense’ has subsided and that we can now get on with our business. As Rayne lies back on the sofa, I crouch between his legs in a prayer position…. My mad slurping and an orchestra of crickets outside; other than that, there is silence. Some nights, Rayne is still on my sofa as the sun is rising, hungry sparrows making a racket in the garden, me still worshipping, Rayne still hard, still silent.

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During the 1990s, the penetration of neo-liberalism into ASOs radically reduced the substance of political deliberation about programs and services for PHAs to a market-driven assessment of their value. The changes in social welfare policy in Canada over the ten years (from 1992 to 2002) were not in accord with the value of ‘concern for the individual’ (Armitage, 2003, p. 197); instead they were driven by a private market concept of individualism (e.g. PHA as ‘consumer’). In the context of ASOs, neo-liberalism privileged an ‘accountable’ (vs. social justice) approach to HIV/AIDS prevention and treatment, based on principles of individual responsibility, choice and self-determination. These principles could be invoked to rationalize the shrinking of governments’ (and, by extension, taxpayers’) contributions to publicly-funded health and social services for communities hardest hit by HIV/AIDS. These were the principles of the new dominant social ideology, implicitly justifying the social inequality that would follow those who ‘chose’ risks associated with HIV infection (e.g. ‘unprotected’ sex).

This re-orientation of HIV/AIDS toward a predominantly economic and individualized sphere informed my (un)balance, the tightrope’s tension manipulating the meanings of ‘quality’ and ‘accountability’ in community service. Valuing ‘accountability’ (i.e. through evidence-based service outputs) and ‘quality’ (i.e. through service standards) was paramount to successfully performing my balance as ED. Such values were disciplinary technologies for managing the work that flowed in and through my queer body, functioning to normalize dominant practices (i.e. ‘management’) and creating more authoritarian and objective modes (e.g. supervision) of knowledge production (Beddoe, 2010; Polster & Newson, 1998, pp. 174/5). To balance, my every step assumed the new managerial priorities (e.g. risk reduction and cost containment) that constituted the tightrope’s tension.

As an ASO manager on a tightrope, my (un)balance was ultimately achieved as a calculating *and* performing subject, simultaneously the target *and* vehicle of new forms of governance (Delhi, p. 85). By privileging certainty (e.g. service outputs data) in an era of uncertainty, my (un)balance re-produced highly modernist responses (i.e. individualized, fragmented, technical, impersonal, non-reflexive, etc.), leading to a proliferation of ‘quality’ technologies (e.g. service standards and documentation) in practice (Webber, 2008, p. 47). In the organization’s early years, support workers used brief, solution-focused and informal, peer approaches with a focus on social determinants of health. In 2000, my (un)balance on the tightrope was rendered more challenging by the pressure to reform community HIV/AIDS work to align more closely with a biomedical, case management approach, where there would be greater emphasis on the individual as the locus of social change (i.e. HIV/AIDS prevention), as well as greater emphasis on the distinction between workers and PHAs. As the ‘new’ ED, I morphed into a ‘designer employee’, my queer body (un)balanced through a performance of multiple, responsible but conflicted selves (Aronson & Smith, p. 442).

AIDS service organizations found themselves at the nexus of many of these contending forces, attempting to realize the democratic project of community self-governance in the face of an implacable biological peril. At the same time, ASOs as hybrid institutions of civil society and government, acted as agents of ‘responsibilization’ especially for gay and bisexual men, calling upon them to re-make their sexuality. (Adam, 2005, p. 334)

Gone were the days of vigorous, community-supported activism and fundraising. The necessity of complying with the expectations of government funders, particularly at a moment of organizational crisis, informed my each and every strategic step as ED. Like other community-based, human service organizations, ASOs were increasingly pressured into adopting new managerial standards and strategies that diverged from their traditional, organizational cultures (Browne, 1996, p. 41). On the tightrope, I became trapped in my own self-justifying, neo-liberal rationalities. I needed to not only balance but to appear to be balancing ‘professionally’ in order to ensure the survival of the organization.

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“Stop,” Rayne said abruptly, pushing my head away from his erection. “I need to piss.”A few minutes later, when he returns from the washroom, he is holding my metal nail file in his hand.

 “Rayne, are you okay?” I ask, but he isn’t answering. “Are you okay?” Inside my throat, a fear flutters its tiny, trapped wings. “What’s the matter Rayne?”

“I need you to take my virus away,” he replies. “If you don’t take it, I’ll die and Dr. Lovelips will take all the credit. That’s what the asshole wants.”

I’m not about to ask for clarification, or how the nail file fits in with Rayne’s plans. Tonight’s visit needs to end now. I have a challenging day ahead.

“Well Rayne, it wouldn’t be even possible to do that,” I say somewhat nervously. “You know, chances are you’re probably not HIV-positive and even if you were, you can’t get rid of the virus. You wouldn’t be able to give it away to me, or anyone else. Trust me; I should know. I’m an AIDS worker. Or I was, anyhow. Until today.”

“No, but you can reduce the hurt.”

“Okay listen, it’s getting really late, and today is my last day at work, so I should probably get some sleep. Got a farewell speech to deliver and a desk to clean out. Let’s just call it a night,” I suggest, trying to sound nonchalant. “And get some sleep. How does that sound? You can come back tomorrow night. Or the next. I’ll have the rest of the summer free.”

“I want to fuck you now, Mr. Fix-It. So I can reduce my virus.”

 I stand there, looking at my reflection on the dark window, free-falling off a perilously high tightrope, and the blur of Rayne’s body whizzing by. An AIDS worker. Plunging.

 “Let me get some condoms then,” I suggest.

 “It doesn’t work that way, and you know it. Mr. Fix-It.”

 In all likelihood, Rayne is not infected; I start rationalizing away the risk. He’s only 20. He told me during our first encounter that he was a bisexual virgin. “Never been with a guy before,” he reported, “Let alone fucked one.” But that first night, he seemed trustworthy and stable. Now, he is looming over me, twisting a nail file in his hand and smiling.

 “I have some lube right in here,” I offer, stalling for time, opening a cabinet beside the sofa, hoping to divert his attention. “Do you like gay porn?”

 “Take off your bathrobe,” he says.

 I stand there, dumbfounded. “Rayne, can you put the nail file down, please.”

 “Take it off.”

 “I will, but I’d like you to put the nail file on the table please.”

 “Is this a trick?”

 “It’s not a trick, Rayne. I wouldn’t do that to you.”

 “Just take off your bathrobe.” Resigned, I toss my bathrobe on the sofa. It is unlikely that I could successfully wrestle Rayne for the file or outrun him. “Get down on all fours.”

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The organizational review deployed lean values that, as a ‘responsible’ ASO manager, I ‘freely’ chose to adopt as technologies of self: “a series of processes and practices that were embedded in and organized by neo-liberal relations of power and privilege” (Scott-Dixon, 2007, p. 268). Even here, in the telling of this story, a pre-occupation with my performance (as ED) reflects a persistent, internal surveillance, daunting to negotiate with respect to what constitutes quality and accountability in my practice as a social worker. The bureaucratic technologies of self that the tightrope demanded were exhausting, not to mention profoundly isolating. A new managerial imperative positioned me (however reluctantly) as the key person (i.e. decision-maker) in the organization (Tsui & Cheung, p. 438) rather than, for example, distributing that ‘key’ more equitably amongst all staff members and ‘consumers’. On my tightrope, managerial knowing (e.g. risk control) superseded professional knowing (e.g. health promotion), which superseded insider, community knowing (e.g. activism) as key to my ‘competency’

Self-questioning my integrity intensified my (un)balance on the tightrope, particularly as the value of my ‘performance’ became market-oriented, externalized and at odds with the community knowledge on which my previous practice was based (Davies, 2003, p. 95). What was left for me in ASOs? And how would I bear it? And how bear the ‘banalities’ of my good intentions (e.g. social justice) as a gay man? I was, as some PHAs in the organization argued, only partially an insider, an HIV-*negative* gay man, not a person living *with* HIV/AIDS, as if those were somehow fixed and mutually exclusive identities. As a ‘professional manager’, I was also now cast (by staff and ‘consumers’) as an agent of governmental change, in spite of my self-presentations to the contrary.

Exacerbating my self-doubt was a nagging concern about an ‘authentic’ self that seemed increasingly compromised or lost in balancing on the tightrope (Aronson & Smith, p. 444). I was alone, tired, the soles of my feet bloodied. After ten years of community service in the painful, conflict-ridden climate of ASOs (Cain, 2002), I surrendered my balance. I quit that work, once and for all. I imagined the promise of gravity: peace, weightlessness and a freedom from HIV colonization, as if such a ground might exist. More than anything the ground served as a goad to happier days, where the importance of HIV/AIDS community service could finally recede in my life.

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Understanding my fall from community HIV/AIDS work as a natural outcome of the development of my critical consciousness provides a useful reason for narrating my story of walking the tightrope in ASOs. (Cain, 2002, p. 110) As an ED, I was trapped in a complex ambivalence between, on the one hand, performing familiar and already recognizable neo-liberal terms (e.g. cost-cutting), and on the other, performing a queer resistance to that dominant principle: *the bottom line (not social justice) will prevail*. For example, the ‘no questions asked’ policy with respect to the distribution of more than one condom or syringe in a single service-interaction became too expensive. Service-users were effectively forced to explain and justify their needs in order to receive more than one condom. Or clean needle. In this way, neo-liberal technologies of self infused and challenged my balance on the tightrope, particularly as government agents made clear that ongoing funding was contingent on compliance with prescribed terms of recognition (i.e. fiscal responsibility). The detrimental force of those ‘new’ terms, however, was not at the forefront of my political awareness, particularly as they were camouflaged (or self-rationalized) through ‘responsible’ management values such as ‘quality’ and ‘accountability’.

Responsibility for minimizing the risk of organizational foreclosure nurtured a highly rational form of management (Rees, p. 194) in my practice. The devolution of responsibility from governments to individual managers, accompanied by the individualizing and fragmenting effects of being alone on the tightrope made it difficult for me, as an ED, to identify my (un)balance as a matter of politics and to organize collective strategies of resistance (Davies, 2003). Besides, my resistance to neo-liberal terms of recognition, at least in any outward, ‘radical’ manifestation (Carey & Foster, 2011), would have most certainly resulted in the demise of the organization, including my job and the jobs of my co-workers, including over 100 community volunteers.

As an ED, I needed a framework for social justice management that would help me to resist the angry, neo-liberal climate in a way that re-politicized my (un)balance. A first and critical step in counteracting the penetrative force of neo-liberalism is to cultivate a vigilant, reflexive awareness about its constitutive power and its capacity to be divisive. Neo-liberal reformation undermined the importance of identity politics in ASOs by dividing ‘individuals’ from their communities and recasting them with consumer identities. Where ASOs had originally united community members as engaged citizens, it now effectively divided them through marketized, residual and fragmented services. The notions of ‘community’ and ‘service’ became more relevant to one’s socioeconomic needs than to one’s identity or political affiliations.

A critical reflection on my tightrope walk reveals “more than the *how* of [neo-liberal] government; it includes, *what* is governed, *who* is to be governed and *why* as equally central questions” (Dean, 1995, p. 581). The governance of my ED work functioned to ensure fiscal responsibility, but also (more indirectly) to limit my ability to steer the organization in a politically progressive direction. That is not to say, however, that ideals such as compassion, social justice and the public good simply disappeared in my work. In ASOs, neo-liberalism was “not entirely successful in replacing other norms and rationalities, or in eradicating professional discretion and autonomy” (Connell *et al*, 2009, p. 336). Thus, I brought to community service a critical awareness of my ability to manage changing structural conditions (i.e. neo-liberalism, capitalism, etc.), while being managed by them. And I let that inherent contradiction multiply vs. divide me. My subjectivity. Performing a multiple, engaged voice. From one queer body. Telling me how to walk the tightrope successfully. And, ultimately, to jump when it was time. True to the ground, my landing, where I could finally begin to see how my (un)balance on the tightrope was indicative (vs. contra-indicative) of my integrity (Banks, 2010) and my empowerment, if not my departure from living with HIV/AIDS.

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Rayne is kneeling on the floor behind me, the nail file in one hand, the other clenching the base of his erection, which he is using to club my ass.

“You want it?” he asks me.

“Yes. Make it fast though.”

“Don’t worry, man. You won’t miss your last day at the AIDS centre,” he reassures me. His penetration sears in one, sharp thrust, with the full force of his athletic pelvis.

 “Nice and easy,” I say through my teeth. Once inside me, deep, Rayne is intensely silent. Not even a blissful grunt or one labored breath. Just the sound of his chlorinated flesh slapping mine. Otherwise, my body is silent too, where once it was loud and raucous. ACTing UP no longer.

After a few, rapid minutes, Rayne stops.

“Now, fix me,” he groans loudly, his body seized, gripped by his twisted, individual ‘truth’. His urgent, productive emission. Accomplished. And mine: community service. Finishing too, but with no bodily pleasure, no transformative orgasm. The file released from his hand, falling unperilously to the floor.

In actuality, Rayne’s body is devoid of HIV.

My body, too: released from another impossibly high and risky tightrope, still physically free of a pandemic virus.

**Section II: Infection**

 **3**

**Asking for it Raw:**

***a story about ‘safer’ sex***

It is a hurt that refuses to keep us apart, but also does not bring us together. I know enough of this pain to know the limits of what I can know, [writing] as I am in this time and place, with this body, arranged as it is, here, now.

— Ahmed, 2004, pp. 37-38

**2007**

“Hello, my name’s Brick Wallace.”

All twelve men seated in the circle of plastic, orange chairs respond resoundingly and in unison, “Hello Brick”.

“I’m here because, according to my doctor, I have an anxiety disorder, associated with compulsive sexual behaviour,” I explain, providing my ostensible reason for joining SOS. *Smart-On Sex* (SOS) is a psycho-educational support group, offered by the local public health agency, specifically for HIV-negative “men who have sex with men”, men who ‘endorse’ the inconsistent practice of ‘safer’ sex. Nigel, who is the facilitator of SOS, smiles and nods encouragingly at my self-introduction. “Addicted or not, I’m the first to admit that I like sex too much, and I need to do something about it,” I add. Nervous feet shuffle, squeaking on the shiny, linoleum floor. “And I’m attached, which is part of my problem.” Everyone looks bewilderedly at Nigel, who is a recovering sex addict from the 1970s, when being a slut was considered relatively inconsequential and emancipating. Then, of course, along came HIV, changing forever the basic mechanics of sexual liberation.

 “Thanks for coming today,” Nigel replies.

Seated next to me, a strapping leather daddy[[6]](#footnote-6), a senior citizen, nudges my elbow, amicably stretching out my introduction: “Well you’ve come to the right place, Brick. *Brick*, is it?”

“Yes, Brick,” I say. “As in masonry. Sounds like a porn name, I know.”

The leather daddy’s laugh is robust and infectious. “Well, I guess that makes me a brick*layer*,” he continues, flirting outrageously.

“Behave yourselves gentlemen please,” Nigel implores.

The last man to introduce himself is seated directly across from me in the circle, slouched back on his chair, legs open, jeans stretched thin over his mouth-watering bulge. A cardinal rule of SOS, painstakingly reviewed by Nigel, is that members are strictly prohibited from engaging in sexual activity with one another. Nothing more than a hug is permitted.

 “Tell us your name, please, and what brought you here today?” Nigel asks the man whose crotch I’ve been ogling.

 The man clears his throat and sits up politely in his chair. Momentarily, his hand contemplates the dark stubble of his unshaven chin. “Ah, well, it’s a little complicated,” he finally says, looking down at his feet, which are clownish-huge in dusty work boots. “Let’s just say that I’m doing it for my wife.” He stops speaking and sits there, smiling uncomfortably at Nigel. SOS is designed to assist “men who have sex with men” who are struggling to maintain ‘healthy’ sexual practices. “Oh, and the name’s Mike,” he adds, pointing at his nametag.

Everyone responds resoundingly and in unison, “Hello Mike.” Everything about Mike is charged by testosterone: the way he talks, his commanding voice, the sharp, decisive gestures of his meaty hands. After his self-introduction, I barely follow anything anyone else says for the remainder of the meeting. There is only Mike, and my wanton desire for his body. Throughout the other members’ confessions and empowering epiphanies, Mike’s fleeting eyes meet mine not infrequently. Already, we are on a twisted path, heading fatefully toward one another’s lust.

Before that first meeting finishes, Nigel asks the group, “What makes a sex addict an addict? Any closing thoughts?” A confused silence ensues until, finally, a bi-curious bear[[7]](#footnote-7), clutching a wad of soaked Kleenex, volunteers to answer. “What’s different about being part of a support group for sex addicts is that we’re both the addict and the substance,” he proposes. “It’s sort of like sending an alcoholic to an AA[[8]](#footnote-8) meeting and expecting him to tell all his problems to a room full of liquor bottles. It wouldn’t be ethical.”

 “I don’t know about ethical,’ Mike pipes in, “but there’s a cold beer somewhere with my name on it, right now, waiting to hear my problems.”

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After Nigel dismisses us, I linger outside the church, where SOS rents its meeting space. Eventually, Mike pushes open the heavy, wooden door, stepping into the sweltering August night, alone, adjusting a baseball cap on his shaved head. He pulls a pack of cigarettes from one of the pockets in his camouflage vest and glances at me, acknowledging my agenda with a smile.

“You smoke?” he asks, offering me a cigarette.

 “No. But thanks.”

 “You don’t mind if I do?”

“No, not at all. Please go ahead.” As he’s lighting his cigarette, holding it tight between his thick, pink lips, I know, right then, that Mike is going to fuck me.

“Damn hot out here,” he says, initiating the small talk. Mike looks Hispanic or possibly Middle Eastern, with rare, luminous green eyes. “Supposed to be 42 tomorrow with the humidex,” he reports. “Hopefully, anyhow.”

“You like the heat, I guess.”

“No, I hate this shit, but I could use a day off. I work in construction. We don’t work when it gets this hot.” Here is my opportunity, never mind that Nigel might banish me from the support group: a breaker of the cardinal rule, a hopeless cause, and an irresponsible slut.

“I live just down the street,” I say. “We could go hang out at my place, if you want. I’ve got air conditioning. Grab a cold beer, or something?”

 Mike grins at me, a delinquent co-conspirator. “You think I’m that easy?” he asks. The sexual attraction is mutual and intractable. “You know, we’re not supposed to be doing each other.”

 “Who said anything about sex?”

 There was the briefest moment of rational hesitation. Of calculation.

“And you got cold beer at your place?”

 “For sure.”

 “And air conditioning?”

 “On full.”

 “Okay, let’s do it.”

“Perfect, let’s go.”

“But we won’t tell Nigel.”

“No, we won’t tell Nigel.”

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Reflexively maneuvering between these interlocking, cultural spaces — the support group, the church, my bedroom — I attempt to clear a path of critical self-awareness, here in the telling of this story, with respect to my subjectivity as a ‘responsible’, gay man. In particular, I seek greater awareness of how my queer, sexual subjectivity is constituted, at least in part, by dominant discursive forces (e.g. ‘safer’ sex) that originate outside my body, in a moral, rational and public sphere. In considering a more private sphere of amorality, emotionality and intimacy, I explore how the self-governance of my sexual pleasures, in the context of HIV prevention, is guided, ultimately, by a marketized ethic of individual responsibility and accountability. I examine how my public performance of ‘responsibility’, as reflected in my participation in SOS, was scripted and enacted convincingly through the moral discourses that disciplined (Foucault, 1979) my vulnerable body, a ‘healthy’, queer body on the edge of an epidemiological abyss. My performance of ‘constraint’, however, was less convincing.

In 2007, how did I continue to make sense of my commitment to the practical morality of ‘safer’ sex? By valuing my robust health, by linking its value significantly to my HIV-negative ‘status’ — the promise of a long, productive life with, perhaps, my own biological children — was certainly one of the ways in which the ‘safer’ sex praxis continued to have relevance in my life. And there were other ways: by valuing my long-term relationship with Sean, my partner of 10 years; our list of hopes and dreams, as a couple, already written and posted on the future. Meanwhile, no longer as civically engaged (i.e. via activism and community service), my consciousness of ‘risk’ atrophied to the point where I could still hear a din of the hurricane raging, but I misperceived its trajectory. In positioning my ear, as a knowing, ‘responsible’ (and longtime ‘negative’) subject of ‘safer’ sex, I believed the hurricane to be less threatening, less in control now of my destiny. In distancing my own vulnerable subjectivity as a queer man, I unwittingly adopted a neo-liberal faith in individual choice and self-determination as the basis for my personal practice of HIV prevention.

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As it turns out, Mike is a closeted bisexual. At my place, the beer transforms him into an effusive, talkative person.

“Actually, I joined the group on the wife’s orders,” Mike explains, slurring his words as he recounts how, a few weeks earlier, his wife caught him cheating on her, with a guy, for the third time. “I think I need another beer,” he says. “You got me talking too much here.” Sitting that close to Mike, I can smell a day of hard labour on his body. It won’t be long before my hand is sliding into his growing arousal. “Nice ass,” he says, as I stand up to get more beer, finally making his intentions clear, grabbing my butt through my jeans, assessing it like cantaloupe in a shopper’s hand.

“One of us will have to quit SOS if you keep that up,” I say, encouraging him.

 “You like that?” Mike asks.

I turn around to kiss him, and instantly we are necking and undressing like hastily disembarked sailors.

“Gorgeous,” I tell him, running my hands over his hairy, granite chest, following the trail of black fur from his navel to his tumescent splendor.

“Go down on it,” he tells me.

 “Let’s go to the bedroom,” I suggest.

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My sexual choices were rationally calculated as a means to control my body’s desires and pleasures, to live out my desires and pleasures in ways that evaded HIV. This meant that I remained HIV-negative until 2007. When it came to making my ‘choices’, however, the mechanistic calculus of ‘safer’ sex miscounted my body’s non-rational variables such as sexual desire, feeling and pleasure. Thus, I tended to integrate economic, rational variables such as ‘health’ and ‘individual choice’ as key components of my sexual decision-making. For me, *not* preventing my body from becoming infected with HIV would represent an ‘irresponsible’ dependency on publicly-funded services such as health care. It would mean that I, too, after my sustained resistance of 25 years, could easily be collapsed into the arithmetic of epidemiological numbers, including their institutional control (e.g. public health surveillance) and public accounting (e.g. criminalization). HIV infection would most certainly mean more stigma and discrimination in my queer life, more nauseating revolutions in the spinning door of my closet, where I vowed to never return.

In broader, socio-cultural terms, becoming infected with HIV would mean that I had failed, in my choices and actions, to uphold the value and meaning of a neo-liberal bottom line: *market individualism should prevail*. In other words, my individual choices and actions, including those that are sexual in nature, should contribute to the strength of the market economy (e.g. through ‘productivity’, through consumerism, etc.). Likewise, they should not detract from its strength by: increasing the need for taxes (i.e. money that would otherwise be dollars in consumer pockets) to pay the costs of expensive health care related to treating ‘preventable disease’; or, by compromising the individual’s consumption capacity. This cultural bottom line is particularly insidious when applied to a social welfare ‘problem’, such as HIV infection, that is primarily conceptualized as ‘preventable’ at the level of the person. As HIV-positive, my body would cost more to maintain as part of the larger, economic body, particularly one bound by social principles such as ‘universal’, publicly-funded health care. At an estimated cost of $1.3 million per Canadian infected with HIV, representing lifetime costs associated with treatment and loss of productivity (Canadian AIDS Society, 2011), becoming infected with HIV (i.e. my ‘risky’ sexual choices) could have significant socioeconomic consequences.

HIV infection could cost me gravely with respect to my health and productivity, in measurable, marginalizing ways. More importantly, from a neo-liberal perspective, it would add to the costs of operating the welfare state, including the ‘management’ of a persistent pandemic. From this perspective, my sexual practice as a HIV-negative, gay man was rendered ‘accountable’ and ‘responsible’, tied closely to institutional concerns and preoccupations, including economic priorities such as public cost-saving and individual consumerism. To prevent my HIV infection, I operationalized a managerial governance of my body’s risks. Pervasive neo-liberal shifts in responses to HIV/AIDS — represented in my self-narrative as the dissolution of my civic engagement in activism and community service (Adam, 2005) — informed the management of my queer sexuality. With respect to HIV prevention, in particular, I integrated more marketized ways of relating to cultural bodies and persons (e.g. assuming an informed individual/consumer choice vs. a shared responsibility for identifying and mitigating risk).

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Mike positions me right at the edge of my bed, where he is standing proud and tall, engorged with desire, ready to ride.

“Got any condoms?” he asks, practically an after-thought.

“Uh… yes. There’s some on the night table.”

“Sorry, I don’t think that kind fits,” Mike says, examining the package, shaking his head pessimistically.

“That’s all I’ve got.”

Mike proves himself right, of course, as he tries unrolling the latex over his monolithic, impatient erection. “No luck,” he concedes, frustrated. “I fucking hate condoms.”

“What man doesn’t?” Instantly, that nagging, multiple voice — my neo-liberal society, my cultural and personal history, my political identity — is conspiring to control my ‘risky’ body: “make the responsible choice, stop now, put reason before pleasure, protect yourself”. After practicing ‘safer’ sex religiously for 25 years, after watching Jamie and countless friends get sick, suffer and die, after working in AIDS service organizations for over a decade, after all that, I am finished narrating HIV in that way, finished narrating the wise parables of a plague: the stories to discipline my queer body. Or so I *think* I am finished. In my mistaken mind, if not my body, the story is heard and understood more as a relic of my past than a salient reference point for my present orientation as a gay man. “I just want to feel you inside me for a minute,” I say, guiding Mike into my body, desperately resigned to my forbidden desire. “But please don’t cum.”

 “No worries,” Mike replies. “I won’t. Not inside you.”

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In 2007, barebacking was widely considered to be “a transgression of the [‘safer’ sex] covenant worked out in the 1980s and 1990s, and barebackers [were] constructed s ostensible rebels or deviants beset by too much AIDS optimism, condom fatigue or safe sex relapse” (Adam, 2005, p. 334). Such condemnations and causal rationalizations — conceptualizing unprotected anal sex as intentional, ‘dangerous’ and marginal — privileged the neo-liberal governmentality in contemporary health and social policy, particularly with respect to discourses that reinforced ‘risk’ and ‘responsibility’. In doing so, however, the possibility of a different understanding was lost, one that circumvented the risk/responsibility binary all together: a critical possibility that barebacking might represent a kind of a radical openness to the other (Dean, 2009) a positive, queer force in terms of the development of more egalitarian socio-cultural responses to HIV prevention: an “openness through its acceptance of risk and its willingness to dispense with barriers” (ibid, p. 30). For example, as a gay man, I might understand becoming infected with HIV as an experience that provides me with a kind of cultural initiation or an opportunity for the development of interpersonal and community relationships, creating new forms of queer relatedness (e.g. through making connections to a critical disability identity). In short, albeit as a privileged subject, I might understand HIV infection as the transmission of connectedness and life, rather than divisiveness and death.

Where the governmentality of HIV prevention is concerned, the risk/responsibility discourse ultimately failed for me, and obviously for many hundreds of thousands of other queer men. The persistence of barebacking — that is, ‘unprotected’ anal sex, whether selectively, indiscriminately, rarely or frequently — in the sex lives of many queer men, including my own, represented a fundamental insustainability of HIV prevention, particularly when relegated almost entirely to an individual sphere of responsibility. It demonstrated the weakness of the once strong collaboration among governments, AIDS service organizations and queer communities — particularly among people otherwise divided by their HIV-status — in taking responsibility for HIV transmission (Adam, 2005, p. 334). The HIV-neutralizing effect of such collaboration fostered less divisive discourses with respect to how HIV prevention should be accomplished in the face of socio-cultural complexities such as “asking for it raw”.

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By the time Mike is lacing up his work boots at the front door, orgasm-drained, ready to leave, I am already fretting about the fact that I allowed him to penetrate me without a condom, particularly since he’d been leaking significant precum. “You didn’t shoot inside me at all, right?”

 “Not a drop,” he says.

 “And you’re totally clean?”

“Yes, for sure.” Mike looks suddenly perplexed at me. “I mean, I haven’t been tested for HIV in about five years, if that’s what you’re talking about.”

I look through him for a second into his shadow. “You’re not sure if you’re negative, or not?” I ask, incredulously.

“Sorry man, I assumed you were cool with it.”

“You’re kidding me, right?”

“Dude, you’re the one who asked for it raw.”

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In his reflexive observation — “you’re the one who asked for it raw” — Mike invoked the practical morality of neo-liberalism, one that concerns itself primarily with individual choice and responsibility. Perhaps in Mike’s irrational, heat-of-the-moment assessment, it was not a matter of risk or ‘slipping up’; I was simply exercising my body’s right to choose from an unfettered, sexual menu, one that I validated in “asking for it raw”. These were, perhaps, the starting points from which Mike and I negotiated our ethical obligation to one another (vis-à-vis HIV prevention) as queer men. Of course, our bodies were knowingly trapped in a dense web of moral significance and contradiction. As such, there was pleasure and freedom in not having to be more than sexually intimate with one another. To be able to connect through intercourse, rather than discourse.

How did Mike and I confront such ethical dilemmas as HIV prevention and deal with it practically except to bypass it altogether, both of us, assuming an individualistic ethic, the body’s ethic of desire and choice, coupled with an open pursuit of sexual feeling and pleasure. Once we were naked, there was no discursive, moral rationality at play; it was about sex, informed by our bodies’ physical and emotional epistemologies. I “asked for it raw” for one indisputable, irrational reason: sex without a condom feels better. All the reasoning, all the ‘safer’ sex education in the world, all my experience of living with HIV/AIDS before that point, could not change that one bodily truth.

My sexual interaction with Mike unfolded unpredictably and my responsibility, found expression in an unexpected, embodied way. Asking for ‘unprotected’ sex from Mike resisted the neo-liberal discourses that oriented my risk and responsibility toward a public sphere of accountability. “Asking for it raw” also challenged the hegemony of market individualism with respect to the possible meanings and implications of HIV infection (and, by implication, its ‘prevention’). With Mike, I opened my body to pure, exhilarating risk. Barebacking connected me to him in a way that felt, at least in the moment, responsible to ‘the other’ because of its radical openness to his life, its chaos, and to the possibility of a less limited intimacy (Dean, 2009) with his body. Receiving his body, without ‘protection’, to the depth of my openness, was inevitably transformative. It produced the transformative chaos inside my own.

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At the second meeting of the support group, Mike isn’t there. Last week, when he was at my place, I wanted to ask for his number as he was leaving, but didn’t. He seemed perturbed; why did I have to ask about HIV? Now I’m kicking myself. I don’t even know his last name or email address. That’s confidential information, which Nigel cannot release. So I return to SOS the next week. And every week until the group ends. In case Mike shows up. Something about him. Under my skin.

At the beginning of the next several meetings, Nigel counts heads and asks, with growing concern, if anyone has seen Mike or knows if he’s coming. I don’t say a word; I am still secretly obsessing about him. Mike’s power over me partially resides in my awareness of our sexual interaction as a transgression (Dean, 2009, p. 157) of the ‘safer’ sex covenant, not to mention the rules of SOS. Whatever the case, I keep looking at the door, but Mike never comes, and I never see him again. In my life. In my body.

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My testing unfolds agonizingly in step with my seroconversion. On August 30, I visit my doctor for an unrelated matter. While there, I request a full STI[[9]](#footnote-9) screening, including HIV testing. My ‘transgression’ with the vanished Mike, which occurred on August 7, is now on constant rewind in my head. Besides, it has been over six months since I was last tested. Other than barebacking with him, I calculate that my risk exposure has been low since last being tested: admittedly, an idiosyncratic, sexual mathematics that relies heavily on the probability and rationality of ‘safer’ sex practices, coupled with the impossibility of knowing every microscopic detail about every anonymous, sexual encounter.

On September 18, five minutes before the last meeting of SOS is set to begin, my doctor calls my cell phone to inform me that my HIV test result has come back *indeterminate* and suggests that I get retested as soon as possible.

“Likely just a lab error,” he says, attempting to reassure me. A terrifying error, nevertheless. But I’m certain he’s right, and I white-knuckle that certainty until the final, interminable moment of SOS. In closing, when Nigel asks us to share what we will take away from participating in the group, I remain speechless.

On September 19, I surrender more vials of stressful blood for testing, and that result, also, is indeterminate. Even more terrifying. On October 11, 20 years to the day that I was marching in Washington to end the AIDS epidemic, I get tested for a third time. On October 26, my doctor calls urgently to explain that “the result is still indeterminate, but this time it’s *weakly reactive*. You should refrain from any unprotected sexual activity until we can get this clearly sorted out,” he cautions.

“Weakly reactive,” I repeat. “What does that mean?”

“You’ll need to be retested again to be absolutely sure, Brick.”

“So it’s not certain?”

 “At this point, we can probably make the diagnosis.”

“I’m HIV-positive?”

“It’s looking that way, Brick. You must have been quite recently infected.”

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The ‘transgression’ of barebacking with Mike consisted in our disregard for such biopolitical imperatives as “health and longevity, the chronos of futurity” (Dean, 2009, p. 66). “Asking for it raw” elucidated manifestations of personal deployments of neo-liberal power (e.g. the assumption of rational control), elements that I perilously, unwittingly engaged in my resistance to the specific formation of those powers over my body (Foucault, 1990). Becoming infected with HIV positioned me in greater jeopardy with respect to the neo-liberal discourse of ‘individual health’ as a type of personal and social commodity, informed by notions of ‘risk’ and ‘responsibility’. More than ever, I felt the power of this discourse over my queer body, including the jeopardy and vulnerability that accompanied any resistance to it.

Since HIV prevention, at least in my socio-cultural conceptualization, is almost entirely a biopolitical endeavour, taking neo-liberal discourse seriously is a fundamental starting point for asking questions about the personal, sexual practices and norms that such discourse encodes (Adam, 2005, p. 335). Why did I not ask Mike *before* sex about his HIV status? The question loomed there, in my consciousness, but I chose not to ask him until after my pleasure was accomplished. Why did I assume that Mike would not only know, but also tell me, if he *were*, in fact, HIV-positive? What was it about 20 years of living with HIV/AIDS that made possible an irrational morality when it came to barebacking with Mike? Why would I surrender my body’s safety so that it might feel a fleeting, vulnerable and irrevocable connection with a stranger? By 2007, the relative improvement in quality of life and health for PHAs, including several close friends, undoubtedly contributed to the loosening of my ‘safer’ sex practices and norms. Still, those rational factors were not at work in that transformative moment when I “asked for it raw”, when I opened my body radically to ‘the other’.

When I refer to ‘the other’ I don’t only mean Mike and his masculine power, his sexual body or risky desire, but ‘the other’ inside of me that I don’t yet fully know, the one that became infected with HIV, the one that I am narrating here, coming into knowledge. How could I *be* HIV-positive? How could that be true? Unfortunately, receiving my test result was not just a terrifying comedy of errors. The next several months were the worst of my life as I spun existentially from one tornado to another over a bleak uncertainty. First, I had to tell Sean, my rock-solid partner of ten years, (with whom I have an ‘open’ relationship) that I was probably HIV-positive.

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“Keep an open mind, and let’s forget about it for now,” Sean responds, attempting to comfort me. “You’ll be fine. We’ll be fine.” Because he so lovingly understands and empathizes — as a gay man with his own history of HIV scares — I am even more angry and disappointed at myself. And, admittedly, at Mike, or whoever infected me. *Infected*: that word suddenly more a transitive verb than an adjective that I can live with. *Someone infected me* as opposed to *I am infected*.

“I should have known better,” I keep repeating to myself and to Sean, desperately ashamed. That scratchy refrain plays incessantly in my head, a catchy but annoying love song. Playing over and over in my head during the next two months of testing, waiting for a definitive, conclusive word about how my story of living with HIV/AIDS will change. Continue. The not-knowing but fearing-the-worst uncovers a bottomless sinkhole of despair in my body, the hole that formed 20 years earlier when Jamie was screaming painfully in a hospital bed. Through the agony of waiting, I obsessively deconstruct “asking for it raw”, seeking to understand what that particular ‘transgression’ might teach me about my ‘responsibility’ (i.e. the failure of same) as a gay man. I come to appreciate that I am only partially in charge of the safety and protection of my queer body, particularly in the context of a neo-liberal sphere of HIV prevention. I also start to see how “asking for it raw” is itself valuable as provocation for sustained analytic reflection on ‘safer’ sex, as a signpost for finding my way forward as a gay man, particularly since I might have to live now with the chaos of HIV *inside* my body. And so living with HIV/AIDS continues, whether I have a clear and defensible explanation about what is happening in my body that I can narrate to others, or not.

**Section III: Post-infection**

**4**

**Weakly Reactive:**

***critical reflections on HIV diagnosis***

I grew up afraid of illness and disability, inclined to avert my gaze from anyone who was too different — despite all the ways I knew myself to be different.

— Solomon, 2012, p. 677

**2008**

The receptionist scratches her pencil through my name.

“Take a seat, Mr. Wallace. The doctor will be with you in a few minutes.”

 I head for the men’s room instead, my stomach rumbling, unsettled by the impending doom. I know what the doctor will tell me. Or rather, my body knows. Except my brain, of course, which is still foolishly confused and gripping hope.

My body, a multiplicity of bodies, is confused much of the time. I notice hope, somewhere in my belly, and pleasure, a little higher up, alongside a quiet, relentless despair in my heart. Whatever the diagnosis might be, I am reluctant to [know] and loathe to give ‘this’ a label. It would, I fear, serve to close down possibilities, to stifle my awareness of my body as a mobile state of affairs. (Wyatt & Gale, 2013, p. 308)

In the men’s room, I squint at my reflection in the mirror. Maybe I am attractive in an unconventional way, which is what Jamie used to tell me.

“It’s your chin,” I repeat out loud to myself. “The cleft gives you character.”

“Mr. Wallace?” Somebody is loudly knocking on the door of the men’s room, calling out my name. “Brick? Are you in there? The doctor’s ready to see you.”

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I narrate here, this chapter of my story, so that I might critically reflect on my experience of being diagnosed with HIV. I focus specifically on the practice context (i.e. counseling) that I encountered as a ‘patient’. Interwoven in my narrative is an awareness of the temporal, changing nature of my subjectivity with respect to my experience of *living* with HIV/AIDS. Diagnosis brought the *living* painfully into my body, instead of outside and all around it, where HIV had formerly multiplied its numbers. In doing so, it unleashed a traumatizing panic, a chaos in body and mind, my life story suddenly veering off a steep, surreal cliff.

I desperately needed help to make sense of what appeared to be non-sense. *How was I infected?* And, of course: *Why me?* A completely new set of questions were reshaping the parameters of my subjectivity as a gay man, and I needed help to understand them. To chart a way forward. With or without the answers.

Ultimately, I narrate this chapter in order to develop a reflexive representation of the way in which I charted my way forward as a PHA, specifically reflecting on my participation in cognitive behavioral therapy (CBT) as a newly diagnosed ‘patient’. My purpose, in part, is to offer critical perspectives on the counseling that I sought and received at the time of my HIV diagnosis. By representing my embodied knowledge with respect to CBT, for example, I examine the neo-liberal forces of power, surveillance, and control that informed the help that I received. I hope that my reflections provide useful signposts for PHAs who are struggling to find a way forward after diagnosis. In addition, I hope that my self-narrative provides a critical perspective that might be useful in professional practice, assuming, as Ezzy (2000) notes, that “we make as well as tell stories of our lives, and this is of fundamental importance in the clinical world” (p. 605).

It is my objective to create and use my narrative effectively in the context of my research, and to engage with it reflexively (Fook, 2002b, p. 120), which is what I intend to do in this chapter by orienting my HIV infection toward a constructionist notion of disability rather than a diagnostic one. From a critical perspective, I invoke aspects of chaos theory to illuminate other, possible approaches to finding a hopeful present and a way forward in the context of HIV diagnosis. Arriving at critical disability theory, I re-imagine my HIV diagnosis as an experience of personal adaptation and transformation, joining consciousness and action, in order to illuminate my approach to the spiritual, emotional and physical praxis of finding my way forward from a traumatically disrupted present.

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My doctor is sweating, his white coat starched but hanging open comfortably, a Mickey Mouse tie underneath, as he reviews my numbers from the lab report.

“Viral load: 1400,” he muses. “Atypically low for a very recent infection, which suggests that you probably got a weak inoculum.”

“A weak inoculum?”

“A low exposure. You were probably exposed through pre-ejaculate, which has a significantly lower concentration of HIV than semen. CD4: 450 (26%),” he continues. “Also atypically low. We’ll need to keep an eye on that number.” Suddenly, just numbers constitute my subjectivity. In the cramped, examining room, there is no place for the luxury of optimism. My doctor speaks my numbers with the certainty and confidence of science. His cool, clean hands probe my neck, armpits and groin, searching my lymph nodes for swollen treasures.

“Nothing,” he reports factually. “How have you been feeling?”

“Completely fine,” I answer, never mind that I have neither slept nor eaten in days. “Is it possible that the test result is wrong? Why does it keep coming back as only *weakly* reactive? What does *weakly reactive* mean?”

“We don’t exactly know,” my doctor replies sheepishly. “We’re assuming it was a low inoculum. I’ve never seen a result like yours before, and neither has my colleague, Dr. Young. (I know Dr. Young from my work at the local AIDS organization.) I consulted him without identifying you, of course,” he hastens to add. I am frozen in a moment of disbelief, a tidal wave barreling toward my exposed body.

“Maybe *weakly reactive* means a false-positive,” I suggest, desperately unable to budge from my doctor’s scientific truth.

My doctor clears his throat and looks at me conclusively over the top of his sleek, metallic glasses. I am mostly looking down at my feet, which do not seem, at all, like my feet. Not my legs. My hands? None of this *diagnosed* body feels like my own; it inhabits space differently. A disabled body — an alien incarnation — is suddenly climbing out of the space where my former body used to live. And I must learn to live inside it.

“Do you have any idea how you got infected?” my doctor asks. If *how* meant *by whom*, then I was almost completely sure. Mike. Something about him under my skin. In my DNA. Otherwise completely vanished. I gaze into the backs of the desktop portraits of his children or wife, whoever they were, those people who are smiling at my doctor from the other side, sheltered from the hurricane’s impending fury.

“Someone I shouldn’t have trusted,” I finally answer. Mike. Me.

“You let down your guard,” my doctor correctly observes.

“Yes, I did. I shouldn’t have been so trusting.”

“But you need to forgive yourself.”

“I can’t. I’m too angry at myself right now.”

“You were unlucky, Brick. It’s not an easy virus to get.”

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Before my doctor conclusively delivered the lines of my bad ending, I had always referred to *the pandemic* as people might speak of a monstrous hurricane that is swallowing innocent bodies in another country: a faraway, human tragedy. Numerous storm casualties surrounded me — friends, lovers, clients, co-workers — all killed by a senseless act of nature, yet *the pandemic* was outside me. It raged outside me at a subjective distance, over there, in other vulnerable bodies. (Now, of course, I know that I was floating dangerously in a complacent bubble.) I had taken for granted the permanence of my bodily divide from HIV/AIDS; after 25 years of sexual vigilance, being HIV-negative had become integral to my identity as a ‘healthy’, ‘responsible’ gay man. Admittedly, it was also a badge of pride and honour, however easily revocable in the end.

*It’s not an easy virus to get*. This dictum I had heard repeatedly over the years from the mouthpieces — public health officials, doctors, epidemiologists — of dominant medical discourses on HIV transmission. Although I never knew exactly what *not easy to get* meant, I had accepted it as an authority’s indisputable truth, perhaps because it offered some measure of reassurance, however small and obscure, in the face of a gigantic, imminent hurricane. Ultimately, that dictum was misleading and harmful to me as a sexually active gay man. What I failed to realize, while floating around in my complacent bubble of sero-negativity, was that the dictum was mainly ‘true’ from a hetero-normative perspective on sexuality. For me, as gay man, it turned out to be painfully ‘easy’ to become infected with HIV (which does not, at all, suggest intent or will on my part or on the part of anyone else). It happened as unintentionally as a child’s soapy bubble bursting on a gathering wind.

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“It’s not a death sentence anymore,” my doctor says reassuringly, but the storm surge is already flooding the muddy, sliding banks of my subjectivity. Disbelief, fear, panic, fear, disbelief. Stop. Shock. My infected body, circling around headless in an emotional chaos, shellshocked for days and weeks after the storm leaves *weakly reactive*, forever, in my path. Of disorientation and disorder.

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“Life threatening illness, such as HIV/AIDS, threatens people’s sense of identity and taken-for-granted assumptions about the temporal framing of their lives. In response [to diagnosis], people often experience transformations in values, spirituality and life priorities” (Ezzy, p. 605). For me, being diagnosed with HIV triggered a crisis in adaptation, a chaotic state of disorientation, particularly in the context of my sexual identity and relationships. As a ‘responsible’ gay man, how could I have let this happen? How did I get infected? Was it, in fact, Mike? Had he lied to me about his HIV status? Those questions played over in my head like a scratched record, a torturous, dead-ended refrain of self-reproach and scapegoating. Unquestionably, I should have ‘known better’, and I did, yet I still put my body ‘at risk’. Knowledge, alone, was not sufficient to prevent my infection.

Socio-cultural forces, including neo-liberalism, were gathering in the hurricane’s relentless eye. Concomitant with the beginning of the pandemic in the 1980s, “the reduction in state responsibilities and social services [had] not so much produced greater freedom as greater poverty and insecurity along with an accompanying ideology that [held] ordinary citizens ‘responsible’ for their own (mis)fortune. In HIV terms, the withdrawal of the state could be read as relegating the newly diagnosed, then, like the new poor, to the category of ‘irresponsible’ or ‘gullible’, in other words, undeserving and responsible for their own misfortune” (Adam *et al*, 2012, p. 39). Diagnosis (dis)oriented and disciplined my queer body more strictly along neo-liberal lines of individual choice, self-determination and responsibility, particularly in the emerging context of HIV criminalization.

Being diagnosed, in the absence of information and support with respect to my legal responsibilities regarding disclosure, produced a disabling effect: my HIV-positive body restricted by a set of unfamiliar, uncertain rules, rendering me highly vulnerable to discrimination and prejudice, as well as criminalization and institutionalization. In a court of law, HIV exposure/transmission could be constructed as my fault, a criminal disruption of my responsibility, a punishable act of my disabled body. Being diagnosed with HIV disrupted the self-narrative with which I ordered my life experience. It challenged my self-organization, promoting the development of a problem-dominated identity (e.g. potential criminal) and fostering the dissociation of aspects of my experience (e.g. sex) in a way that precluded their integration (Neimeyer *et al*, 2006, p. 127). In this way, being diagnosed with HIV was not only disabling, it was also disorienting and disordering, particularly with respect to my subjectivity as a gay man.

 Diagnosed, the hurricane was sucking me into its silent vortex, a cold raining eye of internalized oppression: a relentless self-interrogation that questioned my value, meaning and purpose in life. I retreated to a closet, a temporary, existential refuge, however colonized. “Something always overflows, escapes our knowledge, comprehension, conceptions. Infinity is the acknowledgment of what is beyond comprehension” (Rossiter, 2011, p. 983). I was ashamed and afraid, utterly unable to see that I exceeded my own and others’ disabling representations of me vis-à-vis HIV, unable to consider the infinity beyond those representations as a place for empowered self-forgiveness. Unable to forgive myself, I was utterly unable to disclose my diagnosis to family and friends, except to a very few people. The closet walls set in. There were no words, no way of naming that place where torrents of salt water rushed past me, changing my life, the hurricane raging. Inside my body. Swallowing my voice as I slipped into the murky infinitude at the back of my closet.

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 Chaotic times in life are “fraught with periods of disequilibrium and the experience of negative emotions such as anxiety and fear” (Bussolari & Goodell, 2009, pp. 102/3). The linear narrative of my future (e.g. career goals, family planning, etc.) had ruptured abruptly, exposing a deep chasm of unknowingness. I peered into an unpredictable future with respect to my health, as well as the direction and longevity of my life. I was flirting with a suicidal edge. “The first two years after diagnosis are typically a time when people have a great deal of difficulty coping with being HIV-positive” (Ezzy, p. 616). I could only foresee an abyss of illness, debilitating treatments, medical appointments, rejection, sexual abstinence and stigma. Understanding *weakly reactive* as a lifelong condition of my subjectivity set me adrift and disoriented in my new, disabled incarnation, directed now (and for the rest of my life) by a single virus.

Such moments do not always present themselves as life choices available to consciousness. At times, we don’t know that we have followed a path, or that the line we have taken is a line that clears our way only by marking out spaces that we don’t inhabit … We can get directed by losing our sense of this direction. The line becomes then simply a way of life, or even an expression of who we are. (Ahmed, 2006, p. 19)

 *Weakly reactive* provided only an approximation of how I might perceive my diagnosed body and disability, particularly with respect to my experience as a gay man living with HIV. What I needed, at diagnosis, was a life-affirming, cognitive framework that might help me to adapt to a significantly more colonized future. As my illusion of a future populated with dreams and aspirations vanished, I needed help to live more presently, in the here-and-now, as an antidote to my body’s vulnerability to unpredictable disorder. I needed help to open doors that would re-orient me toward joy and empowerment not in spite of HIV, but because of it.

We can lose our direction in the sense that we lose our aim or purpose: disorientation is a way of describing the feelings that gather when we lose our sense of who it is that we are. Such losses can be converted, [however], into the joy of a future that has been opened up. (Ahmed, 2006, p. 20)

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In response to my perception of a closed down future, my doctor referred me for counseling: “to a *gay-friendly* social worker who can help you forgive yourself and move on”. Through several sessions of cognitive behavioural therapy (CBT), the social worker and I engaged collaboratively in re-constructing a meaningful, linear narrative for my future (i.e. illness management and the pursuit of health), while de-constructing a past that I could leave behind me in self-forgiveness. To the extent that this narrative was intended to foster individual change and ‘manage’ my infection, the CBT installed a new set of disciplinary practices on my colonized body.

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Simply put, the diagnostic-medical explanation of disability places the locus of disability internally, within an individual who has experienced illness, insult or anomaly. This internal focus results in the interpretation of the disabled individual as defective with reference to normative physical, behavioural, psychological, cognitive, or sensory being. (DePoy & Gibson, 2002, p. 153)

CBT, in the context of the counseling that I sought and received after my HIV diagnosis, focused internally on changing my self-reproach in order to decrease some of my maladaptive behaviours (e.g. social withdrawal, substance use, sexual abstinence, etc.). CBT started with the premise that my maladaptive behaviors (e.g. avoiding disclosure) were shaped by my internal(ized) misperceptions of my diagnosis. The social worker, therefore, attempted to re-orient my cognitive distortions (e.g. self-blame) so that my behaviors would be more conducive to favorable, therapeutic outcomes (Payne, 2005, p 121), particularly with respect to my mental health. CBT methods, as practiced by my social worker, included contingency contracts (i.e. to monitor my suicidal ideation), social skills training (i.e. to assist with disclosure issues) and cognitive restructuring of my depression and anxiety through biofeedback techniques (Robbins *et al*, 2006, p 372).

CBT deployed an evaluative model, focusing on the meaning that HIV held for me, particularly in the context of constructing my self-worth and a positive future. Less attention was paid to what it meant, physically, psychologically and politically, in terms of my queer body and identity. Or what it meant, socially, in terms of my increased vulnerability to homophobia and ableism, as well as to contemporary, neo-liberal mechanisms of epidemiological surveillance and control (e.g. HIV criminalization). Rather than focusing on its psychological or social impacts, CBT focused instead on my conceptualization of HIV, employing a health belief framework to foster individual responsibility and personal change.

In its broader, cognitive objective, CBT encouraged me to examine my feelings, thoughts and actions in a goal-oriented construction of hope, with an “expectation of realizing desirable outcomes” (Ezzy, p. 607). Through my counseling, the social worker and I concentrated foremost on my adjustment to the illness experience (DePoy & Gibson). In its individual-reformist tendency, this approach downplayed the socio-cultural forces (e.g. homophobia) that were shaping my experience of HIV diagnosis, including the conceptualization of my problem(atized) behaviors.

Together, the social worker and I operated with an “understanding of morality in which there is assumed to be one right way to live a [positive] life that follows a clear linear narrative of control and mastery of the future” (Ezzy, p. 607). Our temporal orientation was primarily toward the future. In practice, CBT assumed a continuity or progression of future experience — an assumption at odds with the experiences of many PHAs. Relational and functional continuity can be severely disrupted by the experience of living with HIV. Rather than focusing on integrating disorder and discontinuity as aspects of my changed (and changing) life, the social worker played an adjunct role in heightening my attention to behavioural responses that would avoid or mitigate those ‘negative’ aspects of being HIV-positive.

The fact that my doctor, my social worker and I collectively pursued a narrative of ‘self-forgiveness’ not only assumed wrongdoing on my part, it reinforced the neo-liberal importance of taking responsibility for my body’s ‘transgressions’. “Foucault paid particular attention to localized, institutional contexts, such as clinics and prisons, where one could witness the power of disciplinary practices, those that contributed to the production of particular kinds of social subjects” (Finn & Jacobson, 2008, p. 195). In the context of my diagnosis, CBT functioned as a Foucauldian, disciplinary practice, contributing to the construction of my subjectivity as a PHA, a potentially dangerous body, rendered responsible by biomedically aligned counseling. A disciplined patient. A patient discipline, heralding the neo-liberal value of individual accountability for the health costs incurred by one’s behaviours and choices (McGregor, 2001, p. 3). The value of bodily restraint.

 Focusing on forgiving myself, however well-intended and mutually constructed, neglected the socio-cultural forces that were also shaping my response to diagnosis. I was loathe to become a lifelong ‘patient’. Yet CBT inscripted biomedical discourse on the terrain of the thinkable, talkable and doable, narrowly constructing an illness/health approach to managing my newly infected body. Not only did my counseling lack a critical disability perspective, it missed an opportunity to strengthen my agency in re-constructing a way forward, a life after diagnosis. By individualizing and fragmenting my experience through a set of behavioural problems that required ‘therapy’, CBT failed to attend post-structurally to the mutual constitution of my subjectivity and its socio-cultural context. Without an element of reflexivity, my counseling assumed uncritically that my individual practices (e.g. treatment adherence) would necessarily shape my future health outcomes, overlooking the influence of global factors beyond my control (Ezzy, p. 615), including, for example, the neo-liberal downsizing of health and social services.

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“Hope is important in facing the prospect of a chronic illness, such as HIV/AIDS; it helps in major stressful events and alleviates emotional distress” (Kylma *et al*, 2001, p. 765). In the context of CBT, my hope was defined mainly through the construction of a ‘restitution narrative’ (Ezzy) that effectively minimized my socio-cultural experience of living with HIV/AIDS, delimiting my responsibility to disease prevention and health maintenance. In this sense, my diagnosis represented a disruption or challenge to be personally overcome rather than the intersection of my past, present and future as a gay man. As a counseling approach, CBT helped me to adjust my self-blame, anger and shame so that they would not manifest (or at least not nearly as much) in self-destructive behaviours. Nevertheless, I walked away with precarious hope. Constructing my hope as concrete and outcomes-oriented — (e.g. “I hope that I will still be able to become a parent.”) — left me more anxious and afraid about my highly contingent, post-diagnostic future. Shortly after my counseling had finished, I was again sinking into a nihilistic chaos.

Six months after diagnosis, I was chronically fixated on my HIV infection, unable to sleep or eat, anxious and depressed about the prospects for my future. Living in an empty present, I expected the hurricane to rage ad infinitum. I needed a sense of “hope as not oriented to achieving a goal, but as a different mode of experiencing time and reality … Hope [that] embraces uncertainty and finitude, celebrating surprise, play, novelty and mystery” (Ezzy, 607). In 2008, my HIV diagnosis represented more a disabling, disorienting identity crisis than a health problem, which CBT had overlooked in privileging the ‘patient’ construction of my subjectivity. I needed an approach to hope that would engage (rather than resist) my disorder. Rather than being defined (or disciplined) by individual, ‘healthy’ goals, I yearned for the possibility that my life, the way forward for me, would reveal, as yet, unknown sources of meaning and self-worth (Ezzy, p. 607). I imagined a hopefulness that would illuminate the unpredictable here-and-now, a hope that would facilitate my empowerment and health, relatively independent of any assumption of a future, let alone a neatly ordered one. I went looking for a way forward and stumbled into the opening of chaos.

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Chaos theory posits inherent unpredictability in the universe and its systems (Kiel & Elliott, 1996). For example, the flapping of a moth’s wings results in a tiny change in the atmosphere. This change connects to other changes so that the atmosphere diverges unpredictably by virtue of a single moth’s presence (Stewart, 1989). Or a single virus. The seed of chaos planted in my infected body, growing through my relationships, my community, my world: beginning with one microscopic colonization, the silent, genetic flutter of viral wings. Mundane yet enormously significant. “Sensitivity to initial conditions means that any difference in a system’s input, no matter how small, can eventually produce an enormous difference in output” (Warren *et al*, 1998, p. 363). Maybe HIV’s wings would change my story in such a way that the revolving door of my closet would stop spinning, forever, or maybe not….

Living with HIV (inside my body, that is) exposed a metaparadigm for transcending the constraints of my disordered life, for pursuing a more chaotic but hopeful future as a gay man. “The rules of a metaparadigm contradict the rules of the paradigms on either side. They always produce multiplicity, wild connections, cross-disciplinary leaps and contradictions” (Hodge, 2007, p. 215). Adapting to being HIV-positive occurred on the edge of disorder, where my sexual identity was transformed by a chaotic colonization occurring inside my body. Thus, the way forward, for me, involved finding a “middle ground toward an understanding, acceptance and integration of the importance of entropy for [personal] adaptation” (Bussolari & Goodell, p. 103).

Cultivating an appreciation that life seldom unfolds in a predictable manner, I became better equipped to relinquish the internalized shame and self-blame that reinforced the linear narrative of “made poor choices”, “let down my guard”, “failed to be responsible”, etc. Understanding my HIV infection as entropic, as part of the normal chaos of human life, emancipated me from a deterministic past and supported the unexpected in my future. It also made space for experiencing my present, emotional discomfort as a positive signal that I was constantly creating the changes that made hope possible. Eventually, my disabled self incorporated the knowledge that how I experienced my HIV diagnosis could be altered to fit within a story of personal growth, a narrative of adaptation and re-connectedness.

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A multi-linear narrative of re-connectedness facilitated my acceptance of *weakly reactive* and provided a way forward to the telling of my story, “a doorway to growth and to new, not-yet-imagined possibilities and connections” (*ibid*, p. 106). By ‘befriending’ my HIV status, I re-imagined my infection as a catalyst for constant, life-affirming change, as well as a more advanced, empowered level of self-organization, particularly with respect to my identity as a gay man. In finding my way forward, I discovered an open-ended, dialogic possibility that incorporated not only a critical awareness of my disabled body, but also its inexorable, inevitable chaos, starting from the smallest disorder: the moth of my HIV infection, its fragile flight waiting in the wings.

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For me, adjusting to being diagnosed with HIV required a multi-dimensional approach. The CBT, precisely because of its individualist-reformist analysis, helped me to understand my self-blame as connected to broader, socio-cultural forces such as homophobia and neo-liberal capitalism. CBT also helped me to understand that blaming myself was disempowering and, ultimately, counter-productive in terms of finding a way forward to the place where I could narrate HIV hopefully as part of my life story. Ironically, out of the chaos of my colonized body, I constructed a disability narrative with respect to living with HIV that provided me with a more inter-connected, grounded identity as a gay man: different forms of temporal and bodily unity or order, purposefully incorporating discontinuity, contradiction and unsettledness.

We must name unsettledness as a conscious and deliberate practice of ethics before knowledge, accomplished by embracing the contradiction between the inevitable need to totalize or represent and the need to make space for the sociality that derives from our orientation towards that which is beyond comprehension of an individual. (Rossiter, p. 990)

The chaos surrounding my HIV diagnosis was essential to locating my path forward, (or back to my present) to living hopefully and meaningfully as a gay, disabled man. Paradoxically, the unpredictability of living with HIV became an essential element of my ‘sexual orientation’, my sense of order as a gay man, my “sense of being really alive, whole and, in a temporal sense, a continuous person”. Before diagnosis, my ontological security depended on a unified, consistent hope that developed progressively from a self-controlled present into a rewarding future. After diagnosis, my ontological security depended on my pursuit of a transcendent hope and connectedness, seeking wholeness in the present, opening up the story of my past and reflecting a future of joy.

**5**

**Dividing Me:**

***a reflexive analysis of HIV criminalization***

I’m not talking about the evidence now. I’m talking about the question, about the way they understand reality.

— Dostoevsky, *Crime & Punishment*, 1866

**2011**

“An Ontario man convicted of first-degree murder in the deaths of two of his sex partners through HIV transmission has been declared a dangerous offender. A Hamilton, Ont., court granted a request by Crown prosecutors, who asked that Johnson Aziga be jailed indefinitely because they believe he is a high risk to reoffend” (Gale, 2011).

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“Because we are human and live in the somber perspective of death, we know the exacerbated violence of eroticism” (Bataille, *The Tears of Eros*, 1961). For me, HIV unequivocally draws out the connection between sexuality and death, and chains me, for the rest of living this life, to the power of that relationship. HIV brings an existential disjuncture into focus with respect to my ‘infected’ body as, at once, the site of erotic pleasure and (potentially) the site of criminal charges: capable of committing murder through sex, of causing another person’s death by nothing other than my body’s cells. And an orgasm. I exist, a marginalized sexual being, inside this divided body. Criminalization divides me uniquely and categorically with respect to my legal obligations as a person, setting me apart from the vast majority of Canadians. It divides my body’s rights and responsibilities to others, particularly with respect to intimacy and pleasure. It divides my ability and disability. It also divides my socio-cultural experience of living with HIV/AIDS, draws a mutable line in the shifting sand of subjectivity between Johnson Aziga and me.

For weeks, I anxiously follow the scandalous media coverage of the sentencing of Johnson Aziga. His body of criminal evidence before the public. Brought against him. Against me, and all PHAs. Aziga’s convictions are related to eleven women with whom he had unprotected sex without first disclosing his HIV status — seven of those women became infected, with two eventually dying from AIDS-related cancers.

Like Aziga, if I fail to first disclose my HIV status to sex partners, then sex could be deemed non-consensual and criminal by a court of law. This means, for example, that I risk being charged with sexual assault every time that I have sex anonymously (i.e. where I disclose no personal information whatsoever, including my HIV status). “One of the primary unanswered questions is whether there remains a legal duty to disclose known HIV-positive status in the event of condom use or other ‘safer’ sex approaches” (Adam *et al*, 2008, p. 146). Sex suddenly becomes a minefield, strewn with uncertainties and latent dangers. My simple resolution is to stop having sex altogether, which is, of course, unsustainable, not to mention a perverse capitulation to the socio-cultural forces that seek to dis-able and responsibilize my body. Eventually, I seek sex exclusively with other PHAs, and my doctor cautions me about the possibility of re-infection with a different viral strain. How can I maneuver this body? I am inescapably and increasingly encumbered by my sexuality, a more intensified discourse of risk and responsibility written in my HIV-colonized cells.

Heightened legal responses to HIV transmission increase the jeopardy and vulnerability of my body as a queer man, while inscripting greater risk, accountability and responsibility on me as a sexual subject. In short, HIV criminalization, dis-ables my sexuality. It diminishes and disempowers my sexual body. The rest of my body, at least as it is here and now, remains unchanged and mostly unaffected by HIV, largely due to the effectiveness of one hard, flesh-coloured pill that I must swallow every day for the rest of my life. To live. Dis-oriented: an alien incarnation, HIV, colonizing my differently constructed, ‘dangerous’ body.

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In this section of my autoethnography, I analyze current social policy directions with respect to the growing HIV/AIDS pandemic in Canada. I begin with my perspective on the problem of HIV criminalization**[[10]](#footnote-10)** as an instrument of social policy, invoking the story of Johnson Aziga, as represented by media sources. Using a critical lens, focused reflexively through my experience as a person living with HIV/AIDS (PHA), my analysis situates HIV criminalization in a disabling sphere of stigmatizing, institutional discourses regarding HIV transmission. Second, I consider the scale of this problem by illustrating its social impacts in three areas: epidemiology, the news media and the courts. Next, I consider how a history of inadequate, discriminatory government responses with respect to HIV/AIDS (and, more broadly, with respect to disability) inform the construction of HIV criminalization, highlighting the role of neo-liberal ideology, as well as biomedical and legal discourses, in the ‘responsibilization’ of HIV-positive bodies. I conclude by emphasizing the importance of community-based, health approaches to social policy on HIV/AIDS as an alternative to criminalization.

Although significantly different, Johnson Aziga’s story, on a socio-cultural level, reflects my own story as a PHA, as well as the stories of many other PHAs who are sexually active. I call attention to Aziga’s story in my self-narrative because it resonates with my own vulnerability to stigma, discrimination, surveillance and institutionalization as a PHA, particularly with respect to negotiating the ‘risks’ of my sexually disabled, ‘dangerous’ body. For me, the growing trend toward the criminalization of HIV is a deeply troubling personal and policy concern. One of the difficulties that I have in evocatively narrating my concern, here, is the socio-cultural context (e.g. the trial of Johnson Aziga) in which I am located as the intentionally vulnerable subject of my research. Thus, this chapter of my self-narrative is more analytic in approach, engaging a more distant, relational ‘other’ (i.e. Aziga) in exploring my experience. Admittedly, I am afraid of the stigma. It is not my intent to defend, justify or rationalize Aziga’s choices and actions with respect to his sexual partners. Rather, it is to engage in a critical inquiry of the application of criminal law to the bodies of disabled people, specifically PHAs.

“There are many different definitions of disability, but the Canada Pension Plan defines ‘disability’ as a physical or mental condition that is ‘severe and prolonged’. In Canada and in most industrial countries, HIV has evolved from a deadly disease to a disability” (Canadian Public Health Association, 2012). One of my objectives in framing my analysis in critical disability theory is to explore the hinterlands of my subjectivity as a PHA. Several questions are central to my exploration: How am I dis-abled by HIV? How does HIV criminalization dis-able me? How does HIV criminalization, as an instrument of social policy, limit my full participation (e.g. in creating barriers to disclosure) and equality (e.g. in limiting my employment opportunities) as a Canadian citizen? Although comprehensive answers to these questions undoubtedly lie somewhere outside the scope of this chapter, I raise them here so that I might indicate more of the context of my self-narrative with respect to HIV criminalization, including my critical frame of analysis.

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In Canada in recent years, the state has been shifting resources from social services to law enforcement. At the same time as there are trends toward the responsibilization of citizens to provide for themselves ... In HIV, the prosecutorial arm of the state has expanded while support for ASOs and for HIV prevention has become increasingly tenuous. The move to press for more punitive solutions to HIV prevention has many pitfalls and unintended consequences that amount, in the long run, to a public policy with poor prospects for meaningful reduction in HIV transmission, combined with real damage to the lives and well-being of PHAs. (Adam *et al*, 2012, p. 38)

Government regulation (via the judicial system) is increasingly becoming the policy instrument at work in responding to the social welfare problem of HIV/AIDS in Canada. “Eighty-four percent of criminal prosecutions for alleged HIV non-disclosure to sexual partners occurred in the six years from 2004 to 2010 although HIV was identified more than thirty years ago. Media attention has shifted accordingly so that criminalization has become a primary theme in HIV coverage” (Adam *et al*, p. 1). The intensifying effect of mass media coverage, in turn, impacts the practices of public health, the police and judiciaries (*ibid*, p. 37), not to mention my own personal, sexual practices as a PHA. As court cases, such as Aziga’s, attract extensive media coverage, that (mostly) negative attention influences the public, including governments’ social policies. The privileging of ‘obligatory disclosure’**[[11]](#footnote-11)** as a legal rationale for institutional surveillance, accompanied by stigmatizing media coverage of ‘criminal cases’, renders HIV disclosure a lynchpin of contemporary, public discourse on HIV/AIDS.

Assumptions of personal blame and moral failure are contrary to principles of dignity and equity in Canadian policy on universal health care (Burke & Silver, 2006). Yet, these are precisely the assumptions at work in shifting HIV transmission/exposure to a judicial (vs. social) policy sphere. The emergence of HIV criminalization *and* divestment in community-based, health services (e.g. ASOs) over the past three decades, coupled with a history of discriminatory, institutional perspectives (Armitage, 2003, p. 134), has produced a policy vacuum, ultimately empowering the police and the courts as major actors in the control of HIV transmission as a social problem. A lack of legislative or policy direction with respect to the human rights of PHAs, coupled with the low visibility of AIDS service organizations and public health agencies in a public sphere of HIV prevention, has fostered the governmentalityof HIV/AIDS as a communicable disease (Adam *et al*, p. 1). The failure of federal and provincial governments to respond effectively “is not just a question about the availability of resources; cutbacks in social programs are justified on moral as well as economic grounds” (McKenzie & Wharf, 2010, p. 41).

In the neo-liberal context of health/disease governmentality, criminalization imposes a highly practical morality on my body’s risk of transmitting HIV. It re-enforces values such as individual responsibility, freedom of choice and self-determination, all through reduced government involvement. Criminalization changes the possible meanings of “asking for it raw”, re-orienting pleasures such as barebacking along rational lines of social or public accountability. In one ideological swoop, it disables my ‘risky’ sexuality and renders me responsible. “The central problem of criminalization is drawing the line between criminal and noncriminal behavior” (Burris & Cameron, 2008, p. 579), between risk and responsibility, which cannot easily be done when the legislative context (i.e. sexual activity involving HIV exposure/transmission) represents a highly complex, non-rational, contingent and ever-changing sphere of social and inter-personal relationships.

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“Aziga was the first person to be charged and convicted of first-degree murder in Canada for spreading HIV” (Gale, 2011).

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Out of the disjunctures between the subjects of HIV transmission constructed by leading discourses, and the experiences, expressions, practical moral reasoning, and evolving cultures of people at risk, arise a series of problems that can ironically heighten the possibility of infection by constructing subject images that are not recognizable by, and do not resonate with, those most at risk …The continuing deployment and reproduction of dominant discourses of HIV subjectivity mean that public policy, ostensibly intended to enhance the health of populations, as often populates its narratives with HIV subjects abstracted and reified away from the everyday lives of people who encounter the human immunodeficiency virus. (Adam, 2006, p. 169)

The disjuncture, for example, between my experience of “asking for it raw” from Mike and the possible conceptualizations of that experience by dominant discourse, specifically in the context of HIV criminalization, affects how I construct my self-narrative in this post-infection chapter of my story (i.e. primarily as the reified stuff of analysis rather than embodied evocation). Did Mike know he was infected? Did he lie to me? If so, was my sexual consent invalid? Or just a part of it? Was I the victim of a crime? Such divisive questions arise from the disjunctures. In my self-narrative, less disjunct questions, instead, are considered: To what degree is social policy (or the lack thereof) placing criminal prosecution as a first, rather than last, response to HIV transmission (Adam *et al*, p. 37)? How can this be mitigated, if not eliminated, as an instrument of social policy, as well as a matter of human rights?

In my critical analysis of how HIV criminalization affects me as a PHA, I draw on Mitchell & Snyder (2006), who explain that:

without access to representations of bodies as variable and vulnerable, disability representation [e.g. in social policy] obscures the necessary demand that communities can and do accommodate multiplicity in the body politic … [Policy] responses to physical and cognitive impairments shift from a relatively benign formula, the interdependency of human lives in one’s immediate community, to one of moral and community judgment. (p. 38, pp. 35/36)

Intense HIV stigma fosters coercive, moralistic policy inclinations throughout society, casting PHAs as diseased or, worse, as dangerous and delinquent (Armitage, p. 134; Kinsman, 2007, p. 121). In light of medicalizing and criminalizing discourses, I seek a critical shift of awareness toward a disability paradigm that “is free of or provides alternatives to barriers, both physical [e.g. prisons] and systemic [e.g. discrimination], that prevent [the] full participation [of PHAs] in society” (Hick, 2007, p. 308).

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In the context of HIV criminalization, social policy has the force of the negative on its side – the power to say no and to impose limits. For me, it carries the force of sexual, bodily prohibition, manifesting through neo-liberal governance technologies (e.g. ‘individual responsibility’), if not the imposition of criminal law. In reflexive analysis, I narrate here to demonstrate how I am vulnerable in the midst of punitive social policy. In doing so, I invoke historical examples of social policies that marginalized and institutionalized people with disabilities vs. served any defensible social welfare function. I also briefly explore the connection between the social control and subjugation of people with disabilities and the regulation of our bodies and sexualities.

Analyzing social policy in the context of HIV/AIDS requires situating the pandemic’s socio-cultural power dynamics (e.g. heterosexism, ableism, etc.) as central to my politically empowered frame of analysis. This is particularly relevant with respect to exploring the intersection of my queer and PHA identities. Where HIV criminalization is concerned, my personal is inevitably political. Thus, I narrate this chapter primarily with a queer disability voice. This seems particularly important given the tendency of dominant discourses (e.g. in public health, law and government) to shift the policy focus “from the actions or inactions of powerful social institutions onto the individual capacities and incapacities of [PHAs]” (Kinsman, p. 124).

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“[Aziga] said he didn't disclose his HIV status because of sociological and ethno-cultural barriers, religion and taboos. The Ugandan-born Aziga said that in sub-Saharan Africa, where he was raised, there was no education on sex, sexual health or sexuality” (Gale, CBC, 2011).

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The criminalization of HIV has strong, historical echoes with dominant social responses to disabled people. For example, disabled people were viewed as:

possessing bodily and cognitive deviances that expressed the corruption of their souls … Physical features [e.g. HIV infection] functioned as symptomatic expressions of internal dispositions, and thus, the external body could be orchestrated into a means of grasping the otherwise intangible truth of an individual’s moral character. (Mitchell & Snyder, 2006, pp. 35/36, 41)

My HIV-infected body, in such a policy and discursive context, “provides an opportunity to solidify other social actors’ beliefs in their own moral goodness and proximity to normative ideals” (*ibid*, p. 38). While effective treatment is successful in preventing any visible manifestations of my HIV infection, the invisible ‘mark’ of disability remains on my body. “We can say without exaggeration that the category of ‘disabled’ is created and maintained, even when the ‘formerly disabled,’ even the ‘dis-disabled,’ are integrated” (Stiker, 1999, p.152). The permanent ‘mark’ of HIV on my invisibly disabled body signals the prioritization of surveillance and governance before human rights and freedoms.

With pandemic circulation of HIV, my sexuality gets ensnared in a social web of concern regarding the health of populations. Governments and policy makers conceptualize “human welfare and state intervention in terms of biomedical issues such as reproduction [and] disease … [while] sex becomes the construction through which power links the vitality of the body together with that of the species” (Dreyfus & Rabinow, 1983, p. 140). Public health agencies, in the neo-liberal regime, largely situate HIV exposure/transmission in a sphere of private, moral responsibility, while attempting to manage that sphere as a public, epidemiological objective. Therein rests a fundamental policy paradox. Public health agencies seem not to favour HIV criminalization, yet neither do they take a vigorous stand to oppose it, let alone lead a more effective health policy strategy. Meanwhile, governments continue to adopt HIV-specific criminal laws, and PHAs become more vulnerable to prosecution and institutionalization.

Confining PHAs for HIV-related ‘crimes’ stigmatizes my disabled body and impedes my relationships with others and community, representing an affront to my civil and human rights. “Society’s obligation is not to condemn, but to create policies and conditions in which safe behavioral choices become rational and desirable. The blunt use of HIV-specific criminal statutes and prosecutions does the opposite” (Burris & Cameron p. 580). It presses me deep into the back of a dark closet. Criminalization has considerable potential to undermine the prevention efforts currently under way in Canada, as well as the social achievements of thirty years of HIV/AIDS community development. Quickening the march of a pandemic that is growing more divisive and more tragic. As the band plays on….

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**Scale of the problem[[12]](#footnote-12): And the band plays on….**

### ● In the absence of good social policy, the Canadian pandemic goes on largely unabated. The number of new HIV infections in Canada has remained stable in the past several years, but is still cause for serious concern.

* Approximately 3,175 Canadians became infected with HIV in 201l, indicating a fairly steady rate of new infections since 2008.

### ● Every year, new infections significantly increase the toll that HIV/AIDS takes on groups already disproportionately affected, including Aboriginal and queer communities.

* Gay men (and other men who have sex with men) represent approximately 50% of all PHAs in Canada.
* 9% of all PHAs in Canada are Aboriginal.

### ● An alarming number of Canadians do not know that they are HIV-positive, which poses serious challenges with respect to curtailing (or ending) the pandemic. Many Canadians suspect or worry that they are infected but do not seek testing due to a range of factors, including stigma/discrimination and a lack of accessible, anonymous testing.

* Approximately 18,000 people living with HIV remained undiagnosed in 2011, representing 25% of the total number of people living with HIV.

# ● The total number of PHAs in Canada is steadily increasing. Fortunately, the effectiveness of anti-retroviral treatment means that many PHAs are living longer and can reasonably expect to reach an average (or close-to-average) life expectancy. Nevertheless, PHAs are now significantly more likely to experience social hardships, particularly in the context of health challenges (e.g. increased risk for depression, cancer, organ failure, etc.) and economic marginalization (e.g. increased risk for poverty, homelessness and unemployment).

# Approximately 71,300 Canadians were living with HIV at the end of 2011, representing an increase of 7,300 people (11%) since 2008.

# ● Almost 25,000 Canadians living with HIV/AIDS have died since the beginning of the epidemic. More than just numbers to me: Jamie, Eric, Kalpesh, Ken, Mark, Bernie, Steve, too many more to mention. Lovers, friends, co-workers, clients. Gone. Buried in the numbers.

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In horrified fascination, I watch the media frenzy over the sentencing of Johnson Aziga. “That man, [Johnson Aziga], how many people did he infect and now he’s in jail? I don’t like the thought of jail for anybody but if that’s the only discipline that people will listen to, I guess it has to be” (cited in Adam *et al*, p. 26). Watching Aziga’s body get disciplined in a public sphere, in effect, disciplines my own. In the race to sell ‘news’, the media exploit Aziga’s story, fanning socio-cultural flames of fear about PHAs, re-narrating his sexual encounters as high-profile narratives of despicable criminality. Each news story disciplines my body with internalized judgments, prohibitions and threats of confinement. Aziga’s sentencing becomes my own.

In 2011, Canada had the dubious distinction of leading the world in HIV-related criminal prosecutions. More than 90 Canadians living with HIV have been prosecuted (and almost 70 convicted and incarcerated) of criminal HIV exposure/transmission since the late 1980s (cited by Cameron, p. 63). But it’s not just Canada. The global trend toward the criminalization of HIV is accelerating, increasingly infringing on human rights as it proceeds.

The mediaeval dynamics of public shaming, of gross but partial community condemnation, and of crudely emotive responses instead of considered reactions do not seem too far away. The central part that stigmatized and stigmatizing reactions to [HIV] itself — in contradistinction to anything that those with it have done — continue to play in criminalization should be a profound source of worry. (Cameron, p. 67)

Since the beginning of the HIV/AIDS pandemic, the socio-cultural regulation of HIV-positive bodies has been deeply, oppressively mired in stigma (Block, 2009). The rising number of high-profile criminal cases leads me and many other PHAs to experience an even greater sense of fear, stigma and vulnerability (Adam *et al*, 2012, p. 15). The increasing reliance on the criminal justice system as an instrument for controlling HIV transmission presses me into a double jeopardy. With a legal duty to disclose in advance of sexual activity that poses a “significant risk” of HIV transmission (Adam *et al*, 2008, p. 143), I also find myself in the risky position of increasing the possibility of rejection, stigmatization or, even worse, fallacious criminal allegations (e.g. by an embittered or spiteful sexual partner). “Double binds can scarcely be the foundation for realistic public policy or consistent practice among PHAs” (*Adam et al*, 2012, p. 39). For me, as with many other PHAs, criminalization coupled with intensified stigma render HIV disclosure less safe and less likely. This renders HIV prevention at the level of the individual, likewise, more precarious.

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“The designation *dangerous offender* is reserved for Canada's most violent criminals and sexual predators” (Gale, 2011).

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A growing socio-cultural dissonance (with respect to the structural and discursive factors that fuel the pandemic) is witnessed by the arrival of not only criminalization, but also murder charges and dangerous offender status in the case of Johnson Aziga. Although the AIDS hysteria of the 1980s has passed, “the binaries that separate self from other, observer from observed, responsible and irresponsible remain operative in making sense of HIV transmission” (Adam, 2006, p. 169). Criminalization constructs a subject of HIV prevention consistent with the neo-liberal discourse of individual choice and self-determination. I circulate anxiously through this discourse as I follow the sentencing of Aziga, listening carefully for the moral lessons it encodes, while becoming disoriented by its narrative contradictions and policy dissonance. Inevitably, I fall into the troubling disjunctures of Aziga’s story, more fearful and vulnerable as a secret agent of HIV prevention.

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“[Aziga] said he has filed an application to renounce his Canadian Citizenship because he doesn't feel he faced a fair process” (Gale, 2011).

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In the impulse to criminalize, complex sexual behaviours (e.g. barebacking) are reduced to individual choices devoid of social context and history, allowing policy actors to separate ‘confinables’ from those in society who ‘would never do such a thing’. A moral line is drawn on my body. Imprisoning Aziga for transmitting HIV represents the extension of a confinement that exists first outside the walls of prisons, where the socio-cultural othering of PHAs exerts a hyper-visibilizing effect on ‘risky’ sexual bodies. “Others in body and, therefore, in life. The experience of living in a disabled body, the experience of living in an able-bodied society, the normalcy of a life, particularly an adult life, with a disability – all these complexities are erased” (Barton, 2001, p. 188).

Are the historical policy echoes of eugenics resurfacing in the context of HIV criminalization? Rafter (1997) observes that “in the late nineteenth and early twentieth centuries, some [governments] established eugenic institutions, places where ‘defective delinquents’ and others considered to be innately criminalistic could be incarcerated to prevent them from reproducing” (preface, p. ix). The criminalization (and, by extension, sexual segregation) of Aziga, from a neo-liberal perspective, is a less expensive, more efficient and socially responsible way of restricting HIV transmission (and/or the risk thereof). Historically, Canadian social policies have regulated disabled bodies through bodily marginalization, casting their sexual subjectivities as undesirable or unethical with respect to the health and ‘normalcy’ of the population as a whole (Cairney, 1996).

A history of eugenics in Canada haunts my sexually disabled body, echoes through the empty corridors of HIV criminalization, further dividing my body. Such history seeps eerily into Agiza’s story. And into the narration of my own. It is a history that orients my body toward ‘safer’, monogamous, heteronormative ideals of sexuality. Criminalization confines my queer, disabled body by rendering me highly vulnerable to a history of “incarceration [that is] appropriate to a biologically based deviance that [can] not be cured or punished away” (Mitchell & Snyder, 2002, p. 94).

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“[Aziga] can choose not to have sex. He can choose not to put another person's life at risk. Not because of the Criminal Code of Canada. But because it is the right thing to do” (Spectator, 2011).

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 What is the policy rationale behind HIV criminalization?

To legislate is the equivalent, in almost every domain, to making things more complicated and to centrism, the centralization of political power … To legislate is to impose a norm, a code of the universalist type on phenomena and practices, which until then had been left on their own, to their diversity, empiricism, even their anarchy. A common order is thenceforth imposed. (Stiker, p. 133)

Legislating HIV exposure/transmission imposes a common order on my body, and in doing so, dis-orders it. The threat of criminalization applies less for illegal actions than for a virus that I carry as part of my body. In other words, my HIV status poses no threat with respect to institutionalization, but how my body enacts that status, primarily vis-à-vis HIV-negative others, does. For every HIV ‘crime’ that gets sensationalized across the popular media, my HIV-positive body is further divided and sexually disabled. In the context of HIV transmission, a socio-cultural punishment continuum delivers real threats of public shaming, stigma and discrimination, as well as incarceration and other methods of social regulation.

Institutionalizing Aziga in a Canadian prison for HIV-related ‘crimes’ functions indirectly to monitor and regulate my similarly ‘dangerous’ body. It brings Johnson Aziga’s incarceration into my experience, transports my body into his cell. Now I am sitting beside him in that dismal cell, behind the bars of a federal prison, discussing his conviction for murder**[[13]](#footnote-13)**. I don’t yet know what my role is in this scenario except that I am in critical dialogue with Mr. Aziga about HIV criminalization. I am waiting to be told if I am his social worker or his jail mate. An invisible guard in the panopticon will eventually tell me; he will shout it out from the darkness of the surreal theatre that is my self-narrative.

**Me**: Punishing people in prison for HIV-related ‘crimes’ accomplishes nothing in terms of social welfare or public health. It fails to prevent or reduce HIV transmission[[14]](#footnote-14). Yet, your conviction has negatively changed the meaning of my own infection. Has it changed you, Mr. Aziga?

**Aziga** (laughing derisively): It’s not about changing you, Mr. Wallace. Or me, for that matter. We need to change how HIV-negative people respond to the possible risks. HIV prevention is a mutual responsibility. *I can't force a woman to use a condom … If the woman is a risk taker.*

**Me**: No, but you could disclose your status. Not doing so accomplished little, if anything, in terms of challenging the notion of criminal responsibility for HIV transmission. In fact, your silence produced a troubling legal precedent for all PHAs in this country: a slippery slope of potential danger, aggravated assault, attempted murder, murder. Now the courts can label us dangerous offenders.

**Aziga**: Don’t blame me for that. I’m not a dangerous person. *I am a man of consciousness … I listen to it. It is clear, unambiguous and unmistakable. I had no intention to deliberately pass on my HIV to anyone.* I made mistakes, yes, but in the context of having sex, of doing what is normal, natural and human. And for that, I’m a dangerous offender? Would a man be convicted of murder if he unintentionally impregnated a woman who then died as a result of that pregnancy? If anything is dangerous, it’s ignorance about HIV and the possible range of sexual consequences in being human.

**Me**: I agree with you there, Mr. Aziga. Even if transmitting HIV is a crime, it does not follow that punishment in the form of imprisonment is a necessary response. Criminalization individualizes the solution, but the problem of HIV transmission is, at least in part, the result of larger social conditions. Did stigma or discrimination play a role in your choice to not disclose?

**Aziga**: Yes, absolutely. But it’s still, at the end of the day, an individual choice. Not only mine, but my sex partner’s. *I must give somebody the opportunity to make [a] choice … Beyond that — it depends.* I can’t take responsibility for how other, autonomous people make their intimate, sexual choices. Can you?

**Me**: No, but shouldn’t PHAs focus on creating collaborative social change with people who are HIV-negative, eliminating the divisiveness of stigma and ending the pandemic, rather than inhabiting useless space in prison cells?

**Aziga**: If nothing else, I hope that my imprisonment helps to create the social change that you’re referring to, Mr. Wallace. But, first and foremost, as my wrongful conviction demonstrates, we should focus on protecting ourselves as PHAs. *For my own good, I don't want to get another strain of HIV,* or worse yet, get knifed to death for unintentionally infecting others, which could quite easily happen to me here in this lawless prison.

**Guard**:(yelling out loudly, stage right): You’re his social worker, Mr. Wallace. You work for the prison now. Your visit is over.

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“If any reasonable person could conclude that I am in fact guilty of all the convictions that still stand in this case against me”, said Aziga, “I think that same reasonable person would conclude that I have been reasonably punished for a medical condition” (Loriggio, 2011).

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HIV criminalization represents bad social policy, and it’s wrong, except in cases where it can be proven that a PHA acted with the conscious intent to transmit HIV and, in fact, did so.

The use of criminal law can never be justified when a person with HIV took risk-reducing measures or could not reasonably have used them. These are propositions of policy, but they rest on empirical evidence, practical experience and positive values. (Burris & Cameron, p. 580)

Prisons not only fail to solve social problems (such as HIV transmission) they are more likely to increase rather than decrease crime rates related to those problems (Smith, 2005, p. 121). The over-utilization of prisons to address a range of social problems (e.g. new and emerging pandemics of infectious diseases), which are more appropriately addressed with non-punitive policy measures, constitutes a major crisis for Canadian governments and their public health agencies. Using criminal law to address HIV infection is simply ineffective and unethical (Burris & Cameron, p. 578).

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“Outside the courtroom, Crown prosecutor Karen Shea said the women who survived are experiencing side effects from being infected with HIV and the fact they didn't know about their infection in a timely fashion has directly affected the progress of the disease” (Gale, 2011).

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How might I, as a social worker, play a role in mitigating the use and impacts of criminal law as a policy instrument with respect to controlling HIV transmission? How can I do that in the context of dominant discourses (e.g. obligatory disclosure) and powerful institutions (i.e. public health, the media and the courts)? As a social worker, how might I re-imagine policy initiatives without privileging the individual as the site of epidemiological control, without defaulting to the neo-liberal constructs of risk, choice and self-determination? Unquestionably, there is a need for advocacy and coordinated policy development in key, institutional areas (Adam *et al*, p. 40):

● in ASOsto provide evolving, descriptive (vs. static, prescriptive) ‘safer’ sex education, specifically for PHAs, that does not privilege universal disclosure as the basis for ‘protecting’ others but rather focuses on engaging the unique sexual cultures and discourses of people most affected (e.g. gay men) as a strategy for targeted HIV prevention.

*●* among journaliststo exercise ethical decision-making and extreme discretion with respect to the publication of the identity of PHAs who are charged with HIV-related criminal offences as a strategy for minimizing the possibilities for stigma and discrimination, particularly the media sensationalism of HIV criminal cases.

● among police and prosecutorsto employ a consistent, evidence-informed application of the law when pursuing HIV criminal charges as a strategy to avoid the miscarriage of justice and to uphold the equality and dignity of PHAs who are accused of sex crimes.

The preceding chapters of my self-narrative demonstrate that effective policy interventions with respect to HIV transmission reside in the communities (e.g. queer) that are most affected, rather than in institutions, which is not to suggest that governments have no primary responsibility to act. More than ever, Canadian governments must support targeted and re-invigorated policy strategies at the community level. “Simply put, community governance provides more space for more [PHAs] to participate, to develop a constituency for the human services, and to increase the sense of participants’ self-worth” (McKenzie & Wharf, p. 142). How to reinvigorate the community response is a question that requires obvious attention by policy makers in 2011, yet no such attention is paid. And the band plays on….

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“Aziga has learned his lesson, he says in his closing argument, and the public can rest assured that there is layer after layer of reduced risk” (Huffington Post, 2011).

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Neo-liberalism, in the context of HIV prevention, abandons transmission as a social concern, apart from the ‘criminal’, enlisting the principle of ‘consumer beware’, where governments have minimal role or responsibility. As a Canadian, I am held responsible for my body in a marketplace of HIV risks. Failing that, the government — in its legal apparatus — will take responsibility for my criminalized body. The subjective divide of my sexual/HIV-positive body betrays the complexity, if not sheer impossibility, of attempting to control the problem of HIV transmission exclusively at the level of the individual. This complexity is reflected in the story of Johnson Aziga, a story that exposes the social obligation to provide environments in which ‘protecting’ others from HIV infection is not only feasible and consistent, but also rewarding and empowering.

If eliminating criminalization is politically unattainable, then vigorous efforts to reduce its harms to PHAs are urgently needed. One of the insidious impacts of convicting Aziga for HIV-related crime is that it drags all PHAs into an intractable net of marginalization and stigma, into a trap of no indemnity, into prejudice and greater confinement. Criminalization divides relationships, and it divides communities, which seriously undermines the supportive interpersonal and social environments that are required to prevent HIV transmission. At the end of this reflexive analysis, as the band plays on, it continues to divide the self that I am narrating.

**Concluding Remarks**

I tell these stories not to play on your sympathies, but to suggest how stories can control our lives, for there is a part of me that has never been able to move past these stories, a part of me that will be chained to these stories as long as I live.

— Thomas King, 2003, pp. 8-9

When I came out (as gay) to my mother in 1987, she cried deep, fearful tears, not exactly because I was queer, but because I might, someday, “get AIDS”. I reassured her, in futility, that it would not happen; that I would always, always practice ‘safer’ sex. What else could I say? Already, I was taking responsibility for the queerness of my body, its troubling differences and risky proclivities. But to no avail; my mother’s tears continued to portend…. Sadly, “it is a true saying, that what you fear, you find” (Winterson, *Sexing The Cherry*, 1994).

**~**

My experience of the HIV/AIDS pandemic, over 30 years, constitutes a powerful personal and socio-cultural narrative in my life, permeating my subjectivity as a gay man. The unfolding of my self-narrative over the five, preceding chapters reflects the significance of HIV/AIDS as a formidable object of discourse, not only signifying and inter-connecting my experiences as a gay man, but also informing how I narrate them and what I tell. My self-narrative does not, for example, include the telling of experiences that could directly implicate my body with respect to HIV criminalization. Fortunately, such stories do not exist, but neither would I tell them if they did. And this presents a conundrum for me as a ‘reliable’ narrator, offering ‘valid’ knowledge. Narrating my experience of living with HIV/AIDS, for the purpose of creating useful knowledge, for self and others, represents the incomplete, cautiously selective work of a marginalized narrator, shaping the contours of a face that I can only partially distinguish and reveal.

This conundrum exposes a methodological tension of this autoethnography, particularly with respect to illuminating practical, inter-subjective moralities involved in negotiating the complex, social relations embedded in phenomena such as ‘safer’ sex and obligatory HIV disclosure. My knowing revolves around the presentation of an intentionally vulnerable subject, Brick Wallace, who is also, however, a self-interested narrator with a particular social location. My experience of living with HIV/AIDS would undoubtedly be differently narrated (or, perhaps, not at all) if it were not for my privileges as white, male, economically advantaged, mostly able-bodied and Canadian. These socio-cultural advantages lead me to narrate stories that are concerned more with empowerment and human rights than poverty and day-to-day survival. Thus, the construction of my self-narrative, for all its critique of neo-liberalism, stumbles unwittingly into the prickly bush of liberal individualism, focusing more on civil (i.e. community work) and political (i.e. activism) rights, and less on the social, economic and cultural rights of PHAs.

Nevertheless, throughout my autoethnography, how I conceptualize my narrated self is always as a socio-cultural being, an extension of my individual-ity, contingent and relational in nature. Paradoxically, at the same time that my “I” is relationally, discursively, and textually constituted, my subjectivity as a PHA is singularly and uniquely narrated. As a reflexive subject, I conduct this research as a partially articulated, personal voice. A queer voice that bears witness to the formative, social context in which I live. The urgent calls of “Silence = Death” echoing even still. And Jamie’s voice, too, echoing hopefully through our empty apartment above the fish market.

**~**

 Here, by myself, away from the clank of the world,

Tallying and talked to here by tongues aromatic,

No longer abashed — for in this secluded spot I can

Respond as I would not dare elsewhere,

Strong upon me the life that does not exhibit itself,

Yet contains all the rest. (Whitman, *Leaves of Grass*, 1860, in Groff)

**~**

At many points throughout the process of my research, even now, at this late point, I stop to ask myself: *how is this worthwhile?*

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Until I embarked on this autoethnography, I avoided opportunities to tell my story about living with HIV/AIDS, particularly the infection and post-infection sections of it. Inevitably, a conspiracy of socio-cultural silence permeated my body-self. Diagnosed and disabled, my voice atrophied. My heart stopped calling. I felt a different kind of existential pain as my body’s alien incarnation retreated to a closet, an even darker closet, where I would grope this pain, alone and in silence. And where, in such close proximity, I would eventually (have no choice but to) embrace the pain. Not *in* my body but as an inseparable *part* of it, inscribed permanently in my DNA. Not defining me, but giving meaning to my body’s voice and experience. Extending my queer consciousness.

My proud, queer body-self was temporarily unmade in the pain of becoming HIV-positive. My identity became obscured and devalued through a denial of my voice, which is to say a lack of affirmation of my sense of self, including the meanings of my experience of living with HIV/AIDS as a gay man, both before and after becoming infected, the oppressive as well as the empowering dimensions. My alienated, closeted self, as a PHA, became particularly insufferable to me as I progressed through my training as a social worker, a calling where I could hear and narrate other people’s pain and oppression, but still left mine in a pile of dirty secrets in my closet. And not only my own. Jamie’s also. And Rayne’s. Mike’s too perhaps. And, to a certain extent, Johnson Aziga’s.

My research documents a significant, growing change with respect to socio-cultural responses to HIV/AIDS: “the difference between suffering that has its cry attended to, and suffering that is left in its own uselessness” (Frank, 1995, p. 179), the difference between the empowering, activist responses of the 1980s and the more individualized, institutional ones of today. As my self-narrative suggests, a health/illness (vs. critical disability) discourse is more likely to be heard and engaged in responding to the ‘suffering’ of PHAs’ bodies. ACT UP might well have been less successful, for example, if it had constructed, as its principal concern, the human rights of people with disabilities rather than the health rights of people who were sick and dying. Neo-liberal government responses (facilitated by private market forces) could exploit the health needs and costs associated with a growing, global pandemic. Each new infection represented an opportunistic commodity that could be crafted, for profit, in ways such as pharmaceutical sales or, more insidiously, the incarceration of ‘HIV criminals’ in private detention facilities.

Protesting legal and judicial discrimination would undoubtedly have yielded fewer victories for ACT UP; urgent calls from criminalized, HIV-positive bodies, such as Aziga’s, would be more readily dismissed. To tell my story of living with HIV/AIDS is to claim an inter-related, civic and discursive voice with other PHAs, including those whose ‘suffering’ is rendered ‘useless’ by a prison cell, those whose experience can infuse no such personal or political purpose as the execution of self-empowering research. Thus, I narrate my experience of living with HIV/AIDS in solidarity. And with the hope that the ‘pain’ of other PHAs might feel or hear my response to the urgency of its call.

The irony of narrating my story with a pen name (i.e. disguising my identity), while setting out to challenge stigma, reclaim voice, forge community connections and decrease self-isolation is not lost in the reflexive accounting of my research. Indeed, it represents one of the methodological contradictions and complexities of my autoethnography. Literally, I write myself (and others) beyond identification. Using ‘BrickWallace’, for example. Or I try anyhow, piecing together radically incomplete and figurative accounts of this body’s experience from a trunk of dusty, tattered memories. Paradoxically, so that the I, who is the ‘nameless’ author, might know myself better, what it means to be a person living with HIV/AIDS in my particular socio-cultural context. But, also, so that my readers might participate meaningfully in a kind of cultural remembering, invoking my experience perhaps in other discursive possibilities.

**~**

I release my tongue to the lightning

Memory of Jamie’s body, under blood-

Draining skies, I suck

A past from inside him, that pain

Of his tortured cells filling my mouth

Encoding the billion syllables of our silence

I drink the moon’s light, breathe

Emancipation through my body, his blue skin

Trying until sunrise to distinguish my whispers

Each one toughing lightly, darkly

Oracles for a different future, this voice

Multiplying itself, replicating his life

In my haunted, divided cells

A weakly reactive ghost tracing

The out-

Line of my own unfinished body

**~**

The worthwhileness of my autoethnography, particularly with respect to examining contested socio-cultural phenomena such as HIV criminalization, is not that it tells ‘the truth’, but that it compels me to demonstrate how multiple truths co-exist in a multiplicity of bodies. It reminds me that PHAs have different ways of understanding and making sense of HIV/AIDS, particularly with respect to where and how one is positioned socially as a ‘risky’ subject. I attempted to convey this complexity through both the evocative and analytic narratives of my research. A crisis of identity, meaning and belonging (as a gay man) shaped my methodology by bringing into focus the importance of critical and post-structural perspectives to understanding how complex socio-cultural phenomena, such activism, community service, ‘safer’ sex, diagnosis and criminalization informed my subjectivity as a queer PHA.

Throughout my research, my limited point of view (as a first-person, narrator) emphasized my individual consciousness and fostered a critical awareness of me as the teller (Dillard, 1982). I discovered that as I constructed my self-narrative, my experience of living with HIV/AIDS tended to become psychological and interiorized. External or social conflict (e.g. disclosure issues) risked becoming solely internal tensions with respect to the exploration of my experience as a PHA. As a reflexive narrator, I countered this risk by paying frequent attention to the relational ‘silence’ in my stories, reflecting an awareness that I was also narrating an external world, engaging in the stories of ‘self-with-others’ as a kind of cultural memory and confession. And a quest for self-expression and empowered voice. Ultimately, by engaging with other, ‘silenced’ voices of PHAs, from Jamie’s to Johnson Aziga’s, I recovered my own more external, social voice.

My self-narrative helps to recount important personal/cultural memories such as ACT UP’s occupation of St. Patrick’s Cathedral and the neo-liberal reformation of AIDS service organizations. My research illuminates my past while helping me to situate my own present subjectivity with respect to that history of pandemic colonization: illness, death, trauma, and multiple loss, as well as activism, community service, empowerment and survival. By narrating my experience of living with HIV/AIDS as a gay man, I enrich my critical consciousness as part of surviving and challenging the pandemic. After 30 years, I am still living in the hurricane’s eye. To have expected, as I once did, in 1987, that my vulnerable body would suffer no pain, no colonization, no disability whatsoever, was perhaps to have grossly underestimated the size and scope of the storm surrounding me, its constantly gathering presence in my life. That perfect storm combination of ‘individual responsibility’ and the risk of an intensely scrutinized, deadly virus.

**~**

Living with HIV/AIDS both facilitates and disrupts my connections with other queer men and PHAs, personally and politically, shaping my sense of identity and community, including here in the telling of my story. Drawing out the relationship between living with HIV in my body and being queer, at this juncture in my personal history, is a central function of my self-narrative. The orienting lines (Ahmed, 2006, p. 66) of my body’s seropositive sexuality intersect with its dis-ability in ways that ‘shape’ bodily constraint, ways that “inhibit my body such that it ceases to extend into phenomenal space” (*ibid*) such as the space of unlimited intimacy or the space of sexual freedom, while extending it more into the socio-cultural phenomena of ‘risk’ and ‘responsibility’, spaces that I explored in my final chapters. My other chapters, also, demonstrate how my sexual identity (as an empowered, HIV-negative gay man) intersected importantly with my ability to mitigate my body’s risk for HIV colonization, specifically with respect to the work of activism and community service, both of which reinforced the praxis of ‘safer’ sex as an aspect of my gay identity. Becoming infected with HIV might have happened much earlier in my self-narrative if it were not for the protective, collateral aspects of these able-bodied, community experiences.

Maybe the slash line in HIV**/**AIDS represents a point of blurred intersection between my sexual and disability identities. A complex point where my subjectivity as queer PHA becomes multidimensional rather than simply binary. A line that joins but separates the *living* with HIV/AIDS from the *dying*: the experience of queer activism, community service and critical disability on the one side, and dis-ease, alienation and marginalization on the other.

**~**

My self-narrative betrays a queer subjectivity that is not merely a reified, theoretical entity determined by external, discursive, and ideological dis-orders. Rather, my subjectivity also emerges through my exploration of a reflexive *individual culture*, which changes and connects more broadly through my storytelling and analysis, through engaging in a dense, discursive web of moral significance. I cannot explore my subjectivity without recounting how, as the subject of my research, I am enmeshed in a cultural context, and more specifically, in the context of embodied social relationships and discourses. These inter-subjectivities provide the epistemological and ontological foundations for my autoethnography. Illuminating them constitutes one aspect of the value of my research. My self-narrative challenges the assumption that one’s experience of living with HIV/AIDS is individual, alone, primarily a physical or bodily experience and culturally or socially irrelevant. Creating knowledge about my queer body and embodied experiences as a PHA, my everyday grounded moralities, exposes the structures of power, surveillance, and control (both internal and external) that operate to shape my subjectivity. This is how my research is worthwhile.

At the end of each chapter, I attempted to provide my reader with summary thoughts or ‘conclusions’ about my research. As an autoethnographer, I would be remiss in offering neatly packaged, relevant ‘conclusions’ that necessarily represent valid or transferable outcomes in an objectivist tradition of research. As noted in my methodology section, I set out to conduct a study that would be more about my process of knowing my experience of living with HIV/AIDS, rather than the empirical outcomes of that knowing; more about my HIV subjectivity as a process of *becoming*, rather than *being*,knowledge. In doing so, however, I also produced knowledge in a more conventional sense with respect to how evolving, competing discourses regarding HIV/AIDS, including changing notions of ‘risk’ and ‘responsibility’, unfold in the context of a person’s life. I demonstrated how such discourses matter both to my experience of living with HIV/AIDS and, more broadly, to socio-cultural responses to it. Both to my empowerment as a PHA and to social justice.

From a post-structural perspective, I leave the task of deriving further conclusions to my readers. To those who might participate inter-subjectively. Perhaps some new knowledge or awareness or ‘truth’ glimmered in the telling of my story. Something you can use discursively or practically. Something yours.

My concluding remarks are practical and relevant to the extent that they are rendered ‘truthfully’ through my experience of living with HIV/AIDS. Admittedly, I am a highly subjective, contestable narrator. However, “clean and reasonable scholarship about messy, unreasonable experiences is an exercise in alienation” (cited by Tamas, 2013, in Jones *et al*, p. 199). ‘Clean’ or ‘reasonable’ conclusions might undermine the construction of my intentionally unsettled, untidy self-narrative, including its essential, epistemological commitment to the evocative multiplicity of human experience, to emotion and the body, to chaos and dis-order. My concluding remarks, therefore, reflect what and how I feel about my research, grounded in my body here and now, recognizing that I am constantly shaping and re-shaping my subjectivity as a PHA.

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My autoethnography demonstrates that my knowledge of HIV/AIDS is relational, reflexive and shaped largely by my citizenship and historical location. This is particularly relevant with respect to my queer and disability perspectives. “People in positions of oppression develop a more critical and complex view of social reality, a ‘double consciousness’, so to speak” (Finn & Jacobson, 2008, p. 174). Representing and understanding what constitutes my ‘double consciousness’, with respect to my particular experience of living with HIV/AIDS, is important with respect to how this study is worthwhile for me. And, I hope, to others, particularly other PHAs.

Taking myself and my lived experience as the primary focus of my research produces its own kind of empathic knowledge. A kind that connects, through meaning and power, to both self and others. For me, critical knowledge emerges in narrating how my queer identity is enmeshed in socio-cultural contexts, and more specifically, in the context of the embodied, social relationships represented by the HIV/AIDS pandemic. Creating knowledge about my body and embodied experience engages, however, just iceberg tips of the dominant, socio-cultural discourses on HIV/AIDS, discourses that are increasingly concerned with the surveillance and control of PHAs’ bodies. By troubling notions of ‘safer’ sex, I foreground embodied narrative as a site for creative resistance and engagement with socio-cultural forces (i.e. criminalization) that are increasingly deployed, outside and surrounding vulnerable bodies, to contain the pandemic.

Through examining my experience of living with HIV/AIDS, I came to feel and know the changing contours of my subjectivity as a gay man differently than I had before. My autoethnography provided an opportunity to creatively (re)make myself through an empowering, re-search process. In the end, a socio-cultural journey too. Guided by myriad, evocative practices that informed my approach: dialogue, symbolism, eroticism; reflections that I intentionally disoriented in time and place; experimentation with the representation of lived experience; and the construction of a multiple, connected voice. My interwoven analysis demanded a kind of transformative consciousness. And that consciousness demanded the recovery of the value and meaning of my experience of living with HIV/AIDS, including how narrating and re-searching that experience is worthwhile.

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DATE: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**APPENDIX A**

**LETTER OF INFORMATION /CONSENT**

**FOR POTENTIALLY IDENTIFIABLE PARTICIPANTS**

**A Study about living with HIV/AIDS**

**Student Researcher:**

Brick Wallace

School of Social Work, Department of Social Science

McMaster University

Hamilton, Ontario, Canada

**Faculty Supervisor:**

Dr. Christina Sinding

School of Social Work, Department of Social Science

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905-525-9149 x 22740

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**Purpose of my study**

The purpose of my research is to explore my life story as a gay man living with HIV/AIDS (PHA) in order to better understand social-cultural phenomena such as safer sex, stigma/discrimination, disability and community activism. I am conducting this research as a requirement for the completion of my Master of Social Work.

**Procedures involved in my research**

As you can imagine, as I tell my life story, the people in my life will appear in that story, including you. My intent is not to tell ‘the whole story’ of my life or our relationship, but only specific encounters or events that help readers understand key themes in the experience of being gay and living with HIV.

I want to be sure that you are comfortable with how I describe our relationship and interactions. Therefore, I will send you (by email) a draft of the sections of my story in which you appear. I will invite your comment on these, but you will not be expected to do so. If you are comfortable with what I have written, nothing further will be required of you. If you are uncertain or wish to discuss what I have written, then we can meet to discuss your comments. I would then revise my story based on our discussion. If you are not comfortable with anything that I write in my drafts, then I will not include it any further in my study.

**Potential harms, risks or discomforts**

It is not likely that there will be any harms or major discomforts that result from your appearance in my story. Nevertheless, my stories will deal with emotionally-charged and potentially stigmatizing topics. I will check in with you regarding how and to what extent you are implicated in my stories before finalizing all drafts. If, for any reason, you are not comfortable appearing in my stories, then you can withdraw your participation (as detailed below).

**Potential benefits**

This study could have benefits in terms of implications for HIV/AIDS care, education/prevention, community development, policy and research.

**Confidentiality**

As much as possible, your identity will be concealed. However, since our personal histories and experiences overlap significantly, others could be able to identify you through some of my story’s details or through your relationship to me.

All information that involves you will be kept in a locked cabinet where only I will have access to it. Information stored on my home computer will be protected by encryption. Once my study has been completed, the information in which you are implicated will be securely stored and destroyed, along with the remainder of the data, after two years.

**Participation and withdrawal**

Your participation in this study is voluntary. You will be able to withdraw, without question or consequence, at any time until July 1, 2014, at which time I must begin finalizing my thesis for submission. After July 1, it might not be possible for me to withdraw the data or consents that you provided. I will expect that you notify me verbally, as soon as possible, if you would like to withdraw from my research.

**Information about the study results**

My study will be completed by the end of August 2014*.* If you would like to receive a brief summary of the results or notifications of any outcomes of this research, please indicate (below) where you would like it to be sent.

**Questions about the Study**

If you have questions or need more information about the study itself, please contact me at: (*deleted in appendix*)

This study has been reviewed by the McMaster University Research Ethics Board and received ethics clearance.

If you have concerns or questions about your rights as a participant or about the way the study is conducted, please contact:

 McMaster Research Ethics Secretariat

 Telephone: (905) 525-9140 ext. 23142

c/o Research Office for Administrative Development and Support

 Email: ethicsoffice@mcmaster.ca

**Consent**

* I have read the information presented in the preceding information letter about the research being conducted by Brick Wallace, MSW candidate at McMaster University.
* I have had the opportunity to ask questions about my possible participation in this study, including the risks and benefits, and to receive additional details if requested.
* I understand that if I agree to participate in this study, I can withdraw my participation partially or fully, without consequence, at any time until approximately July 1, 2014**.**
* I have been given a copy of this form.
* I fully agree to participate in the study.

Signature \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Name of Participant (printed) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

In addition to participating in this study, would you like to receive a summary of the findings and/or notifications about any outcomes of the research such as publications or presentations?

Study results: Yes or No (*circle one*)

Notifications about outcomes: Yes or No (*circle one*)

If yes, please send to this email/mailing address: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

DATE: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**APPENDIX B**

**RECRUITMENT SCRIPT**

**FOR POTENTIALLY IDENTIFIABLE PARTICIPANTS**

**A Study about living with HIV/AIDS**

**Student Researcher:**

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**Faculty Supervisor:**

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**I will cover these main points when recruiting all participants:**

- I am conducting a research project, looking at my life story as a gay man living with HIV. My research is as a requirement for the completion of my Master’s of Social Work at McMaster.

- I have selected you as a potential participant because you figure importantly in my life story.

- Your participation would involve:

 - meeting to sign consents

 - reviewing draft sections of my thesis in which you appear

- Your confidentiality would be completely protected.

- I have absolutely no expectation that you participate. I can still complete my research if you choose not to participate.

- If you choose not to participate, our relationship/friendship will not be affected in any way.

- I’m wondering if you might be interested in taking part. Please take whatever time you might need to think about it.

1. Brick Wallace is a pen name. [↑](#footnote-ref-1)
2. I borrow the notion of ‘queer’ that Ahmed (2006) invokes: “*queer* can only be read as the source of injury: a sign of the failure to repay the debt of life by becoming straight” (p. 91). My use of the term ‘queer men’ applies inclusively to all men who have sex with men, whether they identify as gay, bisexual, straight (or something else). [↑](#footnote-ref-2)
3. When I refer to the ‘criminalization of HIV’, I mean both introducing laws specifically aimed at punishing people who might expose/transmit HIV, as well as the application of general laws in ways that target people living with HIV who have allegedly acted in that way (Cameron, 2009). [↑](#footnote-ref-3)
4. The presence of familiar others is critical to my analysis, revealing “behavioral repertoires and mental structures” (Tamas, 2013, p. 191), as well as discursive practices. [↑](#footnote-ref-4)
5. Kaposi’s sarcoma [↑](#footnote-ref-5)
6. A *daddy* in gay culture is a term meaning an older man sexually involved in a relationship or having a sexual interest in a younger man. [↑](#footnote-ref-6)
7. In male bisexual and gay culture, a *bear* is a large, hairy man who projects an image of rugged masculinity (Wikipedia, 2014). [↑](#footnote-ref-7)
8. Alcoholics Anonymous [↑](#footnote-ref-8)
9. sexually transmitted infection [↑](#footnote-ref-9)
10. When I refer to the ‘criminalization of HIV’, I mean both introducing laws specifically aimed at punishing people who might expose/transmit HIV, as well as the application of general laws in ways that target people living with HIV who have allegedly acted in that way (Cameron, 2009). [↑](#footnote-ref-10)
11. This rationale “holds that disclosure is required in all sexual interactions of HIV-positive people. Failure to disclose *per se* warrants criminalization” (Adam *et al*, p. 37). [↑](#footnote-ref-11)
12. source for all epidemiological statistics: Public Health Agency of Canada, 2012. [↑](#footnote-ref-12)
13. In the imaginary dialogue that follows, I integrate direct quotes (in italics) from Johnson Aziga, reported during his court proceedings (by Clairmont; by Gale). [↑](#footnote-ref-13)
14. (Burris & Cameron; Adam *et al*, 2012). [↑](#footnote-ref-14)