

**The Lived Experience of HIV/AIDS:
A Poststructural Analysis of the Impact of Stigmatization on the
Identity Constructions and the Experiences of Grief for Persons Living
with HIV**

By

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ABSTRACT

Since the beginning of the HIV/AIDS pandemic, the typical (mis)perception of HIV/AIDS held by Canadian mainstream society has been that it is a disease of “social deviants.” Despite evidence that HIV/AIDS does not discriminate, HIV/AIDS myths persist. Even in a time of new advancements in highly active antiretroviral therapies when the lives of persons living with HIV/AIDS (PHAs) are being lengthened, stigmatization continues.

In the beginning, the intention of this project was to address how stigma influenced how participants experienced grief, if they do so, and (re)constructed their identities in stigmatizing social environments. As this project unfolded, however, participants identified stigma as more significant in its relationship to their subjectivities as citizens. Grief appeared in interviews only as a background piece. Therefore, this thesis has finished as an analysis of how stigma experienced by 10 PHAs has influenced their subjectivities as citizens and, to a lesser degree, their experiences of grief.

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LIST OF ABBREVIATIONS

- AIDS: Acquired Immune Deficiency Syndrome
- ASO: AIDS Service Organization
- HAART: Highly Active Antiretroviral Therapy
- HIV: Human Immunodeficiency Virus
- LGBTQQ*: Lesbian, Gay, Bisexual, Transgendered, Two-Spirited, Questioning and/or Queer
(This abbreviation is followed by an asterisk to denote any other sexual and/or gender identities that are not represented by the abbreviation itself).
- PHA: Person living with HIV/AIDS

CHAPTER 1: INTRODUCTION

Since the early years of the HIV/AIDS¹ pandemic, the typical (mis)perception of HIV/AIDS held by Canadian mainstream society has been that it is a disease largely affecting “social deviants,” including intravenous drug users, sex workers, “promiscuous” individuals², men who have sex with men and racialized peoples, particularly persons of Haitian descent (Demmer, 2001; Ryan, Hamel & Cho, 1998; Singhal & Rogers, 2003). In reality, these activities, forms of paid employment and identities do not in and of themselves result in exposure to and contraction of HIV. Instead, it is the sharing of used needles and engaging in penetrative anal and/or vaginal sex without the use of lubricated condoms, dental dams or gloves that place individuals at risk of exposure to and contraction of HIV. Nevertheless, despite the evidence that HIV/AIDS does not discriminate based on drug use, occupation, sexual identity or race, myths around HIV/AIDS have endured for 25 to 30 years (Ryan et al., 1998; Singhal & Rogers, 2003). Unfortunately, with marginalized and stigmatized groups carrying disproportionate percentages of infection, HIV/AIDS continues to be classified as an illness that only infects and affects persons who deviate from that which is perceived as “the norm” (Lewis, 2005; Ryan et al., 1998; Singhal & Rogers, 2003).

In the third decade since the initial discovery of HIV/AIDS, with the advancements of highly active antiretroviral therapies (HAARTs), HIV/AIDS has been re-classified as a *chronic or manageable disease* instead of one that is an *acute infection*

¹ Human Immunodeficiency Virus and/or Acquired Immune Deficiency Syndrome

² In mainstream Canadian society, for a person to engage in sexual activities with multiple partners seems to automatically be viewed as “bad” or “immoral” given that monogamy has been constructed as “the norm.” Furthermore, it is also often presumed that such individuals are at greater risk of being exposed to and contracting HIV than persons in monogamous partnerships; however, individuals who have multiple partners may be practicing safer sexual practices than such couples because these individuals may be using forms of protection, such as condoms, dental dams, gloves and/or lubricants, in their sexual engagements that couples may not be utilizing.

(Ciambrone, 2003, 2001; Doka, 1997; Rosengarten, 2005). In a time when one would expect a celebration was in order to honor the lengthening of the lives of persons living with HIV/AIDS (PHAs)³ with such advancements, the prejudice and alienation experienced by PHAs has not declined (Demmer, 2001). In reality, PHAs who are fortunate to be living longer are now being confronted with extended periods of oppression, discrimination and social stigma (Demmer, 2001).

In this thesis, I will examine how a small group of PHAs experience stigma and discrimination and how, for these individuals, such stigma has shaped their subjectivities and influenced the presence or absence of grief.

Significance of Project

The major purpose of this research project has been to draw on the narratives of a small group of PHAs to evaluate how stigma surrounding HIV/AIDS has influenced or has not influenced their lives, particularly around their subjectivities and their experiences of (or lack of) grief. I began this project with the goal of examining the identity (re)construction of PHAs and the (potential) grief PHAs experience given the reality that they often have to come to terms with their diagnoses with limited spaces to openly discuss their experiences of living with HIV/AIDS. Overall, the initial intention of this project was to address how PHAs construct and/or re-construct their identities and experience grief, if they do so, in social environments that are stigmatizing and that do not often enable or encourage them to candidly talk about their experiences of living with chronic illness.

³ It is important to note that within the HIV/AIDS movement *persons living with HIV/AIDS* can be abbreviated as either *PHA* or *PLWHA*. In this research project, PHA has been used in order to be consistent with the language of participants.

Quite interestingly, as this project unfolded it became clear that, for participants, stigma was more significant in its relationship to their notions of citizenship and subjectivities as citizens, than in its relationship to grief. Specifically, participants told their life stories in ways that not only challenged or reduced stigma and discrimination they experienced, but also simultaneously and inadvertently reproduced and reinforced particular kinds of citizenship. Furthermore, while grief was present in our interviews, after I reviewed the transcripts, grief appeared more as a background piece in our discussion than a main focus. Therefore, this thesis has become as an analysis of how the stigma experienced by a small group of PHAs influenced their subjectivities particularly as citizens and, to a lesser degree, their experiences of grief.

Research Question

Initially, the main question that guided my research was: How does social stigma impact identity (re)construction for PHAs? As time passed and I talked with more participants, my question shifted and split into two questions. The first having been: How does social stigma influence the subjectivities of PHAs? While the second was: In what ways do mainstream perceptions or ideas around grief influence the ways that PHAs grieve or do not grieve?

Theoretical Framework

Throughout this thesis, I will be working from a poststructural perspective, drawing particularly on the work of Michel Foucault. In using this theory, I will be attending to the discursive relations in which people are framing their experiences

(Hardin, 2003). More specifically, in this project, poststructuralism has offered me the opportunity to examine the ways in which broad and dominant systems of language within western societies influence how our subjectivities are continuously shifting, being (re)constructed through language and influencing how we, as citizens, come to understand and experience our lives (O'Reilly, 2004). For this analysis, the works of Barbara Cruikshank (1999), Jan Fook (2002), Karen Healy (2000), Nikolas Rose (1990), Paula Treichler (1999) and particularly Michel Foucault (1978, 1986, 1988a, 1988b, 1994a, 1994b, 1994c) were found to be most helpful.

In my search for the theoretical framework most suited to this project, I realized that in more traditional interpretive research practices:

...[I]anguage produced by research participants is treated as if it (a) provides a transparent window into internal experience or understanding and (b) originates with the participant. This treatment of language obscures the relationship between individuals and the discourses to which they have access. (Hardin, 2003, p. 538)

Poststructuralism, on the other hand, alerts us to the ways that language is laden with the values, beliefs and norms of mainstream society that influence how our lived experiences are constructed (Belsey, 2002; Treichler, 1999). As argued by Treichler (1999), "Language is not a substitute for reality; it is one of the most significant ways we know reality, experience it, and articulate it" (p. 4). Since social stigma, grief and identity construction (or subjectivity) are all expressed through language, the experiences of these phenomena are all influenced by and created through language and the meanings behind that language. Language used in various mediums, including mainstream media, research literature and everyday discussions, reinforce many stigmatizing and problematic social values and beliefs, particularly around HIV/AIDS (Treichler, 1999). For instance, words

used to describe our perceptions of HIV/AIDS such as “disease,” “sexually transmitted” and “virus” are often loaded with meanings that facilitate the perception that HIV/AIDS is outside of our realities, which allows us to address this pandemic only in abstract ways (Treichler, 1999). It was, therefore, helpful for this research to examine language, stigma and (particular expressions of) mourning as social constructions that have the potential to influence the lived experiences of PHAs.

Poststructuralism, as the theoretical foundation of this project, has also been chosen because it challenges structural conceptions of *power*. Structuralism holds that power operates in a top-down fashion (Foucault, 1994c; Rose & Miller, 1992). As a result, power and freedom are generally viewed as opposites, where the state is believed to control populations by exercising its power over individuals or groups of individuals and their freedoms (Cruikshank, 1999; Foucault, 1994c; Fook, 2002). Although such theories are helpful when describing oppression and domination, such conceptions of power are limited in describing the complexity of these experiences. For Foucault (1994a):

...[structuralism's] reductionist vision of the relative importance of the state's role...renders [the state] absolutely essential as a target needing to be attacked and a privileged position needing to be occupied. But the state, no more probably today than at any other time in its history, does not have this unity, this individuality, this rigorous functionality, nor, to speak frankly, this importance. Maybe, after all, the state is no more than a composite reality and a mythicized abstraction, whose importance is a lot more limited than many of us think. (p. 220)

As an alternative way of thinking about power, Foucault (1994c) suggested that power shapes the lived experiences or the *subjectivities* of individuals by:

...operat[ing] on the field of possibilities in which the behavior of active subjects is able to inscribe itself. It is a set of actions on possible actions; it incites, it induces, it seduces, it makes easier or more difficult; it releases

or contrives, it makes more probable or less; in the extreme, it constrains or forbids absolutely, but it is always a way of acting upon one or more acting subjects by virtue of their acting or being capable of action. A set of actions upon other actions. (Foucault, 1994c, p. 337)

In this way, the power relations in which citizens engage influence the language they use, the knowledge they adopt and the activities in which they partake; however, power in this sense is not only restrictive, it is also productive. The role of the state and its institutions is not only to define the actions one citizen takes, but to also *shape* the citizen and to compel her or him to do particular actions (Cruikshank, 1999; Mills, 2003).

It is this intricate dynamic of power operating over citizens and within citizens that Foucault (1994a) described as *governmentality*, which is believed to be:

...[t]he ensemble formed by institutions, procedures, analyses, and reflections, the calculations and tactics that allow the exercise of this very specific albeit complex form of power, which has as its target population, as its principal form of knowledge political economy, and as its essential technical means apparatuses of security. (p. 219)

This ensemble is comprised of “experts” (or “professionals”), agencies and organizations that have been authorized to provide interventions to individuals “in need” (Cruikshank, 1999). These experts, which include case managers, social workers, psychologists, physicians, police officers, lawyers and judges, to name only a few, are not actors operating directly from positions within state power, but rather are actors at the level of the social (Cruikshank, 1999). In other words, these experts are members or citizens of the “target populations” over which power is operating. For Foucault, again, governmentality did not just involve these experts imposing ways of acting, being and living upon individual citizens; instead he suggested that governmentality involved the interaction of *technologies of power/domination* of others and of *technologies of the self*. Technologies of power/domination “determine the conduct of individuals and submit

them to certain ends or domination, an objectifying of the subject,” while technologies of the self⁴:

...permit individuals to effect by their own means or with the help of others a certain number of operations on their own bodies and souls, thoughts, conduct, and way of being, so as to transform themselves in order to attain a certain state of happiness, purity, wisdom, perfection, or immortality. (Foucault, 1988b, p. 18)

In other words, governance (or governmentality) involves individuals or subjects adopting disciplinary expectations and norms put forward and reinforced by the state and its institutions that define “appropriate” language, behaviour, beliefs and one’s general “ways of being” and applying these ways of life to their everyday interactions. Governmentality, thus, functions and is successful not because it is forced upon individuals, but rather individuals (or citizens) personally commit to adhering to particular values, beliefs and general ways of life through *choice* (Cruikshank, 1999; Rose, 1990). Individuals make or consume choices in line with what they perceive, or what they have been encouraged to perceive, will help them to achieve the “good” life and citizenship (Rose, 1990; Rose & Miller, 1992). In other words, one is:

...required to construct a life through the exercise of choice from among alternatives...[and] every choice we make is an emblem of our identity, a mark of our individuality, each is a message to ourselves and others as the sort of person we are. (Rose, 1990, p. 227)

Subjects are, thus, engaging in *regulated freedom*, where they are defining their actions according to predetermined norms (Rose & Miller, 1992). It is through this regulated freedom that citizens are made (Rose & Miller, 1992).

It is important to note that Foucault also argued “where there is power, there is resistance” (Foucault, 1978, p. 95). As Lupton (1997) writes:

⁴ This technology will be discussed in greater detail further on in this paper.

Foucault himself was careful to emphasise frequently that where there is power there are always resistances, for power inevitably creates and works through resistance. He acknowledged that the existence of strategies of power does not necessarily correspond with the successful exertion of power, and that intended outcomes often fail to materialise because disciplinary strategies break down or fail. (p. 102)

In other words, although relations of power may always be operating around and through us, resistance always accompanies these relations, where citizens can defy these techniques and strategies of power (Lupton, 1997). The concept of *resistance* is important in this research project because it encourages me not only to address and think about the ways in which participants (and myself) reinforce particular notions and norms, but also the ways in which we simultaneously challenge certain notions.

Another perspective of poststructuralism that will be evident in this thesis is *citizenship*, particularly through the literature of Deborah Lupton (1997), Sarah Nettleton (1997), Alexandra Howson (1998), Eric Oddvar Eriksen & Jarle Weigård (2000), Mark Philp (2000) and Ashley Currier (2003). Many of these writers draw on Foucault's notions of governmentality, discipline and surveillance to help explain notion of citizenship. The common concept of citizenship generally describes one's standing in politics, where one has access to particular rights and entitlements (Eriksen & Weigård, 2000; Philp, 2000). These rights include those that are *civil*, which defend the individual citizen from the abuse of power by the state; *political*, which enables citizens to partake or participate in government and to hold their rulers accountable for their actions; *social*, which ensure citizens the protection of a social safety net consisting of, for instance, support services and *economic*, which permit citizens to financially support their families in dignity (Eriksen & Weigård, 2000; Philp, 2000).

This notion of citizenship, although it may seem cut and dried, is actually quite paradoxical. On the one hand, citizenship allows a person to access certain rights and entitlements but, on the other hand, it also subjects that individual to various responsibilities and to particular types of regulation, which constrain how she or he thinks and acts in certain environments (Eriksen & Weigård, 2000; Howson, 1998; Philp, 2000). Citizenship involves partaking in practices of surveillance and regulation not only by institutions of the state, but also by the self (Howson, 1998). Subjects are encouraged by the state, its institutions and fellow citizens to adopt particular ways of living in order to be considered or classified as “responsible” citizens (Currier, 2003). Considering the issue of health, for example, in order to “stay healthy,” responsible citizens manage the foods they eat, take their vitamins and/or medications regularly, exercise frequently and manage their levels of stress (Nettleton, 1997; Stacey, 1997). The citizen, thus, comes to represent a person who takes care of the self, in addition to caring for the family, so that she, he and/or they do not become burdens on the state and its institutions and so that she or he can demonstrate her or his care for society (Nettleton, 1997). In this research project, the theory of poststructuralism and the concept of citizenship will be used to facilitate the analysis of participants’ narratives in such a way that we are able to address how mainstream perceptions of HIV/AIDS, of stigma and of grief influence participants’ accounts of their experiences.

Literature Review

Defining Stigma

The first body of literature that is of relevance to this study is that relating to *social stigmatization*, or *stigma*. Stigma is an imprecise term, which is evident given the numerous definitions of the term (Link & Phelan, 2001; Page, 1984). Nevertheless, its many definitions and conceptualizations can be helpful in providing potential explanations and descriptions for the experiences of those who have been labeled, stereotyped, alienated and discriminated (Link & Phelan, 2001).

Most literature reviewing stigma tends to have an *individualistic focus* (Link & Phelan, 2001; Goffman, 1963). A number of definitions of stigma use words such as “attribute,” “mark” or “stain,” which works to place the given experience or identity *within* the individual (Link & Phelan, 2001). For instance, in the mid-1960s, Erving Goffman provided some of the earliest literature about stigma being a lived experience for many people. Goffman’s definition, although valuable for the dialogue that it began and for laying the foundation of addressing stigma as an actual experience, is also problematic in that he regarded stigma as “an attribute that is deeply discrediting” (Goffman, 1963, p. 3). In definitions such as this one, instead of stigma being regarded as an external designation or tag being affixed or projected upon an individual by others in her or his environment, “[t]he stigma or mark is seen as something *in the person*” (Link & Phelan, 2001, p. 366). This individualistic focus put forward by authors such as Goffman turns attention away from the problematic nature of how mainstream society places expectations on its citizens to be particular kinds of people, who make particular

kinds of choices that uphold “righteous” and “proper” practices. Instead of using this individualistic, internalized notion of stigma, this paper will rely on the construction of stigma as representing and reproducing certain relations of power (Link and Phelan, 2001; Herek, 1999). In such a definition, the significant aspect of stigma is its role in supporting particular relations of domination and submission. It is a mechanism through which we regulate citizenship, where good, valuable, responsible citizens are recognizable because of their lack of stigma.

Another important concept to this thesis that is related to stigma is *choice*. We live in a time where our choices are believed to be plentiful and independent from our social contexts; however, in our everyday lives, our choices reflect a complex interplay between individual agency and social relations (Rose, 1990). In other words, our choices are regulated in that some choices are perceived as responsible and, thus, shore up the possibility of us being regarded as accountable and good citizens, while other choices place our citizenship in jeopardy. For instance, linking this concept to literature of “risk groups,” engaging in practices that are deemed risky is believed to be a choice that we make. Sharing used needles and/or engaging in unprotected sexual activities are believed to be controllable behaviours since one can *choose* to engage or not to engage in them. Individuals who partake in such activities are held responsible by society if they, for instance, are exposed to and contract HIV and, thus, are “assigned more blame, receive less sympathy, and face more anger, than those [persons] who are perceived as ‘innocent victims’ [living with HIV/AIDS, such as children and individuals who have received blood transfusions]” (Singhal & Rogers, 2003, p. 250). Although diagnoses of HIV have been identified as increasing amongst less stigmatized groups, persistent concentration on

HIV/AIDS in marginalized groups and groups that are socially stigmatized supports the classification of this condition as a concern for only peoples of the margins (Ryan et al., 1998; Singhal & Rogers, 2003). This conceptualization of choice is interrogated in this study because experiences of stigma are often heightened for individuals who are believed to be “responsible” for their circumstances (Herek, 1999). Such a placement of responsibility upon the individual by mainstream society, however, is not generally regarded as being complicated by a person’s social-political contexts or by her or his desires. Without such an examination, many PHAs are perceived as engaging in activities that left them vulnerable to being exposed to HIV and, thus, are held responsible for their diagnoses, which heightens their experiences of stigma and discrimination.

Another body of literature that will be used for this study in discussions around stigma focuses more specifically on how HIV/AIDS stigma has been engendered by early discourses of *risk groups* that linked HIV/AIDS to drug use, sex work, promiscuity, gay male sex and racialized groups (Herek, 1999; Ryan et al., 1998; Singhal & Rogers, 2003). These works attend to the ways this pairing has further stigmatized individuals who engage in one or more of these practices or identify as existing within one or more of these constructed groups. With health literature focusing on HIV/AIDS diagnoses in stigmatized groups rather than on means of transmission, there has been an emphasis on or a labeling of risk groups, instead of *risk factors* (Doka, 1997; Mallison, 1999; Ryan et al., 1998; Singhal & Rogers, 2003; Weitz, 1991). There is an assumption, for instance, that HIV/AIDS is “more common” amongst men who have sex with men because of the “risky” sexual acts in which they are believed to engage, such as anal sexual intercourse

and fellatio (Doka, 1997; King, 1993). The fact that many female-male couples engage in similar sexual activities is often ignored or perceived as “normal” due to female-male couples being “the norm.” The result of this construction is that men who have sex with men are considered, both implicitly and explicitly, as a “risk group.” This classification of HIV/AIDS as a “gay man’s disease” (in a local context and as an “African disease” in a global context) can leave individuals who identify as straight (and as non-Africans) to mistakenly believe that they are “safe,” when in fact, depending on the needle exchange practices and the forms of protection we each use or do not use, we are all at risk (King, 1993; Patton, 1993). In general, through the construction of risk groups, activities such as intravenous drug use and non-marital vaginal and/or anal sexual activity, along with the individuals who partake in them, have been classified as “deviant” and “dirty,” while practices, such as monogamy, marriage and sexual engagements only for procreation, are deemed “righteous” and “pure” (Treichler, 1999). In reality, intravenous drug use, along with vaginal and/or anal sex, are not necessarily risky behaviours. It is the sharing of used needles and engaging in sexual activities without the use of lubricated condoms, dental dams or gloves that places individuals at risk of being exposed to and contracting HIV. The literature on risk groups has been interrogated in this study as it provides a context for how participants understand themselves and their experiences given dominant, western perceptions of HIV/AIDS. This literature also offers an interesting viewpoint from which one can examine how participants position themselves within the HIV/AIDS pandemic.

It is important to note that more recently a shift in discourse has occurred in HIV/AIDS literature where less emphasis is placed on labeling risk groups, and greater

focus is placed on certain behaviours being acknowledged as risk factors (Singhal & Rogers, 2003; Treichler, 1999). Still, as the HIV/AIDS pandemic persists, certain negatively perceived identities and characteristics, such as using intravenous drugs, working in the sex trade, having a variety of sexual partners, identifying as a gay man and being a racialized person, are still associated with the pandemic, which has acted to strengthen the stigma surrounding HIV/AIDS (Singhal & Rogers, 2003; Ryan et al., 1998). The stigmatization around HIV/AIDS may have been much less “had the epidemic first been identified...among upper-class, straight, heterosexual individuals, hemophiliacs, or children” (Singhal & Rogers, 2003, p. 251). Instead, populations who are already marginalized are further stigmatized by this pandemic. Moreover, stigma is not only an external phenomenon; research suggests individuals internalize this stigma, seeing themselves as inferior human beings (Ciambrone, 2003; Link & Phelan, 2001). When society repeatedly puts forward messages that imply that anyone who deviates from “the norm” and who is diagnosed with HIV is “lesser than,” it is likely that one could begin to feel shame about one’s identity. It is this relationship between the experience of stigma and the shaping of one’s subjectivity that will be a major topic discussed throughout this paper.

[The Complexity of] Defining Grief

The Role of Bereavement Models: [Mis]Shaping Grief

The second body of literature that is of relevance to this research project is that relating to *grief*, *bereavement* and *mourning*. A great deal of research has been completed and a number of models have been constructed around theories of grief. Since

the middle of the twentieth century, researchers such as Eric Lindemann (1944), Elizabeth Kübler-Ross (1969, 1987), Peter Marris (1974), John Bowlby (1980), Colin Murray Parkes (1986), J. William Worden (2002) and many others have all proposed various theories and models of their perceptions and interpretations of the “grieving process” (Showalter, 1997). Although these models each make contributions to bodies of literature addressing bereavement and increase our understanding of the emotional responses to loss, they also reinforce particular practices of grieving. Driven by the desire to obtain measurable and structured data, the results of “scientific” research are analyzed and interpreted in ways that categorize particular forms of grieving as “normal” and others as “pathological” (Foote & Frank, 1999; Foucault, 1988b). Foote and Frank (1999), in their discussion of grief therapy, suggest:

The practice of therapy depends on a ‘true discourse,’ which, whether it is called psychiatry or mental health or clinical social work, has at its core the possibility – indeed the imperative – of a ‘true’ division of the normal from the pathological. (p. 160)

In other words, within therapeutic relationships, people’s emotional response to traumatic experiences are guided by specific “truths” that have been pre-established and, thus, restrict and define the language that individuals may use to describe their grieving experiences. Through various models of bereavement and the therapies that arise from these models, grief is conceived as a phenomenon that is predicable and fixable (Foote & Frank, 1999).

In addition, bereavement models have come to construct grieving as “a task to be mastered and finally accomplished” (Foote & Frank, 1999, p. 168). In other words, grieving is expected to have an “end point” (Craib, 1998). Furthermore, deviating from the stages that lead to this end of one’s grieving, taking too long to progress through each

stage or not reaching the end at all is perceived to be “unhealthy,” “pathological” and “complicated” (Craib, 1998; Foote & Frank, 1999; Showalter, 1997). According to many bereavement models, individuals are expected to eventually accept their situations; however, doing so may be challenging given the existence and persistence of social stigma such as the potential rejection by loved ones or the inability to talk about one’s experience, which can be the case for persons living with stigmatized identities.

Another weakness of bereavement models is that they do not account for individual diversity or the social-political contexts of persons experiencing loss. Such persons may have different ethnicities, cultures, gender identities, sexual identities, socio-economic statuses, drug activity and support networks that shape their lives (Demmer, 2001). To leave out such dimensions of one’s life from grief models is to ignore major pieces of one’s existence and to reinforce particular identities, such as the young, white, middle-class, able-bodied male, as “typical” subjects of bereavement therapy. As a result, within therapeutic groups, grief “is mapped out according to a view of the appropriate emotions and their expression, rather than on an intimate understanding of the different inner worlds of the group members” (Craib, 1998, p. 163). Therefore, it would be helpful to enrich these models in ways that speak to the broader experiences accompanying and influencing bereavement (Demmer, 2001).

Finally, and possibly most importantly, traditional bereavement models do not explicitly acknowledge the particular experiences of discrimination had by persons living with stigmatized identities (Ryan et al., 1998; Weitz, 1991). By not considering potential factors such as stigma, discrimination or oppression, major pieces of the potential

grieving experiences of PHAs are left unacknowledged, which is problematic. Generally, mourning:

...implies a social acknowledgment of the survivor as deserving sympathy by virtue of his or her relationship to the deceased...The public display of grief (e.g. lamenting, weeping, or wailing) is an integral element of mourning and is intended to encourage social support for the mourner. (Mallinson, 1999, p. 165)

Due to dominant perceptions of HIV/AIDS, mainstream society typically places responsibility of exposure and contraction on an individual (Singhal & Rogers, 2003). Therefore, empathy becomes a luxury to which not everyone is entitled. Many PHAs may not be able to share their experiences of grief with others as a result of the secrecy and stigma surrounding HIV/AIDS.

Therefore, the grieving processes of PHAs are not adequately accounted for in existing models of grief. Although the terms “grief” and “grieving” will be used within this study, doing so is not intended to imply that participants, other PHAs or any individuals experiencing grief progress systematically through predetermined or predefined stages. Instead, the grieving processes for participants will be considered to be dynamic responses that are complex, unpredictable and specific to these individuals (Foote & Frank, 1999; Mallison, 1999; Ryan et al., 1998; Sherr, 1995).

In addition, the grieving process will not be considered time-limited (Foote & Frank, 1999). As discussed above, in most grief work, the common expectation is that bereaved individuals will eventually progress from early stages of incomprehension to a final stage of accommodation (Foote & Frank, 1999). For some PHAs, accommodation may happen, but for others it may not. The pain of personal losses may never be resolved

for an individual, but rather, in an on-going process, she or he may identify ways to incorporate such pain and grief into her or his life (Mallison, 1999).

Finally, it is not the intention of this paper to regard certain aspects of grief as normal versus abnormal, or healthy versus pathological. Grief will not be considered a psychological state or capacity that requires treatment to be “cured” or that involves a series of phases through which individuals who have experienced distress or loss move naturally and systematically (Butler, 2003; Foote & Frank, 1999). Instead, when discussed in this paper, grief will be understood as the emotions or feelings described by the individual PHA. The intention of this research project has been to address how such emotions or expressions of grief are affected by the stigma with which an individual is faced in her or his social, political and economic environments.

Grief: A Technology of the Self

Although the work and efforts involved in constructing models of bereavement and forms of grief therapy are valuable in that they focus on helping citizens address their complex emotions around traumatic or critical incidences in their lives, it may also be valuable to consider the ways in which such work may *shape* and *discipline* our experiences of grief (Craib, 1998; Foote & Frank, 1999).

In the twentieth century, many individuals within western nations have been presented with and participated in a number of procedures and practices that are believed to “enhance” our selves and our well-beings. Such procedures and practices include those that are intended to perfect the physical aspect of our selves, including “healthy lifestyle” routines, food management programs (i.e. diets) and cosmetic treatments, as

well as those that are intended to enhance the mental facets of our selves, including self-help guides, motivational seminars, recovery programs and talk therapies (Foote & Frank, 1999). A consequence of many individuals in western nations coming to view these procedures and practices as everyday means of improving our selves has been that these procedures have become *technologies of the self* (Foucault, 1988b). According to Foucault (1988b):

Technologies of the self...permit individuals to effect by their own means or with the help of others a certain number of operations on their own bodies, souls, thoughts, conduct, and way of being, so as to transform themselves in order to attain a certain state of happiness, purity, wisdom, perfection, or immortality. (p. 18)

By partaking in these technologies and accepting them as paths for improvement, one can care, learn and manage one's own subjectivity, including one's expression of grief (Foucault, 1988b). As noted by Foote & Frank (1999), "to know the self is to care for the self, and to care for the self is to transform the self through self-knowledge" (p. 162). As such, it is through this caring and learning about various self-truths that individuals work to improve their self-awareness and become more competent and emotionally self-controlled (Foote & Frank, 1999). We, as grieving individuals, may be very willing to engage in the various forms of grief management that increase our self-knowledge due to the emotionally painful toll that bereavement can have on us; however, through our willingness to partake, our grief management becomes a technology of the self.

It should be noted that while through various technologies, such as the grieving process, we, as individuals, are acting upon ourselves, "[we] do not act alone" (Foote & Frank, 1999, p. 162). Truth-seeking and technologies of the self occur within power relations, whether these relations occur between an individual and her or his fitness

instructor, dietitian, motivational speaker, therapist or social worker (Foote & Frank, 1999). Within such relationships, one is not a powerless subject over which another “powerful” individual has control, but instead both parties partake in an interaction where they work together and aspire to enable the individual (seeking self-awareness) to be directed toward a self-truth or self-knowledge by the other individual or guide (Foote & Frank, 1999; Foucault, 1988b). For instance, when considering grief therapy:

...the Foucauldian critique does not suggest that [the therapist] seeks to wield therapeutic power over those she classifies as pathological in their grief. Rather, [the therapist] seeks to care for the bereaved by directing them toward the truth of their grief and of their selves. This truth is the *mutual obligation* of both the therapist and client, doctor and patient, observer and observed. Within their relationship the one directs the other, but this direction is not *having* power. Rather, providing direction is the role one plays in the relation of power that encompasses both. (Foote & Frank, 1999, p. 162)

Although many individuals may perceive this guidance as a noble act on the part of therapists, social workers, counsellors and other professionals, it can also be perceived as means of restricting the language and ways of grieving that an individual can access and use to express her or his emotions. In other words, these professionals are perceived as “experts” with knowledge that is to be used to guide other individuals (without such knowledge) in directing their selves (Craib, 1998). This conceptualization of grief management and expression is helpful in this thesis as it makes visible the ways in which participants may have come or have not come to talk about their experiences of bereavement, as well as shape or not shape themselves as “grieving” individuals.

The Complexity of Subjectivity

The third body of literature that is of relevance to this study is that relating to *subjectivity* or *identity*. Liberal theories of identity hold that individuals have the freedom to define their own identities. Alternately, structural theories hold that one's self or identity is formed through the imposition of power by one individual and/or group of individuals upon another (Cruikshank, 1999; Fook, 2002; Foucault, 1994c; Mills, 2003s). However, a third theoretical approach, Foucauldian thought, which will be used in this thesis, holds that:

...modern forms of power tie the subjectivity (conscience, identity, self-knowledge) of the individual to that individual's subjection (control by another). The subject is one who is both under the authority of another and the author of her or his own actions. (Cruikshank, 1999, p. 21)

In other words, although individuals are active in selecting, upholding and practicing their own particular styles of speech, values, beliefs and behaviours, these selections are influenced by dominant discourses (Cruikshank, 1996; Foucault, 1994c; Lamb, 1999; Rose, 1990). For instance, mainstream perceptions of chronic illness as "unhealthy" can result in PHAs being expected to incorporate "unhealthy" into their identities, although they may understand themselves as healthy (Weitz, 1990). This anticipated incorporation or redefinition of one's self to be in line with mainstream perceptions is problematic because "to say that someone has a disease or (more strongly) is diseased implies that the person is less whole, functioning, or worthy than 'normal' people" (Weitz, 1990, p. 37). These feelings of "lesser than" were reflected by participants in a study completed by Ciambrone (2003), where some of the participants reported often feeling different from persons not currently living or diagnosed with HIV/AIDS and "unworthy of gain[ing] entry into [the] social worlds [of such individuals]" (p. 46). In this way, one's

subjectivity (or definition of one's self) and subjection cannot be distinguished. Even with our active participation in the choices we make around our ways of speaking, thinking and knowing our selves, how we partake in such activities and live our lives is limited by what society perceives as "acceptable" and "normal." Our subjectivities are shaped and articulated within and through language, which is influenced by the values, beliefs and "norms" of mainstream society that are imposed on (and replicated by) us through various mediums, including media, literature and everyday discussions (Belsey, 2002; Gamble, 2001). As Belsey (2002) writes, "[C]onsciousness is not the origin of the language we speak and the images we recognize, so much as the product of the meanings we learn and reproduce" (p. 5). Through our restricted, yet active, choices we are regulated and regulate our selves. This regulation of choice and freedom shapes the types of identities we adopt and the kinds *citizens* we become (Cruikshank, 1999; Foucault, 1994c; Rose, 1990). Armed with particular knowledge of how to think, act and be, and with constrained language around how to describe such experiences, the information we, as citizens, use are reflective of how we have come to understand our experiences within certain discourses, particularly those supporting notions of citizenship that reinforce the binary of "good" versus "bad" ways of existing. As a result, the information one provides may represent the "facts" or "truths" of one's circumstances as one has come to know it (Gulrium & Holstein, 2001, p. 34). It is in this way that power:

...applies itself to immediate everyday life [and] categorizes the individual, marks him [sic] by his own individuality, attaches him to his own identity, imposes a law of truth on him that he must recognize and others have to recognize in him. It is a form of power that makes individuals subjects [and citizens]. (Foucault, 1994c, p. 331).

Through dialogues with participants, I worked to examine the ways in which the identities of participants, particularly around health and illness, have been influenced and shaped by our dominant views and perceptions around HIV/AIDS. Furthermore, I have analyzed the effects of participants choosing to take up such dominant perceptions and the benefits and limitations of such perceptions. This analysis of subjectivity has been important in examining how participants talked about their conduct, behaviours and choices following their diagnoses of HIV in ways that reinforced or upheld particular forms of citizenship.

Methodology

Participants

Within this study, ten HIV-positive individuals, one transgendered person (male-to-female), four women and five men, were interviewed in the Ottawa region (See Appendix A for Profiles of Participants). Their mean age was 42.7 years, with the youngest participant being 26 years old and the oldest participant being 59 years old. The mean number of years participants had been living with HIV was 11.5, with the least number of years being three and the greatest number of years being 21. The sample was somewhat racially and ethnically diverse, with one participant identifying as black, two identifying as Aboriginal and seven identifying as white. Within the sample, two participants identified as gay, two identified as bisexual and six identified as heterosexual. The group was also diverse in their levels of education, where some individuals had completed some grade school, some high school or all of high school (i.e. obtained a Grade 12 diploma), while others had started college programs, completed

college programs or had begun university programs. With regard to sources of income, one participant accessed an income through paid employment, one through private insurance, one through both Ontario Disability Support Program (ODSP) and Canadian Pension Plan (CPP), two through Ontario Works and five through ODSP.

Recruitment Strategies

Participants for this study were recruited by placing posters (Appendix B) in AIDS service organizations (ASOs), community health centres, public libraries and a hospital program within Ottawa. Workers at the ASOs were asked to explain or to clarify the project to any interested participants. In addition, the poster was placed in a community agency's monthly newsletter for April and May 2006. Furthermore, the poster was also placed electronically on Live Journal in late April 2006 and removed in August 2006.

Interview Protocol & Data Management

In conducting this study, the greatest emphasis was placed on protecting the privacy and the identity of each participant due to the sensitive nature of living with HIV/AIDS. The identities of participants, thus, remained anonymous and confidential. Participants were asked to only provide their first names and withhold their last names, along with any other identifiable information.

Other precautions were taken to ensure that the identities and personal stories of participants remained confidential, including the establishment of a pseudonym for each participant. This pseudonym has been used in this written portion of the research project

and will be used in any future publications and/or conference presentations. In addition, all physical data (i.e. non-electronic) information (i.e. contact information, interview notes and so forth) was placed in a locked filing cabinet in my apartment, to which only I had access, in order to secure the protection of participants' identities. Any information documented electronically (i.e. computer documents) was located under a separate user account on my personal computer, to which only I had access through the use of a private password.

Each participant was able to choose where she or he preferred to meet, including a reserved office at an ASO or a private room on the Carleton University campus. To ensure the emotional and physical well-being of each participant (i.e. not to place strain on the individual), the duration of interviews were maintained to approximately one to one and a half hours.

In order to ensure that participants in the study, as well as the general public, have access to the resulting data and thesis of this research project, participants were notified that two Ottawa ASOs would be receiving copies of this thesis and that this thesis could be found in the MacOdrum Library at Carleton University.

Research Instruments

The overall research approach for this study was qualitative. I began by reviewing literature regarding the social construction of stigma, of identity construction, of grief and of HIV/AIDS. I then developed an interview guide (Appendix B) that I utilized to engage participants. Participants were able to decline from answering any questions that they chose not to answer. Upon receiving approval from each participant, interviews were recorded and were later transcribed by myself. I had initially intended to

hire a private transcriber, however, due to limited finances and time restrictions I decided to transcribe the interviews on my own. In addition, notes were also taken during each interview, but only with the approval of the participant. Participants were made aware that they were entitled to review the notes taken following our interview. In addition, upon request, individual participants were provided with a copy of our transcribed interview.

Ethical Considerations

Confidentiality

In this project, participants' identities have remained confidential. When direct quotes are used in the written portion of the project, pseudonyms replace the participants' real names and/or the names of family members and friends. Furthermore, the names of community agencies were also removed in order to protect the identities of participants.

Informed Consent

Emphasis was placed on ensuring that each potential participant had sufficient understanding of the information regarding this study so that she or he could decide whether or not she or he wished to participate. In order to guarantee that participants comprehended the study, upon meeting, each prospective participant was presented with a letter of information (Appendix D) to read or to have read to her or him. This letter included a description of the study, its goals, an invitation to participate and my appropriate contact information. Upon review of the letter, each potential participant was given the informed consent form (Appendix E) to read or to have read to her or him. Within the consent form, the purpose of the study was discussed, in addition to possible

benefits and risks, a description of the study's process, and the right of the participants to make inquiries about the study and to withdrawal from the study at any point if not satisfied with its direction. Following the reading of the consent form, I summarized the key points of the form to all participants to ensure they understood their entitlements. If participants agreed with this project and were interested in participating, they signed the consent form and the interview began.

Benefits

The results of this study will hopefully inform the ways in which individuals who are working with PHAs, whether counsellors, social workers, physicians and other professionals, engage with such persons to discuss their experience of discrimination and their self-perceptions. The results of this study will also contribute to literature that accounts for the grief experiences for PHAs as unique relative to those experiences often presented and generalized in bereavement literature and models. In addition, I hope that this study will promote the importance of not only working directly with PHAs who have been diagnosed to promote positive self-image and to empower them in their communities, but also to work to educate the general population about HIV/AIDS issues in order to deconstruct social stigma and misconceptions about HIV/AIDS.

Finally, I hope that participants will directly benefit in that they are provided with an arena to describe their personal experiences and to contribute to knowledge and literature around how stigmatization affects their life experiences and self-perceptions.

Risks

Due to the serious nature of this research topic, the potential for harmful consequences was present. To begin with, interviewing PHAs required such individuals to recall and re-examine their personal experiences of their diagnoses, their disclosures to family members and/or friends and their personal journeys from the time of their diagnoses to present. To remember upsetting or negative experiences in their lives could result in depressed or negative feelings for some individuals. Furthermore, with face-to-face interviews anonymity is unfeasible and again may cause a participant to feel that her or his privacy is being invaded.

In addition, according to the Canadian Association of Social Workers Code of Ethics, I, as a social worker student, was (and continue to be) obligated to keep participants' identities and any identifying personal information anonymous and confidential. Due to the limits of confidentiality, however, I had to make participants aware that it was also my responsibility to report any situation that I was made aware of or observed that placed a participant at risk of harming her- or himself and/or other persons. No such incidences arose in the interviews with participants.

Approaches to Preventing and Overcoming Risks

In order to ensure that that participants in this study received the support they need after discussing potentially negative experiences, I provided each individual with a list of supportive or counselling resources in the Ottawa area (Appendix F).

To minimize any feelings of intrusion or discomfort a participant experienced in our face-to-face interview, I reminded her or him that her or his identity would be kept

confidential. In addition, I worked to create a safe space that was open and respectful to each participant and aimed to conduct interviews that were participant-directed. Although, as the interviewer, I hoped to guide or facilitate the discussion, I also wanted to follow the lead of the participant and enable her or him to talk about her or his experience and feelings. I intended to listen and learn from the participant. I also ensured that participants knew how much I appreciated them sharing their testimonies with me and contributing to HIV/AIDS literature.

Limitations

Within this research project, there were a number of limitations. The first is the small sample size, which makes generalization impossible. A second limitation is that participants were a self-selected sample. One consequence of this self-selected sample is that any number of experiences of living with HIV/AIDS and of mourning may not be evident or represented and, thus, cannot be unpacked in this research project. Thus readers of this work, may want to ask themselves: What responses would have been different if other individuals had volunteered? How would such individuals have vocalized their experiences differently or similarly? Even more, did some individuals not self-select because their grief was so traumatic that they could not talk about it with a stranger? These are only a few questions that arise from the construction of the study's sample.

In addition, the self-selected sample did not include individuals who had been recently diagnosed with HIV. The majority of participants were individuals who had been living with HIV for some time, with the average length of time post diagnosis being

11 and a half years. This may have had an effect on the types of stories that were told. Although interviewing people who were more recently diagnosed may have captured different narratives, accessing such populations would have been and continues to be challenging due to the length of time often necessary to begin to come to terms with and make sense of an HIV diagnosis. Without such individuals, however, the full spectrum of possible responses or experiences of mourning by PHAs is incomplete.

In addition, I, as the researcher, likely influenced the participants and the data. In other words, my identity as a young, middle-class, bi-racial female may have had an effect on the answers provided by participants. For instance, my experience as a young, female researcher interviewing middle-aged, male participants may have created and reinforced an age and/or gender dynamic, where such participants may have felt that they needed to be stoic and less emotional (as is generally expected of men by mainstream society) so as to appear strong, in control and authoritative to younger individuals. Further, as a virtual stranger to the individuals whom I was interviewing, my role as the researcher or interviewer may have impacted the data. Further, it is likely that my responses, whether sympathy, shock or a variety of other emotions shaped the narratives told to me. Although, when asking questions, maintaining a neutral demeanor was important to me, it was difficult to divorce myself from my sentiment and gut reactions.

The location of our interviews, given the sensitivity of the topic of bereavement, may have also impacted the narratives and emotions participants shared in our discussions of their experiences of mourning. In other words, the majority of interviews took place in a private room in a public ASO. As a consequence, some participants may have been less inclined to describe experiences during our interviews that may have

caused them to displace certain signs of mourning, such as crying, especially when they were conscious that after completing the interviews they would be joining other people in the more public areas of the ASO. Participants, for instance, may have expressed different emotions if interviews had been held in their private homes. Therefore, conducting interviews in a more public space may have made certain discussions or expressions of emotions possible, while others impossible.

One final factor shaping the data was that each participant was interviewed within the Ottawa region. The quotes, references and discussions that took place in each interview, therefore, should be situated within the particular geographical experience in which they occurred. If I had interviewed 10 individuals from any other community (for instance, a small northern Ontario town), their responses may have been very different. Thus, the information obtained from this group of participants is specific to their experiences of living in a larger municipality.

Summary

Within this introduction, my intention has been to lay the foundation for the upcoming chapters by discussing literature that addresses the concepts of stigma, grief and subjectivity. As was noted above, the focus of stigma literature is generally individualized, where the experience of stigma is regarded as being within an individual, as well as the responsibility of an individual. Literature discussing the issue of grief has typically worked to normalize particular types of grieving, while pathologizing other forms. These normalizing and pathologizing effects can work to shape our expressions of grief in particular ways. Finally, liberal literature discussing subjectivity has typically

regarded identity construction as being under the control of the individual, while structural literature addressing subjectivity has generally conceptualized identity construction as being in the ultimate control of individuals in positions of power (i.e. the state and its institutions). Alternatively, a poststructural and Foucauldian perspective, which will be used in this thesis, regards this construction as being an intricate dynamic between the simultaneous imposition of particular notions of citizenship by the state and its institutions and the adoption of such notions by individuals.

With the foundation for this thesis laid, I will now use a poststructural analysis to examine the ways in which stigma influences the subjectivities and affects the experiences of bereavement (if it does so) of the 10 participants I interviewed. From the review of interview dialogues, I have arranged the analyses into five chapters. In Chapter 2, I will interrogate the ways in which participants narrated the stories of their lives, experiences and practices in ways that reflected and reinforced the disciplining of individuals by the state and by the self to meet the contemporary expectations of neo-liberal citizenship. In Chapter 3, I will carry on the discussion of citizenship as it is interwoven into dominant views of health management to create the category of the *good patient*. I will examine how this discussion of the good patient affected the experiences of participants. In this chapter, I will also unpack how other health/illness narratives, particularly those of persons living with cancer, influenced the narratives and experiences of participants. I will address how persons living with chronic illnesses may be pitted against one another (for instance, to secure resources) in ways that obscure the complexity of oppression and stigma for individuals living with chronic illness and our role in such oppression. In Chapter 4 and Chapter 5, I will address the different types of

talk participants used in their private and public lives and the ways stigma influences such talk. In Chapter 4, I will examine the role stigma and notions of citizenship play in participants' more personal and intimate talk with individuals within the medical and justice systems, their paid employment and/or volunteer opportunities and their everyday life. In Chapter 5, I will address how the practice of sharing personal narratives in more public forums is structured in particular ways, both by the institution in which they occur and by the individuals speaking, in order to deliver particular messages to the audiences. I will also interrogate the ways dominant perceptions of HIV/AIDS influence these stories and work to construct and have the speakers construct themselves as particular types of public citizens. Even more, I will unpack the ways this public talk also works to reinforce and perpetuate rigid gender roles related to citizenship. Finally, in Chapter 6, I will link this discussion of citizenship to the issue of grief. I will address how particular experiences, such as living with chronic illness, have been constructed as circumstances to be mourned. Furthermore, I will examine how dominant views of health and of grief have worked to structure particular expressions of grief as "normal" and others as "pathological" so as to maintain a population of productive, neo-liberal citizens.

Through the chapters of this thesis, it is hoped that a more complex picture will be generated around the ways in which stigma, neo-liberal citizenship and bereavement intersect and interact for PHAs. By the end of this paper, it is hoped that the reader will be able to identify even more the intricate ways citizenship is both imposed upon and adopted by each of us, so that we can become particular types of citizens who approach the principles of citizenship and the experiences of grief in certain ways. The intention of this thesis is not to discourage people from living their lives in their present ways, but

instead to be conscious of the ways in which our lived experiences or subjectivities are decided for us and by us in very complex ways.

CHAPTER 2: NEO-LIBERALISM AND TRANSFORMATION: FROM “UNHEALTHY” BODIES TO RESPONSIBLE CITIZENS

Introduction

This chapter is intended to generate a discussion around the various ways in which mainstream discourses and individual agency shape our *subjectivities* in terms of *citizenship*. In talking with participants, discussions of their experiences (or their subjectivities) centred primarily around their role as citizens. In this chapter, I will analyze participants' narratives to contemplate how their senses of citizenship were reflected in the stories they told about themselves.

As discussed in Chapter 1, citizens are not only manufactured and disciplined through the imposition of dominant discourses, but also through their self-constructions and adaptation to such discourses (Cruikshank, 1996; Cruikshank, 1999; Fook, 2002; Foucault, 1994c). The ways in which our subjectivities are constructed and the practices through which we construct our subjectivities are inseparable. The language, knowledge and social practices deemed “acceptable” within mainstream society influence the ways in which we come to understand and talk about our experiences.

We are continuously subjected to a system of classification that distinguishes between citizens who think and act “appropriately” and those who do not. Society, including the state, its institutions, fellow citizens and ourselves, imposes expectations that uphold the *good* and *productive citizen* as representing particular “moral” ways of living. Notions of citizenship, particularly good citizenship, are important within neo-liberal societies because when citizens adopt the knowledge produced and put forward by “experts” and use such knowledge to manage their values, beliefs, practices and overall lives, then the state and its institutions do not have to do so (Nettleton, 1997). The neo-

liberal “[g]overnment requires the ‘risky selves’ to be wise about their investments for their future health and for their future wealth” (Nettleton, 1997, p. 216). In this way, the responsibility for one’s self, health and well-being is placed upon the individual citizen (Nettleton, 1997). When individuals “behave” themselves, they are better able to focus on being productive (Cruikshank, 1999). Individuals who meet the demands of the productive self are generally considered to have earned legitimate citizenship. On the other hand, individuals who do not fit such criteria are typically perceived as *lesser than* or *irresponsible (non)citizens*.

For the participants of this study, this polarized notion of citizenships seemed always to be in play. During each conversation, there seemed to be a push to construct one’s self in terms of the viable, productive citizen. More specifically, describing one’s self as someone who becomes involved in public awareness, who manages her or his (limited) funds, who participates in activism and/or advocacy, who volunteers, who does not use recreational drugs, who restricts her or his sexual activities (and when she or he does engage in such activities, she or he uses safer methods), who discloses her or his status openly and so forth (Cruikshank, 1999). Describing one’s self as such, I will argue, demonstrates the ways one has been disciplined and has disciplined one’s self by supporting and engaging in certain practices of the self, while obscuring others in the project of citizenship.

The participants’ narratives that I will be reviewing in this chapter are instructive both in terms of what the storytellers share about the HIV/AIDS movement and also in terms of what they recognize or construct as representative of productive citizenship (Cruikshank, 1999; Foucault, 1994a). What is interesting for me, as the researcher, is

that the efforts of participants to reconstruct themselves as citizens requires the invention of a particular shadow individual who is illustrative of the *bad citizen* against which they represent themselves. In turn, what at first glance appears to be a progressive, disruptive story can also be read as instructive, providing clear imagery of the responsible person living with HIV/AIDS (PHA). It is this re-reading, in terms of disciplining, that forms the foundation of this chapter.

In the following sections, I will address how we are each encouraged to portray ourselves as good and productive citizens and how doing so, specifically in this project, works to shape experiences of living with chronic illness. In order to build this argument, I will identify four types of narratives that were put forward and emphasized in interviews with participants. The first narrative is one of *moving on* or *beyond* one's diagnosis of HIV/AIDS as a means of upholding particular notions of citizenship. The second style of narrative is one where participants shared stories of *giving back to society* as a means for (re)creating themselves as responsible, ethical citizens. The third type of narrative is the articulation of one's *responsibility* for one's diagnosis of HIV/AIDS as a way of constructing one's self as the “transformed” citizen who takes ownership over one's actions. Finally, the last narrative that will be examined is the discussion of restricting one's involvement in *risky activities* in order to produce or reinforce certain notions and practices of citizenship. The intention of this chapter is to analyze and deconstruct the making of an HIV-positive citizen through embracing certain attributes, while rejecting others. This remaking of the self as the “citizen” seems to be in the theme of creating or taking advantage of the limited space afforded to HIV-positive citizenship.

Techniques of Governing and Managing Our Selves

Moving on with Life

Some participants, in order to communicate a sense of self that was productive, effective and without self-pity, often used the narrative of *moving on*. For instance, Phyllis commented:

For me it's different than for a lot of other PHAs because I'm out in my work...I have my own supports in place. I do provincial work [around HIV/AIDS], national work, stuff like that. So it's different for me because I kind of picked myself up and dusted myself off. I kind of got on with life. It just pisses me off when people feel sorry for themselves. (02/05/06)

Here, Phyllis describes overcoming the challenges of being diagnosed with HIV through a shift towards HIV/AIDS activism and establishing her own social supports. This move is positioned as a better, or even the best way of living and adjusting to one's diagnosis of HIV/AIDS. For Phyllis, the idea of living with HIV as being an overwhelming or consuming experience is met with hostility. Her resentment is in line with neo-liberal expectations that citizens are independent, highly motivated individuals, who “pick themselves up” after trying times and who do not feel sorry for themselves (Cruikshank, 1999; Nettleton, 1997; Travers, 2006).

Later in the interview, Phyllis continued:

I think that it's just because I've been positive for so long that I really don't have the issues that newly diagnosed people have. I think you need to build your own support circle, but you can't totally rely on other people. There comes a point where you got to look in the mirror and say, “Yeah, I'm positive. Moving on with life.” I mean, life doesn't stop. I mean, for some people it will when they get their status, but for other people it's more of a stepping stone. (02/05/06)

Here, Phyllis sees moving beyond the diagnosis of HIV as an important, even healthy, functional performance of the self. As the researcher, I often found myself wondering

exactly how “moving on” would look. As I delved into the data, it became clear that moving on meant overcoming any challenges that arise, include health complications, and using such experiences to “better” oneself by turning inwards, engaging in self-reflection, enhancing one’s self-knowledge and engaging in self-regulation of one’s feelings, thoughts and behaviours. Moving on, therefore, is not only the perfect neo-liberal practice, but is also reflective of the therapeutic technology of the self described in the Introduction of this thesis (Stacey, 1997). The expectation that PHAs regulate themselves to move on requires perceiving oneself in positive terms with minimal self-pity and moving towards “healing” so as to engage in productive behaviours (such as paid employment) and make minimal demands on the state for support. It is in this way that the individualized, self-contained and self-regulated neo-liberal citizen is maintained, even re-imagined to include a certain construction of a PHA as an example of contemporary citizenship.

Giving Back to Society

Another metaphor through which participants manufactured themselves as citizens could be found in their stories of *giving back to society*, particularly in becoming involved in HIV/AIDS activism and/or advocacy. When asked what changed his life following his diagnosis of HIV, William reported:

What turned my life around was when I came out of isolation...I realized I wasn't alone and that changed my life dramatically. I started getting involved as a volunteer. Training to be a volunteer speaker in the schools, to tell my personal story, help others...Within three years after be[com]ing a public speaker, I became a frontline worker. I got hired as an outreach worker for an AIDS service organization (ASO) in [a major city] and then I became the Coordinator of the Speakers Bureau at the same AIDS organization, so I ran the program...You know, I was in charge of

administration, reports, funding proposals, a lot of office work...And so then...I came to Ottawa...I got involved with [an ASO] where I'm a volunteer speaker ever since. I speak at a lot of schools, [other community organizations], street youth organizations. I speak wherever I'm asked to speak. And that's how I give back to society. (20/03/06)

In this quote, I think it is important to examine how telling one's story and giving back to society become synonymous. For William, being able to share his story with fellow community members was considered a means of “giving back” or helping fellow community members. Although genuine, it may also be important to examine how this desire is shaped by neo-liberal expectations that we, as citizens, be active, productive and self-sufficient (Cruikshank, 1999). Furthermore, if we are not able to be financially self-sufficient through paid employment for one reason or another, such as living with chronic illness, we must at least demonstrate that we would be willing to do so, if health were not an issue (Nettleton, 1997). In other words, this desire to give back reinforces the mainstream expectation that we, as citizens, must “hold our own” (by engaging in paid labour) or, if we are not able to do so, we must by some other means (such as volunteering) give back to “the hand that feeds us” (no matter how small the scraps). In this sense, paid employment and volunteering become means of producing responsible, self-reliant citizens who care for and inform the community so that the state does not have to be responsible for doing so. It is important, however, to note again that we do not do these acts solely because we are told to do so by the state and its institutions. We adopt particular ways of acting, being and living so that we can identify ourselves as responsible, autonomous citizens.

Another related issue that was emphasized intensely by participants in this study was their inability to work because they were unable to find paid employment with an

income or salary great enough to pay for their HIV medications. This imposed reality seemed to result in a lot of frustration for participants. As noted by William:

This disease is very much a disease of isolation and poverty. And the reason I say that is because a lot of people who are employed, and [they] may even have good jobs, who find out that they're HIV-positive, unless they have a top-notch drug program [or] drug benefits, [they] are forced on[to] welfare or disability to pay for their medications. (20/03/06)

In this way, the performance of the productive citizen is inaccessible for many PHAs. Their paid employment endeavours cannot cover their health costs and they are not allowed to work while receiving social assistance, which ensures full medication coverage.

This practice or system of exclusion, again, seemed to be quite devastating for some participants. For instance, when asked how not being able to use her talent or trade because she could not afford to work and purchase her medications, Barbara commented:

I'm not contributing to society. I'm counting on society to help me live. And, basically, every month I'm not verbally begging, but emotionally begging, mentally begging for my cheque every month. (09/05/06)

Here, we see the strain, stigma and guilt experienced by Barbara because she was not able or entitled to engage in paid employment and was forced to “beg” for social assistance. Feelings of not contributing to society reflect the idea that only citizens who are paid for their work are “true” citizens. Furthermore, despite being involved in making public presentations about her experience of living with HIV, Barbara did not view that form of public education as being a contribution to society, which most likely reflects the imposition and taking up of pressures and expectations from the neo-liberal state and its institutions.

It also seemed that paid employment, for participants, was understood as a means of overcoming discrimination. As noted by Phyllis, who held a paid position within a community agency, “I think [for] PHAs who are working, it’s a matter of wanting to be recognized for doing a job and not having anybody question whether you can do your job” (02/05/06). Here, the desire to work is influenced by the desire not to have one’s level of ability or competency questioned. Taken together, these factors demonstrate the ways that engaging in paid employment and/or volunteer opportunities as PHAs and “giving back to society” is complicated in that doing such work disrupts the perception of the PHA as incapable or as the welfare recipient, while simultaneously speaking in support of mainstream expectations that all citizens “work for their keep.”

Taking Ownership of One’s Diagnosis of HIV/AIDS

During interviews with participants, citizenship also seemed to involve taking *responsibility* for one’s diagnosis. For example, Kent mentioned:

I even had family members, like aunts, saying, “Poor [Kent].” No, no, don’t feel sorry for me. Like, I am who I am. I done what I did and this is what happened. And I don’t want people to feel sorry. It was my choice in life. (27/04/06)

In this quote, we witness Kent taking ownership of his role or choice in the matter of being exposed to and contracting HIV. Prior to his diagnosis of HIV and for some time after, Kent engaged in intravenous drug use. For Kent, his choice to share needles while using recreational drugs (prior to his diagnosis) was an act or choice for which he felt responsible. As I heard his statement, I could not help but reflect upon how the notion of responsibility contributes to mainstream opinions that choices are associated with consequences, everyone has knowledge of such consequences and, therefore, these

consequences are the sole responsibility of the individual. In this way, choices come to be acknowledged as always being cognitive, free from social context and the same for each of us. This concept of responsibility fails to attend to the ways in which the choices we face and subsequently make are shaped by our social-political circumstances and social conditioning.

Interestingly, the only context that was identified by participants was that of having learned about prevention strategies prior to their diagnoses, which worked to reinforce their sense of responsibility and blame for their illness. As noted by Mark:

I mean, you had the option of taking sex ed [in high school] and I said, “No, I don’t want to know about it. You know, forget it. Don’t want to know about it. Why bother? You know, “There’s nothing to it,” and then I was kind of kicking myself right after I became positive. You know, I should have actually paid attention in that class. You know, it was that class you should have paid attention to. Well, you know, mistakes happen. (28/04/06)

Again, here, we can see how Mark links his HIV-status to his ability to cognitively learn about HIV/AIDS and to modify his behaviour in accordance to such knowledge. For Mark, his lack of attention in school, or his failure at self-discipline becomes an error on his part and the cause of his serostatus. What is erased here are all the other structural and intrapsychic dynamics that are at play in moments of learning and moments of sexual engagements. This sense of accountability of one’s lack of attention, again, reinforces perceptions of the misconduct of the self (Nettleton, 1997; Travers, 2006).

Taken together, these pieces of dialogue reflect the ways in which our behaviours are reworked through a neo-liberal ideology, where isolated choices reflect how we do and do not manage ourselves. To engage in particular behaviours then becomes linked to the personal “mismanagement” of the self. As a result:

...there is the suggestion that it is possible for "you," that is the individual, to be in control over his or her destiny; it is the individual who is best able to effect change to make his or her life "better." (Nettleton, 1997, p. 208)

In this way that illnesses have been constructed as problems of morality (Greco, 1993; Travers, 2006). If the citizen:

...constitutes both the locus and the ultimate responsible agency of preventive intervention, the event of illness has become a moment of truth about a subject's moral aptitude to form part of the society within which he or she lives. This is a truth, moreover, which, like a sin, may be exorcised through a therapeutics of confession. (Greco, 1993, p. 362)

The diagnosis of illness leaves a citizen vulnerable and exposed for judgment, where one is believed not to be upholding one's responsibility for caring, cultivating and monitoring one's self. The mainstream perception of "risk behaviours" (versus risk factors) as the root cause of one's diagnosis of HIV/AIDS is dangerous because certain behaviours, such as intravenous drug use and unprotected oral, vaginal or anal sex with multiple partners, are constructed as needing to be changed or stopped, which obscures the roles risk factors, such as poverty, violence and racism, play in influencing one's susceptibility to the virus once exposed to HIV and one's ability to alter these behaviours so they are safer (Stillwaggon, 2004). The real issue is that while anyone and everyone is at risk of being exposed to and contracting HIV, we do not bear an equal risk. Taking responsibility for one's behaviour has been an expectation placed on citizens to obscure state and institutional responsibility to challenge the inequalities that place people at differential risk for HIV/AIDS (Stillwaggon, 2004).

Restricting One’s Involvement in Risky Behaviours

Another framework that was used to build notions of the responsible citizen living with HIV/AIDS was evident in stories about discontinuing or rejecting what was imagined as *bad* or *risky behaviours*, such as engaging in recreational drug use, sex work and having anal sex. For instance, after talking about his experience of being financially stable and his perception that such stability was a major factor in helping him to remain healthy and to have less stress, Joseph discussed his perceptions of individuals who use recreational drugs:

A lot of people [living with HIV/AIDS] are on welfare...and they’re druggies. Their money goes to the wrong thing. They’ll get [their cheques] Friday and by Monday they have no money. (25/04/06)

With this statement, Joseph made an interesting move. By invoking familiar class narratives, Joseph was able to separate himself from people who were receiving social assistance and were HIV-positive. These images (of the HIV-positive individual who is accessing welfare and of the HIV-positive individual who is financially self-sustaining) are not neutral, but instead rely on a notion that poor people are reckless and irresponsible. Joseph also applied the image of the drug addict, who is perceived as equally reckless and uncontrolled, so as to provide a contrast that helps us imagine him as the conscientious, clean citizen who knows how to behave himself. When combined with HIV/AIDS, the practices of accessing social assistance and of using recreational drugs are even more of a concern as they are also behaviours that mainstream society views as needing to be controlled. They are, in fact, the characteristics that are highlighted to support removing the rights of citizenship accessible to PHAs. The effect of the construction of the citizen as being welfare-free and drug-free is that the image works to

exclude the welfare recipient and the drug addict from ever being included within the framework of responsible citizenship. In other words, “we,” as welfare-free and drug-free citizens, come to know ourselves as good citizens because we cast the welfare recipient and the drug addict as bad. This binary is part of dominant perceptions of how citizens should behave, play and live.

Kent provided a different, yet related narrative about his experience of giving up recreational drugs following his diagnosis and also the birth of his child:

I guess I had to prove to myself that I didn't need the drugs. And I guess it made me understand more about the HIV because having HIV isn't the end of the world, it's a different path and you can either make it a good path or you can make it the bad path. I've chosen to make it the good path and try to let people understand that just because you catch it, [it] doesn't mean you're finished. Like, there's a lot that [PHAs] can still do for people, like...the next generation...Some of us go out and do speaks and that. (27/04/06)

Here, we can see how this inspirational story of self-transformation relies upon a belief in the good and bad paths of living with HIV/AIDS, where the good path involves the valuable citizen as one who uses a diagnosis of HIV/AIDS to help others and end behaviours that are seen as self-destructive or antisocial. The idea that one can identify and choose the right path is also important for this notion of citizenship, as it is this *wisdom* that offers Kent the opportunity to inspire others to change. The project of citizenship then extends beyond the self to the next generation. This message of hope is an important disruption of the “helpless,” “hopeless” or “aimlessness” that some might perceive as accompanying life with HIV/AIDS (Kylmä, Vehviläinen-Julkunen & Lähdevirta, 2001). At the same time, the invocation of choosing the right path and of self-regulation points to the central mechanisms through which contemporary, neo-liberal citizens are made. In other words, to be a responsible citizen is to govern one's

behaviour and to make the “right” choices, which includes raising public awareness through activism while not putting one’s self at risk, for instance, by using recreational drugs. Through such mechanisms or technologies of the self, we become specific types of citizens who adhere to and promote social norms and values (Foucault, 1988b).

Barbara provided another example of managing one’s involvement in “dangerous” behaviours when she spoke of her disclosure to her grandchild:

“[Grandchild,] you can never say anything until people understand that normal people, like [Grandma], who’s not a prostitute, who’s not a drug user, cannot give it to anybody.” And I did not explain it to [my grandchild] that the only way I could give it to my partner is if he had abrasions on his penis or if there was a blood interaction, you know, because we don’t have anal sex. There’s none of that at all. This is one of the reasons why [my partner is] still negative. Because I’m very, very careful. (09/05/06)

In Barbara’s story, the dangerous PHA is clearly articulated: she or he is the sex worker, the intravenous drug user and/or the individual engaging in anal sex. On the other end of the spectrum sits Barbara who is recognizable by her self-discipline, self-care and care for others; she comes to represent the perfectly regulated citizen. In this way, Barbara’s invocation of the bad citizen comes to represent the image against which her grandchild can position Barbara as an innocent victim within the HIV/AIDS pandemic. The direction of this discussion with Barbara’s grandchild is complicated in at least two ways. First, it is undeniable that Barbara was talking with her grandchild about an illness that has been highly stigmatized and frequently misrepresented within many institutions, including mainstream media, health care facilities and the justice system. Consequently, there are few, if any, models to help her navigate this discussion. Disclosing to family members is difficult, particularly when doing so with a younger family member who may have witnessed such misrepresentations and may not yet understand the complexity of

living with HIV/AIDS. While Barbara was, on one level, challenging stereotypes of PHAs, she also reinforced such stereotypes as she clearly expressed herself as “not being one of them.” In this way, this interaction became complicated by Barbara’s sense of urgency to highlight her innocence.

Second, it is also helpful to think through Barbara’s story in terms of dominant images about risk and exposure. What is interesting is that prostitution and anal sex are not necessarily the evil activities that Barbara (along with many citizens) imagines them to be. With the use of condoms, dental dams, gloves and lubricants, oral, vaginal and anal sexual intercourse are relatively low-risk activities. Despite this, many western nations still hold anal sex as a specter of “bad” and “irresponsible” behaviour that must be avoided at all costs. Consequently, for individuals such as Barbara, separating one’s self from the category of anal sexual activity as a means of distinguishing one’s self from “bad” behaviours secures her story of innocence. As Barbara highlighted when talking about her experience of discrimination within the medical system:

These are health care providers and they’re not educated. I mean I can go into a first-year nursing school and tell the whole class what I want as a patient. That I want respect, I want a hug, I want a smile. I don’t want a “Oh, how did she get it?”-type of look. Because, number one, I was never a prostitute. Number two, I was never an injecting drug user. Never, never, never. To this day I still cringe at the sight of needles and I got it from my husband through careless sex, which I wasn’t informed on.
(09/05/06)

Again, the respectable citizen is made visible through positioning of the prostitute and the intravenous drug user as “dangerous.” Respectability is secured by an articulation of a sanctioned mode of transmission: heterosexual, martially-sanctioned sex. Irresponsibility can be dismissed since the idea of unsafe sex in such a clearly legitimized relationship is inconceivable.

For the purpose of this thesis, these passages noted above are regarded as working to reinforce ideas about citizens needing to work to reduce, to discourage and to prevent engagement in activities that are constructed as “bad” or “risky,” such as intravenous drug use, sex work and anal sex. The right to citizenship is imagined as involving minimal or absolutely no engagement in “deviant” practices (Nettleton, 1997). As a consequence, certain behaviours within the HIV/AIDS pandemic come to be the focus of treatment and cure (Nettleton, 1997). This misguided emphasis on discouraging specific behaviours, “contributes to the confirmation of the active citizen, the self who can be, and indeed *ought* to be, in control of his or her self” (Nettleton, 1997, p. 215). Not to adopt such “appropriate” practices or not to discontinue “inappropriate” behaviours comes to be viewed as a malfunction in caring for one’s self and in fulfilling one’s duty as a citizen.

As Greco (1993) writes:

If the regulation of life-style, the modification of risky behaviour and the transformation of unhealthy attitudes prove impossible through sheer strength of will, this constitutes, at least in part, a *failure of the self to take care of itself* – a form of irrationality, or simply a lack of *skilfulness* [sic]...The mastery of the self is thus a prerequisite for health; the lack of self-mastery, accordingly, is a ‘disease’ prior to the actual physical complaint, whose symptoms are detectable as behavioural, psychological and cognitive patterns. If, on one level, the preventive capacity of the individual rests with his or her ability to make informed life-choices towards health, on another level it rests with the willingness to acknowledge and report as a medically relevant problem his or her failure to behave, think and feel ‘healthily’... (pp. 361-362)

For participants to discuss the ways in which they have distanced themselves from particular behaviours that are considered by society to be negative reinforces the idea that such behaviours are outside of normative practices of citizenship.

Summary

Through the interplay of discourse and narrative, we, as individuals, are constructed and construct ourselves as citizens. Given a restricted selection of the ways that we can speak, think and live, we come to understand and talk about ourselves in terms of the language, knowledge and practices that has been authorized as “appropriate” and “normal” for our western citizenship. Through the manufacturing of citizens, a binary is created where specific attributes come to be designated as those of *good citizenship* and others as markers of *inadequate citizenship* (Cruikshank, 1999). Throughout the quotes noted above, the words of participants reinforced mainstream notions of citizenship where particular values, beliefs, actions and attributes were deemed to be those of responsible and respectable citizens and those of unrespectable citizens. According to participants, the citizen seemed to be represented by the effective management of one’s health, finances, motivation and ambitions. The rich pieces of dialogue provided by participants offered examples of how individuals view and further manufacture themselves as citizens (living with HIV) through the strengthening of these attributes and the repressing of others. Participants talked about the ways in which they had changed or began to manage their own lives (and selves) differently following their diagnoses of HIV by changing their beliefs, values and practices of “risky” behaviours and by becoming involved in HIV/AIDS activism and/or advocacy through volunteering and/or working at local ASO. From participants’ feedback, it became apparent that as citizens within our western society, the ways in which we conduct ourselves, the activities in which we become involved, the behaviours that we support and the messages that we promote demonstrate the discourses that operate around us and that we embrace

through the various power relations in which we engage. The point of this discussion is not to demonstrate that to view or to construct one’s self as a citizen is either good or bad, but instead to illustrate that the ways we come to know and talk about ourselves are complicated. To construct our selves one way or another simultaneously challenges particular mainstream perceptions while reinforcing others.

This discussion of citizenship will be a reoccurring theme throughout this thesis. Through the examination of my dialogues with participants, I will attempt to address the ways in which we, as citizens, challenge and reinforce conceptualizations of citizenship through the language we use, the knowledge we consider valuable, the work we do and the ways we live our lives. As such, a Foucauldian analysis will be used to examine the ways these practices and experiences operate within, through and outside notions of citizenship and the ways in which we are constructed as citizens. Throughout this thesis, it will become more obvious that the ways in which we “become” citizens are reflective of a number of complex discourses and forces at play, both separate and interconnected.

In the next chapter I will explore how notions of health connect with stigma and how this issue further textures citizenship. By looking at the issue of health and at notions of the *good patient*, I will begin to demonstrate the ways such ideas are employed to shore up one’s sense of citizenship.

CHAPTER 3: THE INDIVIDUALIZATION OF HEALTH AND WELLNESS: A MECHANISM FOR PRODUCING AND DIVIDING GOOD PATIENTS

Introduction

In this chapter, I will be continuing the dialogue that I began in the previous chapter around citizenship, but will now move on to present the ways in which notions of citizenship are complicated and interwoven into mainstream perceptions of health, particularly around management and maintenance. In talking with participants, two themes arose around the issue of health and living with HIV/AIDS, which will be broken down into two themes in this chapter. Under the first theme, I will speak about how participants worked to become *good patients*. Previously, I discussed how notions of regulated citizenship shape our general lives and influence how we shape our lives. Here, I will continue this discussion of restricted citizenship to specifically analyze participants' adoption of "healthy" practices, including the acceptance of expert advice, the education of themselves on HIV/AIDS issues, the maintenance of the "right" attitude and the overall self-management of aspects of their health, as means of maintaining their health or healthfulness. In order to analyze these practices, I will discuss the role played by *bio-power* (see Foucault, 1978) in the process of influencing persons living with HIV/AIDS (PHAs) to care for, regulate and, consequently, construct their selves within medical settings.

Under the second theme of this chapter, I will address how discourses around various conditions or illnesses, influence the experiences and identities of PHAs. More specifically, I will speak to how participants made sense of their experiences of living with HIV by contrast and in comparison to the experience of living with cancer. During interviews, a number of participants discussed their experiences of living with HIV in

terms of how such incidences were different than experiences of living with cancer, particularly breast cancer. As a result, these discussions operated in ways that constructed what appeared to be a hierarchy of chronic illnesses. Specifically, the experience of living with cancer seemed to be imagined as less stigmatizing than the experience of living with HIV/AIDS. The purpose of this section, thus, will not be to prove or disprove these perceptions, but instead to discuss how such perceptions are created and maintained and what effects they have on PHAs and persons living with cancer.

Exercising Bio-power as a Means of Disciplining Individuals and Regulating Populations

The Concept of Bio-Power

Before addressing the first theme of this chapter, it is imperative to provide a brief overview of the Foucauldian concept of *bio-power*. Although the management of selves has generally been regarded as being a consequence of governmentality (see, for example, Foucault, 1994a), another relevant notion reinforcing this practice of self-regulation, particularly around health, is bio-power. Bio-power has been considered a form of power exercised at the level of life, where bodies are disciplined and populations are regulated (Foucault, 1978). More specifically, through bio-power, individuals are trained to manage their biological processes (such as their procreation, longevity and life expectancy) in ways that will work to optimize or maximize their capabilities and efficiencies (Foucault, 1978). These bodies, once at “full” capacity, are introduced “into the machinery of production,” or systems of economics, and are regulated as populations

through capitalist economic processes, such as wage labour, social assistance and debt, to name a few (Foucault, 1978, p. 141). According to Foucault (1978):

On the one hand [bio-power] was tied to the disciplines of the body: the harnessing, intensification, and distribution of forces, the adjustment and economy of energies. On the other hand, it was applied to the regulation of populations, through all the far-reaching effects of its activity. It fitted in both categories at once, giving rise to infinitesimal surveillances, permanent controls, extremely meticulous orderings of space, indeterminate medical or psychological examinations, to an entire micro-power concerned with the body. But it gave rise as well to comprehensive measures, statistical assessments, and interventions aimed at the entire social body or at groups taken as a whole. (p. 145)

In other words, bio-power subjugates individual bodies and subsequently controls overall populations through diverse techniques that operate to guarantee, support and reproduce life and to set this life (within populations) in order (Foucault, 1978). Once this life has been placed in order, its interests can be put in line with the interests of society, which include encouraging productive, self-controlled and self-sustaining citizenship. However, we are not powerless in these experiences, but instead choose to implement these techniques, as well as the values, beliefs and knowledge promoted by these practices (Cruikshank, 1999; Foucault, 1994c). We do so because of the benefits, the sense of normalcy and the familiarity provided by the adherence to certain ways of living. It is through these technologies that citizens are formed and form themselves.

When this concept of bio-power is applied to the experiences of PHAs who have been generally labeled as drug addicts, as sex workers and as individual who engage in “risky” behaviours, the goal of democratic governance (which are promoted by intervention programs and services) is to change the actions and ambitions of these individuals to be in line with those of citizens, who maintain their health by staying drug-free and controlling their sexual activity/work by using lubricated condoms, dental dams

and gloves or, more accurately, not having sex. This alteration in one's goals is believed to be not only for the good of the individual but also for the good of society (Cruikshank, 1999).

One example of a technique of bio-power has been the *medicalization* of bodies or the physiological conditions within such bodies. Medicalization involves physiological differences being "defined by society at large as...illness[es] (either physical or psychological) and [are] thereby moved into the sphere of control of the medical profession" (Findlay and Miller, 1994, p. 115). These physiological differences or illnesses are then subjected to treatments, such as examinations, tests and prescription drugs, by health care providers, or "experts," and the individuals receiving treatment become "patients," whose knowledge of their own bodies and lives are deemed insignificant in prevention, maintenance and/or cure (Lorber & Moore, 2002). Generally speaking, in structural theories, the power relations of this medicalization process are often perceived to operate in a top-down fashion where medical professionals prescribe forms of treatment and patients accept such treatments without choice or conflict. However, from a Foucauldian perspective, although power relations may involve the imposition of expert medical knowledge and practices upon patients, such knowledge and practices are also simultaneously accepted and selected by individuals as means of regulating the health and productivity of their bodies (Rose, 1990). The governance of individuals and of populations:

...is intrinsically linked to the activities of expertise, whose role is not one of weaving an all-pervasive web of 'social control', but of enacting assorted attempts at the calculated administration of diverse aspects of conduct through countless, often competing, local tactics of education, persuasion, inducement, management, incitement, motivation and encouragement." (Rose & Miller, 1992, p.175)

Through the adoption and adaptation of expert knowledge to one's life, one learns to manage, regulate, govern and care for one's self as all good patients (and citizen) should so that the state and its institutions do not have to do so. As Alana noted, "I call myself the 'Compliant Queen,' medication-wise, because I take them everyday. That's the only way to keep them effective" (04/05/06). Sandra also commented:

Like I said, I know what's going to happen eventually and I don't look forward to it, but I want to last longer. You know what I mean? Medication, living healthy and friendship and all that. It makes me feel better. (25/04/06)

In both quotes, the criteria of the good patient are made clear: compliance, treatment and healthy lifestyles. It is a re-articulation of the dominant health messages, which build up individualized notions of wellness. In other words, how well one is varies positively with how well-behaved or self-regulated one is. As such, the medicalization of bodies relies upon citizens who learn from and put into effect the advice of the experts so they can care for their selves and "stay healthy."

The Manageable Disease: Reconceptualizing HIV/AIDS

One common contemporary narrative within medicalization discourses has been the recent redefinition of HIV/AIDS from an *acute infection* to a *manageable disease* (Ciambrone, 2003, 2001; Doka, 1997; Rosengarten, 2005). Within interviews, this reconceptualization of HIV/AIDS made it impossible for some participants to make their fears, anxieties and worries about HIV/AIDS known to those within their social environments. For instance, for some participants, it was a concern that a person living

with HIV/AIDS will not live as long as a person not living with HIV/AIDS. As noted by Alana:

I find people act like [living with HIV/AIDS has] changed. It's not a death sentence anymore. It's a "manageable disease," which I don't find makes me feel very comfortable. But that's the perception people have and that's the reaction I get now, that "Oh, lots of people are dying" kind of deal, which I find minimizes my feelings. (04/05/06)

Here, Alana provides valuable insight into the ways such a reclassification of HIV/AIDS from a "death sentence" to a chronic, manageable illness does not necessarily offer consolation and actually devalues her feelings about her diagnosis. For Alana, the idea that "everyone is dying" generates a false notion that we are all having the same physiological experiences and, thus, are approaching death at the same rate, which diminishes her worries about dying from an AIDS-related illness.

Furthermore, another major consequence of this reconceptualization of HIV/AIDS is that it *individualizes* the experience of living with illness. In other words, this new conceptualization places responsibility on the person to know her or his body (and self) and to manage her or his health and lifestyle in order to prevent illness and/or to control that with which she or he is living. The management and knowledge of the self is reduced to techniques such as eating "right," exercising, not engaging in any "dangerous" or "risky" activities (for instance, the use of recreational drugs), following medication regimes and monitoring one's viral loads. Therefore, for many PHAs, the term manageable disease generates ideas that a person only needs to carry out certain routines to stay healthy. This perception, however, is problematic because it neglects to attend to the ways that HIV/AIDS interacts with other aspects of a PHA's life. For instance, eating "right" may be difficult for many PHAs since they are often living on

income and/or social assistance. As a result, PHAs may have to access food through various food bank programs and soup kitchens where the selection of healthy foods may be limited. Furthermore, healthier foods tend to be expensive.

This disease construction also ignores the potential experience of some HIV medications causing side effects that are difficult on one's body. As noted by Kent, "[T]he pills are harder on you than the disease itself. Like the side effects and that, it's like, 'Oh, Lord, forbid.' Like, sometimes I wonder if anyone ever tried these [medications] before they gave them to us" (27/04/06). From Kent's description, we hear the strain HIV medications can place on one's body. This experience of medication consumption is also further complicated by the fact that even with advancements in the development of highly active antiretroviral therapies (HAARTs), such medications do not improve or sustain the health of *all* PHAs (Demmer, 2001). As a result of side effects and ineffectiveness, some PHAs may choose not to take any medications. Unfortunately, the common response to such a choice is to classify this decision as a mismanagement of one's condition.

The monitoring of one's viral load also has become another practice that is required to monitor and maintain one's health. This practice, however, may not be an activity in which one wishes to engage. Kent discussed his resistance to this practice:

I'm not one for numbers and stuff like that. I figure if I'm healthy, I'm healthy. And when I'm sick, I'm sick. So to tell you my viral load, I have no idea what it is. I try not to remember numbers because I get a headache. (27/04/06)

In this quote, Kent spoke to the importance of valuing his own internal knowledge of his body versus relying on a medical technique to provide such information. Furthermore, here, we also see Kent challenging notions within dominant medical discourses that

persons living with illness need to value or learn what medical personnel have deemed significant about the bodies of patients. Furthermore, the classification of one's viral load as a key indicator of (the management of) one's health places responsibility on the individual to care for one's self so as to remain healthy (Rosengarten, 2005). This assignment of duty in monitoring of one's viral load ignores the many factors that contribute to one's lived experience of HIV/AIDS (Rosengarten, 2005). Therefore, the monitoring of viral loads, as well as the other practices noted above, are ways in which PHAs are shaped and choose to be shaped by medical discourses to manage their health and their selves.

In these examples, we can begin to see the ways in which designating responsibility to a PHA to know and care for one's self and, thus, to be a good patient, is an exercise of bio-power. Patients are expected to and choose to accept the knowledge of medical professionals so as to direct their biological functions in ways that will ensure they stay healthy. Some patients may challenge this expectation; however, to resist within this power relation is complicated by the reality that within any engagement we are often disrupting certain ideas while reproducing others. Managing one's health, therefore, is a fine balance between professional control and individual agency.

Managing the Manageable: Staying Informed, Stress-free and Optimistic

With this conceptualization of HIV/AIDS as a chronic, manageable illness, not only are citizens expected to control their health statuses, but they are also required to school themselves about their conditions, to manage their stress levels and to maintain the right attitude.

For instance, some participant described additional ways that they worked to stay healthy and, therefore, to be good patients through keeping themselves *educated* about issues around HIV/AIDS in order to maintain their health. For instance, John stated, “You’ve got to keep yourself informed [about HIV/AIDS]. So I’m just attacking [the virus] like it’s attacking me” (01/05/06). William also mentioned this need to stay informed about issues of HIV/AIDS, as well as the need to be aware of how one’s body feels:

I am so in-tune with my body and how I feel because of this disease. You have to be. I am so informed on every aspect on health and HIV and AIDS, and I have been for years. That’s my business. Because I have to portray this in my story on how I’m feeling to give people a clear picture of what it’s like living with this disease. I have to be up on everything and I do. Over the years, I’ve read so much. I’ve read everything that’s available on HIV and I’m so in-tune with my body. (20/03/06)

In these narratives, education and awareness are essential in caring for oneself. For William, specifically, this awareness around HIV/AIDS literature and research and his own self-awareness were key to the story he shared during his public speaking work. In this way, information seems to be essential for one’s self-image and also to be the way one demonstrates one’s care and awareness of one’s self/health. As Foucault (1986) wrote, this drive for “[e]ducating oneself and taking care of oneself are interconnected activities” (p. 55). To be informed about the condition with which one is living not only allows one to gather information about one’s potential prognosis, but to learn about the strategies, treatments and life skills for potentially preventing such a prognosis. Therefore, through gaining knowledge, these participants are able to become better patients who know how to care for themselves. This knowledge, however, is

circumscribed by compliance; one must know enough to behave in ways one learns about or is taught by experts (Gastaldo, 1997).

William also alluded to another way he became a good patient by being aware of the *stress* experienced by his body:

One thing about this disease is the emotional stress is one of the biggest killers with people who are HIV-positive and progressing towards full-blown AIDS. Regardless of any medications that they're on, the people who do not deal with this disease constructively and are constantly stressed out tend to get sick far quicker than the ones that are able to deal with it properly. (20/03/06)

Although one cannot be certain of how William defined constructive or properly, his interpretation seemed to emphasize the importance of an individual PHA being responsible for finding ways to manage one's emotional stress or attitude in order to stay healthy. Stress then becomes a controllable feature of life that must be regulated. To learn the emotions or anxiety of one's body has become an indicator or expectation of the good patient in that doing so demonstrates one's care for one's self.

Most frequently, participants referred to their efforts to remain *positive* and *optimistic* when conducting the techniques required to manage their health. In other words, staying positive became another technique for maintaining one's health, where health was positively correlated with one's happiness, and also another means of demonstrating one's faith in the "healthy" practices with which they were engaging. In these ways, staying healthy became a *state of mind*. This idea of maintaining the right attitude was described by a couple of participants, who talked about the importance of managing their medications in order to stay healthy. For example, Sandra commented, "It's basically keeping myself healthy and if I decide to give up, then I know I'll be

[gone], just like that. Downhill and not go[ing] back up” (25/04/06). Alana also reported:

Some people, they just really don't want me to give into [my feelings about my HIV-status]. Look what happened to my friend [who was HIV-positive], she just gave up. A lot of [living with HIV/AIDS] is attitude and she just decided she didn't want to live anymore. And she had pneumonia. I believe that her brain told her heart to stop beating and her lungs to stop inflating and she flat-lined and they couldn't bring her back. But a lot of it's attitude. I think if you want to live, then there's a chance. (04/05/06)

In these quotes, participants speak to the notion that one can control one's health by managing one's attitude, which, within dominant medical discourses, is an attribute of the good patient. For both Sandra and Alana, maintaining the right attitude meant not giving up or not giving into their HIV-statuses. Alana referred to the experience of her friend who just “gave in” or just stopped wanting to live and died of pneumonia. For each of these participants, managing their emotions seemed to be essential in maintaining their health. One may ask is it really possible to manage one's emotions so as to produce changes in one's level of health? Some research has demonstrated that doing so is possible (Stacey, 1997); however, such research raises questions around the consequences of expecting that one manage one's health via one's emotions. One effect, which was echoed in the dialogues above, is that these expectations reflect and reinforce the ways cultivation of the self has taken:

...the form of an attitude, a mode of behavior; it bec[omes] instilled in ways of living; it [has] evolved into procedures, practices, and formulas that people reflec[t] on, develo[p], perfec[t], and [teach]. It [has] thus [come] to constitute a social practice, giving rise to relationships between individuals, to exchanges and communications, and at times even to institutions. And it [has given] rise, finally, to a certain mode of knowledge and to the elaboration of a science. (Foucault, 1986, p. 45)

In this way, knowing and caring for the self has become an art-form where “masters” of this art or trade are expected to be the “healthiest” since they are dedicated and are conscious of the operations of their bodies. This idea ignores the contexts in which people exist and the ways social determinants affect our health (Nettleton, 1997). Nevertheless, practices such as educating oneself (of the illness with which one is living), remaining stress-free and maintaining the “right” attitude have become, for some participants, the “best medicines” in preserving their health. At the same time, however, these practices have become some of the most effective ways of regulating the patient population and of having the patient population regulate itself. Furthermore, the promotion of these practices of knowing and, thus, caring for the self have been manifested in other discourses of illness. For instance, for persons living with cancer, self-help and healing books often conceptualize cancer as being the result of “wrongly programmed, or damaged, cells,” and as being “influenced [and even cured] by physical and mental ‘input,’” (Stacey, 1997, p. 149). Consequently, these books then work to encourage persons living with cancer to alter their physical lifestyles and emotional states of mind in ways that are believed to improve their chances of their cancers going into remission (Stacey, 1997). In these ways, managing one’s health/illness becomes an individualized experience where, again, the patient is responsible for taking care of her or his self.

With this reference to living with cancer, I will now move onto the next section, where I will examine participants’ experiences of stigma and discrimination and the ways these individuals believed their experiences of living with HIV differed from those of persons living with cancer.

The Complexity of Living with Chronic Illnesses: A Hierarchy of Oppression?

Perceptions of One's Experience versus the Experience of Another

Another reoccurring health-related theme in interviews was the perception that living with HIV/AIDS was quite different from living with cancer. Several participants, without prompting, made reference to the various points where they believed the experience of living with HIV/AIDS and the experience of living with cancer diverged, particularly with respect to social stigma. More specifically, within these discussions it was implied that the experience of living with cancer was regarded as different and less stigmatizing than living with HIV/AIDS. For instance, as noted by Phyllis:

HIV is still the only disease you can lose your job over and your family and your housing and all of that. I mean, can you image what would happen if someone was evicted because they had cancer? (02/05/06)

John also argued:

I mean, people with cancer don't get stigmatized. You know? People with emphysema don't get stigmatized. People with meningitis...So, you know, I don't understand what the thing about [HIV/AIDS] is really. It's just ignorant people are ignorant and there's nothing your can do about it. (01/05/06)

From these statements, we see how Phyllis and John believe that to live with HIV and to live with cancer have different social consequences (Lorber & Miller, 2002). The point here is not to assert such perceptions as right or wrong, but to demonstrate their complexity. To begin with, PHAs are often situated and take up positions within discourses that require them to assert their rights (and their "responsibilities"), as citizens living with chronic illness, to access resources to which they are entitled so as to gain consistent support, legitimacy and respectability. At the same time, I want to interrogate the perception of HIV/AIDS stigma as unique because it works to position the experience

of cancer as not being stigmatized when some cancer narratives clearly show that that is not the case. For instance, cancers of the mouth, throat and lungs have come to be associated with smoking, and cancer of the liver has come to be associated with “excessive” alcohol consumption (Makimoto & Higuchi, 1999; Wakai, Inoue, Mizoue, Tanaka, Tsuji, Nagata & Tsugane, 2006). As such, persons living with one or more of these forms of cancer may be asked, when they disclose their diagnoses, if they smoked and/or drank alcohol at any time in their lives. Furthermore, commercials presented on television, radio and other forms of media, in addition to research, tend to present non-smoking individuals living with lung cancer as having been exposed to second-hand smoke (Hirayama, 2000). These incidences speak to cancer as a stigmatized condition in that some individuals living with cancer may be regarded as having acted in ways that “contributed” to their diagnoses. Overall, such a competition between diseases forces us to look away from the common responses of fear, pity and discomfort to which bodies living with illnesses are subjected (Stacey, 1997). As well, such perceptions diminish the possibility of acknowledging the similar ways all people are disciplined to perform health and/or sickness in similar ways (Goffman, 1959; Nettleton, 1997).

In the section to follow, I will discuss how we situate ourselves and our experiences of living with certain conditions relative to the experiences of individuals living with different conditions. I will examine the ways one might use such a comparison to attempt to explain the focus of society on one condition over the condition with which one is living. In addition, I will inspect the possible dominant discourses reinforcing such a focus. The intention of this section is to explore the dichotomy of the “deserving” and “undeserving” ill persons as recipients of funding and research. In the

first section, a conversation will take place around the effects of stigma felt by participants and the ways such stigma was perceived as different than that experienced by persons living with cancer. Then, in the second section, a discussion will occur regarding the issue of contagion and cause as factors contributing to the experiences of stigma for PHAs and for persons living with cancer. This overall discussion will hopefully begin to provide insight into how, even within the often stigmatizing category of illness, a dualism can develop that pits persons living with one condition against persons living with another.

Narratives of Exclusion in Personal and Private Spheres

As noted earlier, participants referred to and emphasized the existence of a difference in the degrees of stigma experienced by PHAs and by persons living with cancer and in the ways such stigma affected aspects of their lives. Some participants made reference to how they perceived stigma had affected the ways in which their fellow community members accepted them. As noted by Alana:

One of the biggest things I find, especially recently, is that if someone e-mails you and says, "Oh, I have breast cancer, it ain't a big deal to [the recipients of the e-mail]." But I find at first people were generally scared when I said [I was HIV-positive]. No matter how I said it, there was always the reaction, if it was [a] flick of the eye or running away screaming. When I said I had HIV there was always a reaction.
(04/05/06)

It is difficult to imagine a disclosure of breast cancer not eliciting a reaction. While such a disclosure is possibly less likely to bring on a reaction of fear, this construction of difference reinforces the perception that the reactions persons living with cancer receive from people could not be as negative or as devastating as those which PHAs receive.

In addition, when asked if she believed discrimination had affected her inability to come to terms with her diagnosis, Barbara responded:

Uh huh. If I would have [had] cancer, it wouldn't be an issue at all. And that's what I said to my family. I said, "If I would have phoned you and said I had breast cancer, lung cancer, stomach cancer, brain cancer, you would have been on the first plane here. Right here looking after me. But because of this [diagnosis], I can't sleep in your home, I can't be near your children. You know? So it's like a constant reminder no matter where I go. No matter where I go, no matter what I do, it's a constant reminder".
(09/05/06)

This quote illustrates the stigma of HIV/AIDS and the ways in which it denies Barbara support and becomes a defining feature of the illness. For Barbara, this stigma acts as an endless reminder and dramatically divides citizens living with illness into victims of disease and perpetrators of a "dangerous" illness from whom fellow citizens must be protected.

In talking about his experience of becoming a public speaker (on the topic of living with HIV) and about the difficulty of being accepted by fellow community members, Kent commented:

...I got to the point where it was like, 'You know what? I'm tired of living in the shadows of this disease. It's time to get out and let people know [me]. This is me. I'm the same guy that you cared about but I'm sick.' And they'd be different if I had cancer, [people would] accept me, but because I have HIV, [some people] don't want to or don't know how to accept me. (27/04/06)

What is interesting in this quote, as well as the quotes noted above, is that there appears to be the idea that there are worn paths for how to accept and to respond to persons living with cancer making this condition less stigmatized. For Kent, as well as Alana and Barbara, no such worn paths existed for HIV/AIDS since it is a relatively new condition that has been associated with blood and/or bodily fluid exchanges through intravenous

drug use and/or sex. One's experience of a lack of acceptance may contribute to the perception that other people living with different illnesses may receive acceptance. This perception reinforces the idea of an idealized form of acceptance, which may not actually exist.

Another way participants felt their experience was dissimilar from those of persons living with cancer was the ways in which HIV/AIDS advocacy seems to have been constructed or regarded by mainstream society relative to advocacy efforts for cancer:

I'm very hurt that [HIV/AIDS is] not as widely shared as cancer, epilepsy, diabetes. They have all those things on TV all the time, but AIDS you have to turn to Spike TV...The first time I [saw] one of [Spike TV's] commercials, I was shocked. It's like, "Wow," like, two people talking and the friend was scared to go [to get an HIV test]. And it's like, "Wow, that's down to earth." (Kent, 27/04/06)

And:

I'm angry at the media for not recognizing that AIDS is just as important as cancer. That's all I hear and I get so frustrated. There's a walk for this cure, there's a walk for this cure, there's a walk for this cure, but when there's a walk for AIDS, there's nobody out there. You know? People don't want to walk for it. (Barbara, 09/05/06)

Here, participants discuss the ways they felt that society has not regarded the experience of living with HIV/AIDS as significant as living with cancer. This valuing of certain experiences and devaluing others works to reinforce spaces of exclusion, wherein "the process of making something visible, such as through consciousness raising, something else is rendered invisible" (Healy, 2000, p. 41). When we apply this notion of inclusion/exclusion to the current discourse of advocacy, activism, fundraising and research, it seems, at present, that breast cancer is being marketed as a "hot topic" and a "sexy illness." There is great deal of corporate sponsorship through television

advertisements, posters and fundraising events in support of breast cancer examinations, treatment and research. The drives of such advocacy are not without its reason. Each year, large numbers of women and men die from the complications of breast cancer and, therefore, the work of so many advocates and activists around breast cancer awareness is valuable (Jemal, Murray, Ward, Samuels, Tiwari, Ghafoor, Feuer & Thun, 2005). It is also important to note that through this advocacy and activism, persons living with breast cancer are constructed as different types of citizens than persons living with HIV/AIDS. For instance, breast cancer, which has been publicly portrayed as affecting more women than men, has come to be an illness of *mothers* who are constructed as moral, sacred and virtuous citizens (Choi, Henshaw, Baker & Tree, 2005; Guendouzi, 2005). On the other hand, PHAs are seen as “dangerous” citizens. Furthermore, persons living with cancer of the mouth, throat, lung and/or liver have also been constructed as citizens who have contributed to their own diagnoses by engaging in “dangerous” activities, such as smoking and consuming alcohol. The degree of “media-friendliness” of a condition and, thus, the subsequent research funding for that condition depends on who can be most easily recognized as an “innocent victim.” Funders of research, which often include government, multinational pharmaceutical companies, government-based organizations and/or private charitable services, “all have agendas that shape research questions, and they target populations the research is designed to benefit, exploit, or control” (Lorber & Moore, 2002, p. 6). As a result, mainstream perceptions and constructions of HIV/AIDS and cancer affect the ways in which PHAs and persons living with cancer are shaped. With public narratives focusing on the endorsement of breast cancer research, fundraising, advocacy and activism, the narratives of persons living with other chronic

conditions are obscured. This masking leaves some persons living with illnesses feeling neglected and may even pit various groups of people living with illnesses against one another as they compete for visibility and for resources.

Through the promotion of treatment and research for one particular condition over another an environment of exclusion is produced. It also contributes to our inability to see not only the oppression of others, but also the ways in which we contribute to such oppression (Fellows & Razack, 1998). In order to challenge these narratives of exclusion, we might try, as suggested by Fellows and Razack (1998), “to examine how all the systems operate simultaneously, not only to make the centre, but also to structure us...hierarchally and thus to condition our responses to one another” (p. 340). Such an examination may result in citizens living with one illness and citizens living with another illness identifying the ways in which our experiences are interconnected. Without such an examination, PHAs and persons living with breast cancer, for instance, may continue to feel estranged and to advocate separately for their own causes, instead of collectively supporting both causes.

Managing “Contagious,” “[Ir]Responsible” Bodies

In order not to dismiss the feelings of participants around their experiences of stigma, it is important to consider the issues that may be contributing to participants’ perceptions that the experience of living with HIV/AIDS is substantially different than that of living with cancer. To identify potential issues or factors is not, however, to say that a hierarchy of oppressions exists; instead it is intended to help identify contributing factors to the experiences of stigma for PHAs and for persons living with cancer being

shaped differently. To begin with, HIV/AIDS is a condition that can be transmitted through blood products and/or body fluids. In other words, it has been labeled as being *contagious*, while cancer has not been “scientifically” proven to be transmitted in such ways. As commented by Barbara, “You can’t get [cancer] from somebody” (09/05/06). This issue of contagion may contribute to the experiences of living with HIV/AIDS and of living with cancer having a different feel; however, since PHAs and persons living with cancer both experience social stigma, something more complicated must be happening. Furthermore, many illnesses are considered to be contagious. For instance, the common cold and influenza are classified as highly infectious, however, the average person experiencing the effects of a cold and/or the flu would mostly not identify the experience of stigma as an issue. Therefore, the notion of contagion cannot be the only issue at play. The question then becomes what shapes these experiences as different.

HIV/AIDS has been constructed as an illness that is not only contagious, but is so through behaviours commonly perceived as “deviant” (Ryan et al., 1998; Singhal & Rogers, 2003). Therefore, illness is not only about symptoms and outcomes, it is also about *causality*. In support of this idea, Alana talked about continually being asked about how she came to live with her diagnosis:

People, when I tell them [I am HIV-positive], [wi]ll ask the most inappropriate questions. Like, “How did you get it?” And what am I supposed to say? You know? “I was shooting up.” And that identifies me as a junkie. When people have cancer, you don’t ask, “How did you get cancer? Did you smoke a lot?” And I find, you know, people ask that and they ask very personal questions when they find out. It’s almost like there’s no laws about where you should be sensitive once you find out. (04/05/06)

Within this passage, we can see how with a disclosure of one’s HIV-status comes an inquiry that is believed not to be part of the disclosure of many other illnesses. The

purpose of presenting this passage is not to re-examine or question the issue of persons living with cancer experiencing social stigma, but rather to acknowledge that individuals living with HIV/AIDS (and individuals living with cancer) are often *questioned* about the causes of their diagnoses. For PHAs, though, this line of questioning is more uncomfortable because of the nature of transmission. Despite the fact that a PHA and a person living with cancer may experience similar symptoms, their lived experiences may not have the same meanings given the different experiences around contagion and cause (Lorber & Miller, 2002). HIV/AIDS is perceived as a contagious illness with which one comes to live because of choosing to engage in “dangerous” or “risky” behaviours. Similarly, while cancers of the mouth, throat, lungs and/or liver are constructed as being associated with “deviant” behaviours, such as smoking cigarettes and consuming alcohol, other forms of cancer, particularly that of the breast, the prostate, the extremities (such as the foot) and the brain, are conditions that are often perceived to develop beyond the “control” of a person (Stacey, 1997). As noted by Barbara:

Cancer isn't a dirty word, but AIDS is. And because [HIV/AIDS] can be transmitted through sex or through needles, not so much in blood products anymore, it's still considered a dirty virus. (09/05/06)

Here, we see, again, the ways in which stigma around contagion and causality divide victims of disease from dangerous individuals or “social deviants” who make bad choices that lead them to be exposed to and to contract particular illnesses. The stigma is, therefore, in the cause, not in the outcome. As reported by Barbara, “It's not the stigma of not being healthy, it's the stigma of the word ‘dirty’” (09/05/06). The focus of treatment then becomes altering and preventing deviant behaviours.

It is important to note that this fixation on causality is not eliminated for persons living with cancer. Notions of cause and of prevention are also present in health and medical narratives around cancer, where health care professionals endorse “healthy” lifestyle practices as ways of reducing one’s chances of developing cancer. There are common incidences where individuals are encouraged not to smoke and/or drink, but instead to exercise and eat certain foods in order to “prevent” lung and/or liver cancer. Health care professionals frequently promote the idea if one eats well, manages one’s stress and thinks “positively,” one should not develop cancer (Stacey, 1997).

One may now ask how dominant discourses around health have made the issue of causality so significant. Although there is no one answer, Frank (1995) suggests that:

...people want to know what is happening to the ill person. Stories of illness have to be told to medical workers, health bureaucrats, employers and work associates, family and friends. Whether ill people want to tell stories or not, illness calls for stories. (p. 53)

This thirst for narratives or the drive to question persons living with illnesses by fellow citizens is quite strong and is most likely influenced by a number of factors. To begin with, expectations of citizenship call for us to be responsible in choosing “appropriate” behaviours and activities and for us to accept the consequences of our choices (Foucault, 1988a). As such, by asking questions about how one came to live with HIV/AIDS (or cancer), fellow citizens are able to determine the *kind* of citizen one is. When answers are obtained that distinguish a PHA as also being a person involved in intravenous drug use, an individual working within the sex trade industry, a person with multiple sex partners and/or a man who has sex with men, according to neo-liberal values and beliefs, fellow citizens can label that person as a “social deviant” and as a “dangerous” or “risky” citizen (Foucault, 1988a; Nettleton, 1997; Travers, 2006).

The incident of questioning around this notion of the “dangerous individual” has been discussed by Foucault (1988a), where the dangerous individual (or the accused) on trial is often asked an array of questions by the judge, the prosecutor, the jury and fellow community members. These questions may include: *Why did you commit this crime? Do you understand what you did? Have you reflected on your crime? From where did this criminal activity come?* Foucault (1988a) commented that members of mainstream society, particularly the justice system, desire answers to such questions because:

...[t]he magistrates and the jurors, the lawyers too, and the department of the public prosecutor, cannot really play their roles unless they are provided with another type of discourse, the one given by the accused about himself [sic], or the one he makes possible for others, through his confessions, memories, intimate disclosures, and so on. If it happens that this discourse is missing, the presiding judge is relentless, the jury is upset. They urge, they push the accused, [but he does not play the game...[The accused] really ought to speak a little about [himself], if [he] want[s] to be judge. (pp. 126-127)

In other words, individuals may ask a PHA (or a person living with cancer) questions about how she or he came to live with her or his diagnosis in order to frame an “appropriate” reaction to the person’s “degree of responsibility” (Foucault, 1988a). In other words, from the information obtained, “true” citizens questioning PHAs (and persons living with cancer) are then able to better formulate their *responses* to the individual living with such conditions. Therefore, the ways in which we form and deliver our stories influences the emotions, whether sympathy, empathy, resentment or blame, evoked within and from our listeners.

Alana further commented on this experience of having one’s degree of responsibility questioned:

If I don’t want to say [how I came to live with HIV], I’ll lie and I’ll say, “Well, I got it from a man,” and they’ll say, “Well, does he know he had

it?" You know, and they'll start asking all those questions...They're trying to figure out if I legitimately got it or if I gave it to myself doing a dirty hit. (04/05/06)

Here, we can notice that for Alana, being questioned about the "legitimacy" of her diagnosis of HIV centres around curious citizens questioning whether or not she should be held responsible for her exposure and contraction of the virus. This construction and subsequent assignment of responsibility to individual PHAs works to continually stigmatize persons living with this condition and to also jeopardize their citizenship. Identifying as a woman who was exposed to HIV by a male sexual partner may enable Alana to experience less stigma, discrimination and oppression from the individuals to whom she discloses. Quite interestingly, as can be seen in the quote above, even after Alana provided answers to how she came to live with HIV, questions from her fellow citizens still continued. These unrelenting questions (asked most likely by people not currently living or diagnosed with HIV/AIDS) work to construct and to reinforce mainstream perceptions that we need to know as much as possible about the causes of an individual's condition in order to be able to "judge" that person fittingly.

Furthermore, such questions also enable the inquiring citizens to obtain and eventually share this knowledge or these "truths" around causes with other citizens and, thus, to better manage, control and govern their own behaviours. To be a citizen, as noted in the previous chapter, is to take responsibility for managing one's health, finances, family and self. As such, the disclosure of one's story provides listeners with points of reference to which they can and/or will compare themselves and, thus, regulate their selves and behaviours accordingly (Gulrium & Holstein, 2001). In hearing how one came to live with HIV/AIDS, persons not currently living or diagnosed with this

condition may believe they can identify ways that they can “avoid” being exposed to and contracting HIV and, thus, classify themselves as safe. The inquiry into the causes of how one came to living with HIV/AIDS (or cancer), however, is problematic because this questioning works to support common perceptions that certain risky behaviours are the leading causes of a person’s diagnosis of HIV/AIDS, which ignores the role social determinants of health play, and to continuously reproduce the stigmatization of PHAs. Regardless of the ways in which individuals come to live with HIV/AIDS, certain meanings will always be attached to this illness because mainstream conceptions have been constructed since the beginning of the HIV/AIDS pandemic. Instead of questioning one’s legitimacy, it may be more helpful to examine the ways in which we have identified causality and contagion as important factors when listening to one’s story of illness.

Summary

The purpose of this chapter has been to identify the ways in which narratives of health are interwoven with narratives of citizenship. In the first section of this chapter, I examined the ways in which the medical establishment, through techniques of bio-power, disciplines the bodies of citizens to care for their selves in particular ways that have been marketed as means of “staying healthy.” In adopting these techniques, citizens are then able to discipline themselves in ways that allow them to become *good patients*. This production of the good or the healthy patient is reflective of Foucault’s concept of cultivation of the self in that to care for one’s health requires that one’s knowledge be intensified and deepened through self-reflection and through the subsequent adoption of

particular techniques as means of maintaining a healthy self (Foucault, 1986). This expectation of one managing one's self is heightened with the reconceptualization of HIV/AIDS as a "manageable disease." In our interviews, participants referred to the different ways in which they adopted and exercised various techniques for living healthily, including managing their medications, regulating their emotions and being in-tune with their bodies. Since HIV/AIDS is perceived as "manageable," responsibility to care for one's self and health have been placed upon the individual. The imposition and acceptance of these techniques becomes reflective of the way in which the cultivation of the self has been instilled in us, as our duty as citizens. Moments of resistance do occur, of course, where individuals challenge these expectations of responsibility. Within this study, one participant contested the reclassification of HIV/AIDS as removing the opportunity for her to express her emotions. Furthermore, another participant mentioned his refusal to monitor his viral loads because doing so gave him a headache. How and when we reinforce and challenge notions of the good patient or healthy ways of living are complicated and demonstrate that the regulation of the body is a balance between expert knowledge and personal autonomy.

In the second section of this chapter, I examined the ways in which some participants had identified their experiences of living with HIV/AIDS as fundamentally different from experiences of living with cancer and, thus, as existing within a hierarchy of oppression. Participants discussed their sense of exclusion as it worked to deny them a sense of support and community. Through an analysis of participants' experiences, one can begin to see the ways in which the issues of contagion and cause shape the experiences of PHAs and of persons living with cancer differently. Where both PHAs

and persons living with cancer potentially share the similar experience of being questioned about the “causes” of their diagnoses, the issue of contagion being linked to causality, particularly through practices constructed as socially deviant, may shape these experiences and narratives of HIV/AIDS in distinct ways. The construction of causality and contagion as important to mainstream society centres around our need to know about people’s experiences so that we know how to classify and to respond to persons living with conditions different from our own. This construction also helps us to gauge our own risk and to know where to situate ourselves relative to “others.” It is important, however, to examine how such a social structure disguises the oppression experienced by individuals living with illnesses dissimilar from our own and makes it impossible to see the ways in which we contribute to such oppression. In other words, our narratives and our own “race to innocence” contribute to our inability to see how all of our narratives are interconnected (Fellows & Razack, 1998). As a whole, the discussion and the narratives of health considered within this chapter contribute to my overall argument in that these dialogues portray ways in which we, as citizens, are constructed and construct ourselves through prominent discourses, particularly within conversations of health.

In the following chapter, a continuation of this discussion of citizenship will take place with a focus on the ways our *talks*, both private and public, are affected by social stigma, discrimination and oppression, and work to shape how we are constructed and construct ourselves as citizens. This discussion will help to create a more detailed picture of how notions and experiences of citizenship are complicated.

CHAPTER 4: PRIVATE TALK: THE INFLUENCE OF STIGMA ON ONE'S CITIZENSHIP AND PRIVATE (NON)DISCLOSURES

Introduction

There are a number of different types of *talk* that we use to share our stories with others. In sometimes subtle or overt ways these forms of talk create, reinforce and reflect stories of citizenship. Two types of talk in particular that were used by participants in disclosing their HIV-statuses will be discussed in this thesis. The first is a more personal, private experience where one claims (or does not claim) an HIV/AIDS identity based on a variety of factors and the second is a more exposed experience where one's particular self gets manufactured through professing one's serostatus during the practice of *public speaking*. In this chapter, I will focus on reviewing the occasions when participants chose to disclose or not to disclose their serostatuses in their personal, private spheres and the factors influencing their decisions. In the following chapter, I will address the ways in which participants disclosed their HIV-statuses in more public spheres and the impacts of this more public talk.

Before beginning the discussion of these forms of talk, it is important to speak to the ways in which these dialogues occur in environments where participants experienced a great deal of stigma. In talking with participants, stories of stigma, discrimination and oppression were commonplace, particularly within the medical and justice systems, their employment and volunteer endeavours and their everyday lives. It was evident in their stories that these experiences of discrimination influenced where, when and to whom participants disclosed their serostatuses. I will briefly present and examine these experiences in order to set the stage and to illustrate the textured nature of participants'

lives. In the first section, I have organized these experiences around the four spaces: *the medical system, the justice system, paid employment opportunities and everyday life.*

In the following two sections of this chapter, I will present an analysis of factors influencing the choices that participants made around where, when and to whom they talked about their HIV-statuses. This is significant because these factors influence the form of talk selected and used, while also shaping the lived experiences and subjectivities of participants.

Experiences of Stigma, Discrimination and Oppression

The Medical System

For many participants, the medical system was a central space in which they experienced stigma and discrimination. I cannot begin to address here all of the stories participants told since the number was so significant. Therefore, while all stories were valuable, I will highlight only some key examples.

To begin with, some participants discussed negative experiences specifically within hospitals. Barbara, for instance, reported:

I had to have surgery a few years ago. Well, that surgery's nurse knew nothing about Ritonovir, which is [an HIV] drug. [The nurse asked,] "Oh, what's that?" [I said,] "An HIV med." [The nurse responded,] "Uh oh..." [The] nurse was totally shocked and she'd left me sitting in the room for an hour, with my partner sitting outside waiting, wondering what the heck was going on. And [she did] not com[e] back to tell me why I have to sit there for an hour, twiddling my thumbs in the examining room.
(09/05/06)

Barbara also commented, "I couldn't get the surgery from that doctor. No, I had to wait another year to find another surgeon" (09/05/06). As can be seen, this moment of "professional" anxiety around this participant's serostatus reflects, reinforces and

reproduces mainstream society's uneasiness around HIV/AIDS. Within the medical system, we, as recipients of care, often anticipate that professionals will be able to respond to our needs with tact and a "professional" attitude; however, this example demonstrates how, when we step into the roles of professionals, we do not just leave behind our personal beliefs, fears or judgments. Instead, our personal lives seep into our "professional" selves, sometimes affecting the people with whom we are supposed to be providing services. For Barbara, the responses of this nurse and later the doctor communicate feelings that as a person living with HIV, she is not entitled to the same medical care as someone not currently living or diagnosed with HIV/AIDS. Her status as a citizen who is entitled to a certain level of care and service is diminished and/or entirely dismissed as a consequence of being HIV-positive. This nurse's silence and rejection was experienced in particular ways by this participant; it was interpreted as communicating that medical professionals are only required to assist "healthy," "safe" citizens. Although this may not be the objective practice or ethic intended and upheld by this nurse, in this particular instance, Barbara's experienced little respect and recognition from this particular medical professional.

Barbara also described another experience of discrimination, which involved a hospital intern who was aware of her serostatus prior to their meeting:

I had a lump on my nipple. I mean, it was so painful. This was a month after I was diagnosed and I went in and...when [the intern] came in...she took one look at my breast and said, "Oh, it's a sebaceous cyst," and walked out. Didn't touch it, didn't touch me, nothing. I only go now to doctors who accept HIV-positive patients, so I don't have to go through the humiliation of seeing the look on their face. And I don't want to [see doctors who humiliate me]. I don't want to do that anymore. (09/05/06)

In this story, again, perceptions of the valued patient/citizen are demonstrated and reinforced. This intern's response powerfully communicates who is "clean" and who is not. We also begin to see how touch is essential to the communication of acceptance or fear of the body/disease. Universal precautions play a role in this experience in that this practice emphasizes the need to place barriers between oneself and the "other." Such precautions, while deemed essential, also medicalize particular bodies as touchable and others as untouchable. The consequence of such a dichotomy is that one must then protect oneself from the untouchable body. Furthermore, withholding one's contact, as that medical intern did, despite the availability of universal precautions designates the HIV/AIDS body and citizen as dangerous.

Phyllis described similar treatment she received in a hospital emergency room:

I've had some issues going to the hospital when I split my head open. Yeah, I figured they were going to sew me up real quick...They didn't want that blood all over the place. Yeah, I waited six hours to get stitches in my head. I think [the delayed treatment] was related to my status. You can feel it. You can feel it. (02/05/06)

This story stands out in terms of Phyllis's anticipation of mistreatment by the medical staff in the emergency room. Quite interestingly, the interpretation and significance of discrimination then is not a measurement of objective facts, but instead involves how one makes sense of these facts within a system that fails to provide positive affirmation to persons living with HIV/AIDS (PHAs). As a result, situations such as this one are quickly organized into the category of discrimination. This categorization happens because PHAs are forced to develop an extra sensory ability in order to understand experiences of discomfort, anxiety and disdain. This sensory ability is honed to help

people protect themselves, anticipate reactions and comprehend their experiences. In this way, this sensory ability or awareness becomes part of an HIV-positive identity.

Finally, Barbara talked about her experience of meeting the previous Minister of Health:

I met Allan Rock a few years ago at a breakfast and there was a few of us PHAs. We were all lined up to be introduced to him and I said, "My name is [Barbara] and I'm a PHA." He said, "What does 'PHA' stand for?" Minister of Health! Allan Rock! I said, "A person living with AIDS," and he took a step back and was totally shocked. You know? And I think to myself, "You're the Minister of Health and you don't know what 'PHA' stands for? All you know is the word 'AIDS'. You don't know 'PHA'. You don't even know what the world 'HIV' stands for". (09/05/06)

In this quote, the frustration and fear around being invisible and the anxiety of people's lack of knowledge are evident. We also begin to see how a new language has developed for PHAs. *PHA* is a fairly community-specific term, but has become so commonplace that the experience of an official not knowing the term confirms this participant's sense of alienation.

The Justice System

A number of participants also referred to their concerns around discrimination from the police force, the prison system and even Crown attorneys⁵. For instance, Sandra commented:

The justice system, I think, is very stigma[tizing]. I got into a disagreement with somebody on the weekend and if the police were to show up, I probably would have gotten more of a negative [response]. It would happen towards me because the police know about [my HIV-status]. I let [the police] know right away because I don't want them

⁵ One story shared by a participant was a vivid example of an experience of oppression and discrimination; however, due to the high profile nature of the participant's case, it could not be mentioned here for risk of compromising confidentiality and anonymity.

getting [it], you know what I mean? I say, "Yes, I do," when they ask me about sicknesses. (25/04/06)

Sandra, along with other participants who will be quoted in this section, reported a need, or sense of urgency, in reporting to the police that they were living with HIV. In this particular quote, Sandra felt she needed to report this information to the police so they would not "get it." Despite there being very little risk that the police would come in contact with Sandra's blood and/or body fluids, there still exists this sense of urgency to disclose. This feeling of urgency to report could be a reflection of internalizing the mainstream perception of HIV being "dangerous" to others, but for Sandra, who has been incarcerated in the past, her concern is most likely also influenced by her desire not to be charged and/or incarcerated (in this situation, for not disclosing her HIV-status to the police) again.

Sandra also provided some insight into the treatment of PHAs within the prison system:

Even in the jail system they don't give you the right [pain] medication there. I'm on Oxycontin, which is a [pain medication derived from] heroine. It takes away the pain, like joints and all that. [The prison system] only give[s] you [Tylenol 3's], which is not good. They give you the medication to keep you alive, like cocktails and all that, but for pain and all that because they think you sell it. They don't give the right dosage or even the correct medication...They give you the [pain] medications just to tied you [over] for a few hours and then you're suffering until the next medication round. And if you need it in the middle of the night, they don't give a shit. It's their castle and they're the kings...You get [pain medication] in the morning, the afternoon and the nighttime, and that's it. And if you need it in between that, no, you got to wait until medication time. (25/04/06)

Here, we see how perceptions within the prison system create an environment where a person who is living with chronic illness is no longer entitled to the same medical services or aids that she or he would be if she or he were not in prison. These perceptions

and subsequent experiences of neglect work to construct inmates as “not quite” citizens and leave them to live with their pain.

Alana also commented, “[The police] must have it in their file that I’m an intravenous drug user and a danger [for] being infected [with HIV] in [my] apartment because they [will not] come in” (04/05/06). For Alana, the construction of the HIV-positive body as dangerous works to take away one’s entitlement to police services and places a PHA in the category of “risk” to the police. This reaction from the police works to criminalize the HIV-positive body.

Two participants also talked about their concerns around the Criminal Code of Canada requiring that PHAs disclose their serostatuses to potential sexual partners. As Barbara noted:

The stigma is still there. Say, for instance, my partner and I broke up and I wanted to start dating again...I have to disclose even if I used a condom, I would have to disclose. (09/05/06)

In response to this forced disclosure, Joanne commented:

I mean, it’s like, [persons not currently living or diagnoses with HIV/AIDS] say that they can charge us if we do something wrong with our HIV. Why can’t we charge them for [dis]crimination against us? Where’s the law? There’s no justice...They can sit there laughing at you, they can [make] fun of you, they can put you down, they can [bring] you [to] tears, they can [cause you to have] suicidal thoughts. Why? Where’s our rights? We got no rights. (27/04/06)

And:

[F]inding a man that has the same as you, it’s kind of hard, but you find the right one and then you get connected...and it’s like we have to tell them we’re [living with] HIV, but it’s okay for that person to walk down the street [laughing] at us. It’s not fair. But if we give [HIV] to them, they can charge us, but we can’t charge them for [dis]crimination against us. So where’s our protection? And I guess to fight with the system on that it’s going to take a lot of power. (27/04/06)

When specifically asked how she felt about laws within the Criminal Code of Canada that force PHAs to disclose, Joanne reported, "If they would give us a little leeway, it would probably give us a little bit of release. It would be less pressure on us because they don't realize that we're the ones that are sick" (27/04/06). Through these words, we can hear the frustration and the sense of injustice for Joanne around not being able to challenge the discriminatory comments and responses she received from community members. This requirement to disclose one's HIV-status works to criminalize the HIV-positive body and to distinguish and to construct the HIV-positive citizen as dangerous to society.

Paid Employment Opportunities

For some participants, paid employment provided a much-needed space for companionship, while for others it presented a site for the practicing and reinforcing of social norms of disease/wellness. For example, Barbara commented:

I was always afraid that people at work would find out...And I did confide in one girl at work only because she had just found out she had cervical cancer and so I said to her, "You know, you can get rid of what you have, but what I have, I can't get rid of." And she just sort of looked at me and said, "You're not saying..." and I said, "Yeah. I got it from my husband," and she goes, "Oh, my God!"...She [eventually] went and told my boss not to push me too hard because I wasn't a well person and she told him I was HIV-positive. And a short time later, I got fired and I had to fight human rights, which I lost. (09/05/06)

In this quote, similar to the discussion of the previous chapter, we see the ways in which different illnesses are expected to receive different responses. We also see the ways in which disclosures often happen in order to build community and social connections, but can lead to exposure and exploitation. In this way, confidentiality becomes problematic

and impossible to guarantee. When disclosures fail to lead to positive responses and results, the experience is all the more painful.

This participant later described her experience with her human rights lawyer, which speaks to the difficulties in bringing human rights protection into practice around issues of employment:

I didn't have the money to fight [my ex-employer]. I remember being interviewed by human rights. I was sitting with my lawyer and she says, "Have you applied to go work anywhere else?" And I said to her, "Can you guarantee me that any place that I apply for a [...] job and if they ask me, 'Where did you work last?' and if I say [the name of the business] and [my ex-employer's name] that [my ex-employer is] not going to tell that person that I'm HIV-positive? Can you guarantee me?" There is nothing in the world about confidentiality on the outside of our community. There's confidentiality in our community with our service providers, with our health care workers, but in our work place, there is nothing. There is no such thing as confidentiality. (09/05/06)

This passage highlights the vulnerability of PHAs, the dangers of what can occur when the story of HIV/AIDS is released without the consent of the PHA. All the legal protection that exists cannot provide PHAs with defense against discrimination, which also speaks to the degree of citizenship attributed to PHAs where PHAs may be perceived as "dangerous" citizens. This potential for discrimination limits the prospects PHAs can pursue with respect to paid employment.

Barbara discussed additional occasions where she was dismissed from her paid work after her employers found out about her serostatus:

You can't get a job. I went to work for one [business] and the supplier told [my employer] I was positive. So I phoned up the supplier and told them, "You spread anymore of that kind of rumor, whether it's true or not, I'll have you in court," and that was the first time I ever stood up to anyone. But, you know, whether that stopped him from doing it, I don't know, because I applied for another job a year and a half ago and I worked there for three or four days and I was never called back. And [that

employer] uses the same supplier that [my previous employer used], so I don't know. (09/05/06)

In this quote, again, we see the potential hazards of someone disclosing one's status without one's consent. It is also important to note the impact of uncertainty and the toll that must take, not knowing who knows one's status, and the effect of that knowledge.

Sandra, who was interested in returning to school to become a hairdresser, shared similar concern of how employers might and would respond to her serostatus:

Because I'm going to be going back to hairdressing school I'm a little worried about that, too, because when I used to go to this hairdressing school, I cut myself a couple of times with scissors and that. And I'm thinking, if I let them know [about my HIV-status]...But they don't have to know. It's not part of their criteria [to ask], "Well, do you have any sickness?" You don't have to tell that, but I'm just worried if they were to find out, would that ruin my chance of becoming a hairstylist again? (25/04/06)

Here, uncertainty is also expressed in terms of what is necessary to tell. We catch a glimpse of the dilemma Sandra faces, where informing the school may put Sandra at greater ease but may also lead to her being denied an opportunity for paid work. Sandra was also dealing with the anxiety about future situations where her school found out about her serostatus.

These stories illustrate the concern that weighs heavy on the minds of some participants, especially given instances of discrimination that can leave them feeling paralyzed. These quotes contradict the mainstream vision that HIV stigma has diminished over time. Regardless of what mainstream society perceives, these participants demonstrate that PHAs experience stigma as ongoing, common and even expected in their lives. Furthermore, these experiences of discrimination and rejection did not just occur in their interactions with professions, but also in their own personal

relationships. Some participants discussed experiences of being ostracized by family members, friends and fellow community members following the disclosure of their serostatuses.

Within Everyday Lives with Family Members, Friends and Community Members

Other frequently noted experiences of stigma and discrimination were in participants' everyday lives and interactions with family members, friends or fellow community members. For instance, as John recollected:

I called up one of my friends that I've known since I was seven and told him about it and he never called back after that. He probably thinks he's going to get it from the toilet seat or the doorknob. (01/05/06)

In this quote, we witness John understanding this stigmatized response as growing out of ignorance. There remains an overarching belief that behaviours are linked to knowledge and with the right information, rejection and discrimination would stop. This perception is thrown into question, however, by research that suggests stigma may be more emotionally learned than a direct result of cognitive learning (Rudman, 2004).

When asked about the response of her family members to her serostatus, Joanne mentioned, "My sister was heads up. She wanted to sterilize [everything] in her house [after] I went in[side it]" (27/04/06). She also commented:

[My sister] didn't want me to come to her house. I wasn't allowed to go there for Christmas dinner. I wasn't allowed to go there because I wasn't allowed to take a shower. [My sister] goes, "Well, I can serve you outdoors," and I just took [what she said] and I [said], "No, I'm not even going to be here for Christmas," so I left two weeks before Christmas. (27/04/06)

The cruelty of Joanne's sister's remarks is significant, showing the intensity of the dehumanization that can accompany disclosures. Such a reaction from a family member

is devastating. For Joanne's sister not to want Joanne to eat or to shower in her home demonstrates and reinforces the mainstream perception of the body living with HIV/AIDS as unsafe. Even more, we can see the measures Joanne must take to protect herself and her feelings.

Participants also provided feedback about how they believed the general public felt about HIV/AIDS. For instance, when asked about the general attitudes of mainstream society around HIV/AIDS, Alana commented, "I think people are just as afraid of it" (04/05/06). Joanne, in discussing her perceptions of the attitudes of individuals within her community, reported, "[I]f I went out in the public [to talk about my diagnosis], I would be laughed out. I would get judged, 'Get away from me, you have HIV'" (27/04/06). In these quotes, we see how participants felt that public perceptions of HIV/AIDS have not changed overtime.

A brief overview has been provided above of some specific instances of oppression experienced by participants to help establish a picture of the forces shaping participants' lives. Given these experiences of discrimination, I will now discuss how such experiences may influence where, when, to whom and even if a participant is able to *talk* about or to disclose her or his serostatus. I have broken the following sections into two components, the first will address factors influencing or leading to withholding one's HIV-status, and the second will review factors leading to disclosing one's status. I will examine the ways that withholding and disclosing one's serostatus are influenced by a number of complex issues, including stigma, discrimination, protection of oneself and/or of family members and resistance.

Withholding One's Serostatus

When disclosing, PHAs may be subjected to a number of responses, reactions and subsequent (mis)treatments. Reactions to disclosure can be unpredictable and can lead to uncertainty about to whom one can and cannot disclose. As noted by Phyllis:

You never know who to disclose to, how they're going to react. You think they're going to react one way and really they do a one-eighty [degree turn] and react totally in a different way. Sometimes you think someone's going to lose it when they find out your status, but yet they're the most supportive person. It's hard to figure out who to tell, not tell. (02/05/06)

Here, we can see the uncertainty of how someone will react, as well as the presence of an intuition that can anticipate reactions to one's disclosure. This uncertainty of how listeners will respond may cause some individuals to be selective in their disclosures and withhold their serostatuses from some people for a number of possible reasons, some of which will be examined here.

As a Means of Protecting the Self

As might be expected, some participants discussed their desires to withhold their serostatuses in order to avoid rejection from the individuals within their social environments. As noted by Mark:

[My hometown is] a small town and, you know, it was in the end of the '90s, early 2000s, but, I mean, still we're talking about a town of 200. I mean, they're still stuck in the '80s and '90s. There's no way in hell that this town is going to be educated enough for me to come out and go, "You know what? I have HIV and I live in this town." You know, you realize how many people would honestly freak out. I mean, in large, commercial cities, like Ottawa or Vancouver, Toronto, Winnipeg, it's fine, go ahead, there's agencies. But in my hometown, there wasn't [anything]. (28/04/06)

Here, we see how the decision to disclose is influenced by the perception that ignorance is again grounded in a lack of education and knowledge. Furthermore, we witness how Mark's decision was made through an analysis of the geographic environment in which he lived. This participant assessed his rural community as less open to disclosures than a large urban centre.

When asked whether or not stigma had influenced her lived experience, Sandra reported:

It makes me feel like a black dot on a white piece of paper or a white dot on a black piece of paper because...I feel that everybody knows and if they do, I'm not going to have any friends. (25/04/06)

Here, we actually see the decision not to disclose is a way of maintaining community and friendships and of avoiding being ostracized. In this quote, we can hear Sandra's sense of being singled out and exposed by her HIV-status.

As a Means of Protecting the Feelings of Others

Another potential factor influencing the decision to withhold one's serostatus is one's sense of responsibility to protect the feelings of family members, friends and fellow community members. For example, Alana commented:

...I didn't tell anyone [about my HIV-status] for six months. I was afraid of their reaction. And the reason I was afraid was that I didn't want to make them feel bad. I would feel making them feel bad by saying, "Guess what? Mom, I'm dying," you know. I don't want to make [people] feel uncomfortable. (04/05/06)

Although there are a number of issues that may have been at play for this individual, for the purpose of this thesis, I will examine her choice not to disclose her HIV-status in relation to broader social expectations that people living with stigmatized illnesses,

particularly women, attempt to pass as “healthy” to reduce the discomfort and anxiety of those around them (Goffman, 1963; Stacey, 1997). For Alana, her decision to withhold her HIV-status may centre on her identity as a woman. Research has argued that the need to take care of the people's feelings around the disclosures of various issues is largely a gendered experience, where the responsibility of ensuring family members and friends are not upset or disrupted by such disclosures is placed upon and adopted by women (Butler, 1990; Ciambrone, 2003; O'Reilly, 2006). As such, Alana may be speaking to her sense of duty to care for the feelings of those around her and, thus, withholding her serostatus may be the result of social pressures not to burden others with her lived experience. As noted by Stacey (1997) in her discussion of the experience of living with cancer:

Concealing the illness, the effects of treatment, the distress of the diagnosis often contribute to the stress of the whole experience. Don't upset this friend or relative, hide it at work, keep it from your children. The cultural imperatives of secrecy and disguise are a constant reminder of the price of living with a stigmatized identity. (p. 67)

Not disclosing becomes the normative behaviour and to disclose becomes suspect, leaving one living with a condition to put the needs of others before one's own and to remain silent.

As Moments of Resistance

Dominant discourses of chronic illness, such as HIV/AIDS, generally uphold western societal expectations that when living with such conditions, one should disclose one's status to ensure the health, well-being and safety of the “innocent” (Gastaldo, 1997; Nettleton, 1997); however, such discourses neglect to address the complex experiences

and consequences of such disclosures. Given these consequences, individuals may be selective in their disclosures and non-disclosures as moments of *resistance*, particularly to the negative responses and reactions to which PHAs may be subjected.

A demonstration of this form of resistance was made by Alana, who commented:

If I had a choice to tell someone or not, I wouldn't. Whether it's the flicker[ing] of the eye or running away screaming, I don't like their reaction. It just makes me feel like, "Oh, now they feel sorry for me," or, "They're looking at me differently because they're identifying me as the disease, not as [Alana], the pot smoker, the guitar player, the poet and the artist. They're thinking [Alana], the junkie...And like I said...people automatically have an attitude, whether it's, "Oh, I feel sorry for you," or, "Oh, you're horrible for having done that," there's always a reaction. Always. There's always a reaction and they'll range from slight to extreme. (04/05/06)

In this quote, there are two interesting points to note. First, Alana comments about "if" she had a choice, which reflects a sense of not having the option to decide when to disclose. This sense of limited choice around disclosures is not surprising given the mainstream perceptions of HIV/AIDS and also the Criminal Code of Canada requiring that PHAs disclose.

Second, within this passage, resistance is broadened; not only is it a way of avoiding stigmatizing reactions that are hateful, but also those that are framed as *pity*. Alana was not the only participant to speak to this issue of not wanting anyone to feel sorry for them regarding their diagnoses. Phyllis also commented:

I don't disclose to everybody because it's none of their business. Because really, I mean, I want them to see me as the [employee], not [Phyllis], the poor little PHA. And people, whether they realize it or not, they do [view me that way]. (02/05/06)

In these contexts, a person may use the decision not to disclose as an opportunity to deny or avoid society's view of HIV/AIDS as a condition to be pitied. The rhetorical effects of

being the "poor, little PHA" may be disempowerment, dehumanization and patronization, and may remove one's sense of agency. By ensuring one is not subjected to such reactions, it becomes possible to create a sense of self outside of the socially determined response to HIV/AIDS. Although clearly this sense of self is not completely outside, this new construction of self is in opposition to or in denial of society's reaction in all its forms.

In addition, John, when asked if he believed stigma had influenced his ability to talk about his diagnosis, reported:

I don't generally just get up and go, "Hey, everybody..." You know, it's just people I know that I talk to, my family, some friends that I've had for years. And basically if I want to talk about something, I can come down [to this AIDS service organization (ASO)] to talk to somebody who's in the same boat because you can't really talk to somebody [who's not living with HIV/AIDS and] who doesn't know what's going on really because they're not in the same boat. I mean, I can't tell a white person what it's like to be black. (01/05/06)

Here, we see the ways in which the silencing effects of stigma work to solidify community relations. For John, withholding his serostatus was a personal choice that reflected his desire not to disclose to individuals who would not be able to relate to or respect his life because they, themselves, did not have similar lived experiences. Still, this moment of resistance is complicated by other moments in John's narrative. For instance, when asked about his feelings around confronting the uncertainty of how someone will react to his disclosure, John commented:

It looks like fear. Smells like fear or uncertainty. It makes you nervous. So why bother telling anybody. I mean, people I don't know that I tell, don't tell people. People I know that I tell, tell people. It's the total opposite of what it should be. (01/05/06)

For John, withholding his serostatus may not only demonstrate his resistance to being judged by people who did not understand the experience of HIV/AIDS, but also his own concern and fear around how people would react and who they would later share his HIV-status with in the community. Decisions around disclosures, therefore, can simultaneously demonstrate resistance to a variety of responses of their fellow community members, including rejection and pity.

Disclosing One's Serostatus

In the previous section, I discussed some influencing factors that led participants to decide to withhold their serostatuses. In this section, I will discuss some of these same influences, particularly protecting oneself and resistance, as factors that lead some participants to disclose their serostatuses.

As a Means of Protecting the Self and Securing Freedom

There are a variety of potential factors influencing where, when and to whom one chooses to or not to disclose one's HIV-status. The issue of safety, for instance, was presented above as a factor influencing the decision to withhold one's serostatus. Here, it will be discussed as determining one's decision to disclose one's HIV-status.

Some participants within this project discussed incidents where they believed that they had to disclose that they were living with HIV in order to avoid harm from fellow community members. Alana reported her experience with a man who attempted to sexually assault her, "A guy attempted to rape me and I said, 'I have HIV,' which scared him enough that he didn't want to [and] I actually fought him off" (04/05/06). In this experience, although the emotional distress and the feelings of violation following an

attempted assault cannot be easily forgotten, by disclosing her serostatus, Alana was able to temporarily stop the person from attacking her and then physically prevent him from doing so any further. The response of this attacker is a reflection of mainstream fears around the ways in which HIV/AIDS can be transmitted through sexual intercourse. For Alana, this individual's uncertainty around the transmission of HIV/AIDS was to her benefit. Still, even though her body was saved from harm by her disclosing her serostatus, Alana had to also live with feeling the rejection of her body as "dangerous" and "untouchable." Although we did not discuss her feelings around this specific incident, Alana spoke about a reoccurring dream that stemmed from another negative incident with a male acquaintance:

Alana: The first two years I had HIV I had the same nightmare every night where I'm walking down the street and my legs start to give out and they're giving out and they're giving out and I'm stumbling along. And I end up on the ground and people crowd around me and they go, "What's wrong? What's wrong?" I go, "I'm disabled." And they keep going, "But what's wrong? What's wrong?" and I keep going, "I'm disabled." And they keep asking me and then I say, "I had HIV," and they all run away screaming. I had that every night for two years. Every night.

Researcher: Was that related to an experience you had?

Alana: Yeah. A guy came home from a bar with me to smoke a joint. I told him I was HIV[-positive] and he ran out screaming. (04/05/06)

When asked how living with the uncertainty of not knowing how people will react to her disclosure made her feel, Alana alluded to the effects this incident had on her perception of herself:

Well, you fear that they're going to run away from you screaming. Like my dream where I fall down and I finally tell them I have HIV and they all run away screaming...It just makes you feel like a horrible person, [an] outcast, a misfit because of a physical factor, which seems weird...Like, you know, they don't want to smoke a joint with me or share a cigarette. They're afraid to come into my house a little bit. (04/05/06)

Here, we can see how incidents of rejection following disclosure can impact how one feels about oneself in the long-term. The incident of the man leaving her apartment upon finding out her HIV-status has contributed to her feelings of being an "outcast." Although Alana was able to avert one form of harm (i.e. a physical assault) by disclosing her HIV-status to her attacker, she was left with the emotional harm of feeling as if she is untouchable and dangerous.

Sandra also talked about her need to disclose her serostatus in order to avoid a different type of harm: legal action that could be taken against her for not disclosing.

Sandra: I got into a physical [disagreement]. There's this drug dealer and I didn't like what they were trying to sell and I said, "Okay, I'm not into that shit," and names were called...They knew what I had because they knew me from the past and they said, "Don't touch her because she has HIV and Hepatitis C," and I said, "You know what? I don't want to do this," and I basically got out of there. In a sense, [my HIV-status was] protecting [me] because they know [about it] and then I'm not going to get into a [physical] dis[agreement]. But then again, if I do [get into a physical disagreement], I'm worried about myself because I could be charged with attempted murder or whatever.

Researcher: And so how's the fear of living with that? Like, "Okay, I have to tell everybody I know." Do you feel pressured to disclose then?

Sandra: Well, it's like I don't want to, but for their safety and for mine, like [for] my freedom, I have to. (25/04/06)

Here, we see how Sandra has made sense of this experience and disclosure as a means of ensuring her security. Similar to Alana's situation, upon disclosing and experiencing the recoil of her acquaintances, Sandra must live with the knowledge that those individuals were afraid to come in contact with her. We witness the relief from one form of assault, with the replacement by another. What is different within this dialogue is the discussion of the potential for legal action being taken against Sandra. It may also be valuable to take note of Sandra's last comment, "...for their safety and for mine, like [for] my freedom..." Not only was disclosing a way of preventing others from physically harming

her, but also a means of avoiding incarceration for not disclosing her HIV-status. For the purpose of this thesis, the essential point is that for our justice system to criminalize one's decision not to disclose is to ignore the issues, such as those noted above, leading to one's choice to withhold one's serostatus. It not only criminalizes the HIV-positive body, but also regards it as less valuable, less precious and less of a citizen than the HIV-negative body. This issue is exceptionally complex and calls for a greater discussion than can occur here. It is important, however, to acknowledge how disclosure becomes a means of avoiding some forms of harm, which can simultaneously result in experiencing other forms of harm.

As a Means of Resistance

Another possible factor influencing participants' choices to disclose their serostatuses may be resistance to the effects of stigma. Resistance in the sense of challenging the western practice of making PHAs feel bad about their diagnoses of HIV/AIDS and their selves. Joanne, in particular, seemed to emphasize her need to disclose her serostatus so that she could continue to feel positive about herself. Some of her comments included:

You have to [be positive] because it's what carries me everyday. If I didn't have the positive in me and I had the negative in me all the time, where the hell is it going to put me? It's going to put me in death. It's going to put me in the ground. I don't need depression because of these people. But now I don't put up with people like that anyways. It's like, I'm going to say what's on my mind and if they don't like it, well, that's too freaking bad. (27/04/06)

And:

Today, it's like I tell everybody now. I don't hold it back now. And to me, I have to be free-spirited. They don't like it, well, the door swings

both ways because I'm not going to take the [dis]crimination [from] people making fun of me or laughing at me and I know that's my higher power. I have to walk away and I have to be strong. (27/04/06)

Although these statements resemble similar testimonies discussed in the previous chapter about maintaining a "positive" attitude in order to care for the self and "stay healthy," they may also be demonstrations of Joanne's decision to not allow individuals not currently living or diagnosed with HIV/AIDS to make her feel like she is less of a person because she is living with HIV. This refusal to accept the influence of stigma on her self-perception may be a form of resistance. Although this may seem like an unlikely form of resistance, as noted by Mills (2003), Foucault has encouraged us to view resistance to oppression as more frequent and subtle than we might otherwise imagine.

Summary

Throughout this chapter, I have attempted to show the ways in which stigma, along with other aspects of one's life, influence whether or not participants chose to disclose or talk about their HIV-statuses. In the beginning of this chapter, I discussed examples where participants identified moments of stigma, discrimination and oppression, whether in the medical system, the justice system, paid employment and/or volunteer endeavours and everyday life, that create, reinforce or designate PHAs to particular levels of citizenship. Within the medical system, participants reported moments where health care professionals limited their physical contact with them, leaving these individuals to feel as if they were untouchable and/or "lesser than" citizens who were not entitled to the same medical care as persons not currently living or diagnosed with HIV/AIDS. Within the justice system, participants reported incidences where, again, contact from law enforcement agents was minimal and where participants

felt their care within correctional facilities was not the same as it would be if they were not living with HIV. These incidents reinforced the criminalization of the HIV-positive body and deem such bodies as less precious citizens.

In the second portion of this chapter, I talked about moments where participants made reference to a number of factors affecting where, when and to whom they chose to talk about their lived experiences. As can be seen, withholding or sharing one's serostatus is a complex decision, which is most likely influenced by experiences of stigma, discrimination and oppression. As a result, participants' decisions to disclose or not to disclose their HIV-statuses are often accompanied by uncertainty. At times, this uncertainty can lead to participants withholding their serostatuses in order to protect themselves, their family members and their friends and/or to resist mainstream ideas that one should share information around one's HIV-status in order to protect the "innocent" public. On other occasions, however, this uncertainty can lead to participants to share their serostatuses as a means of protecting oneself and/or of challenging other mainstream perceptions of HIV/AIDS. From these experiences, we can see how disclosures and non-disclosures are complex and quite textured and are connected quite subtly with notions of citizenship.

In the next chapter, I will examine the ways another form of talk, public speaking, as an exercise of bio-power and as a technology of the self, works to shape our subjectivities and to portray narratives of citizenship in more overt ways.

CHAPTER 5: PUBLIC TALK: CONSTRUCTING MORALITY, THE SELF AND GENDER THROUGH THE PRACTICE OF PUBLIC SPEAKING

Introduction

In this chapter, I will address the role that public speaking, as a form of *talk*, played in the lives of the participants with whom I spoke. A number of participants talked about becoming involved in HIV/AIDS advocacy and health promotion through public speaking, whether in the city of Ottawa, in communities within the province of Ontario and/or in communities across Canada. Public speaking involved entering into public settings such as schools, health agencies and/or community centres to tell one's story of the challenges and triumphs in living with HIV. In this chapter, I will examine public speaking within such arenas as not the process of telling just any narrative, but of partaking in the confessional-like practice of telling one's story of living with an illness with the intention of influencing the values, beliefs and behaviours of those hearing the story. The specific questions that I will address are: What does telling one's story in such particular ways do to the presenter or the storyteller? How does this practice shape one's experience and one's narrative? Given that HIV/AIDS narratives are affected by dominant perceptions around HIV/AIDS, how does speaking about one's self rely upon and/or disrupt dominant HIV/AIDS narratives? How does this construction of persons living with HIV/AIDS (PHAs) influence the stories public speakers living with HIV/AIDS tell? Such an inquiry is not intended to uncover whether or not one's story is truthful or untruthful, but rather to question what it means to tell a particular story of one's self. The issues I will give specific attention are the ways participants saw their speaking about living with HIV as providing them with a sense of fulfillment or of purpose, particularly with regard to HIV/AIDS advocacy and health promotion efforts. I

want to overlay this sense that participants described with a Foucauldian analysis of how we manufacture a sense of self that both disrupts and replicates notions of citizenship, in general, and ideas of gendered citizenship, in particular.

It is important to acknowledge that the practice of storytelling has taken place for centuries, particularly around encouraging and/or discouraging citizens from partaking in particular practices or behaviours. As noted by Foucault (1988b), “The association of prohibition and strong incitations to speak is a constant feature in our culture” (p. 16). In more contemporary society, public speaking seems to have been transformed into an interesting phenomenon that has been injected into a variety of mainstream institutions. People can frequently be found making public confessions to the media while on talk shows and reality television shows; within therapeutic environments, such as support groups; and in public forums, such as health promotion conferences. The effectiveness of these mainstream institutions to invoke public disclosures relies upon our common-day desires not only to tell our stories, but to also listen to the stories of others, particularly those whom we understand as being somehow outside of our own experiences or of what we construct as “the norm.” We, both as narrators and as listeners, tend to regard the narrative as a window into the life and soul of the narrator (Hardin, 2003; Skultans, 2000). As noted by Skultans (2000), “Narrative gives us an opportunity of understanding others through an understanding of their project. It is pivotal in creating at one and the same time self-awareness and awareness of others” (p. 6). Although this is a valuable interpretation of the narrative, Foucault and his followers encourage us to recognize that the narrative not only provides transparent self-awareness or the understanding of another, but is also reflective of the ways in which one has come to understand oneself

and one's experience within particular discursive power relations (Foucault, 1986, 1988a; Rose, 1990). These relations tend to allow a sort of moral tale to emerge from self-disclosure. In other words, experiences presented are often ordered as either good or bad, resulting in the storyteller coming to know or understand her or his experience in particular ways and, thus, to construct her or his subjectivity within such restrictions.

In order to begin to analyze themes centring around the phenomenon of public speaking for PHAs, two concepts championed by Foucault will be employed: *bio-power* and *technologies of the self*. I will examine the practice of public speaking as an active practice of shaping and of molding the moralities and citizenship of the listeners. As such, in the first theme of this chapter, public speaking will be regarded as a practice of bio-power, where speaking to educate a group of strangers represents a health promotion strategy for supporting the adoption of particular lifestyles and behaviours by the listeners and the general population (Gastaldo, 1997). This exercise of bio-power, however, is complicated by the reality that the narrator, in the case of participants in this study, is a person living with the condition about which she or he is educating others. As a result, I will try to contextualize such narratives and to discuss the ways in which the institution in which one makes such a public disclosure may work to shape both the story told and the citizenship put forward by the narrator.

The second theme of this chapter, thus, will address the practice of presenting one's narrative to public audiences as being representative of a confession-like practice. More specifically, for the purpose of this thesis, the practice of public speaking will be framed as a technology of the self in that individuals must reflect on their past and current values, beliefs and behaviours; seek truths (or "forgiveness") from various institutions

and its “experts;” gain self-knowledge; and impart (or confess) that self-knowledge upon others in order to demonstrate care for their selves (Foucault, 1988b). Furthermore, within these analyses, I will also discuss the ways in which this practice of confessing and caring for the self reinforces notions of citizenship (Foucault, 1988b).

Under this second theme of public speaking as a practice of the self, I will address another issue, which is the intersection of gender and disclosure. Throughout interviews, participants, depending on their gender identity, reported different experiences around disclosing identifiable information during public presentations. Women, for instance, reported withholding their names and any other particular information to ensure the anonymity of their loved ones, whereas men described being quite open about their identities. I will talk about the ways in which public speaking, as a technology of the self, reinforces gender roles, particularly the construction of women as caregivers and of men as authority figures. I will also discuss how this reinforcement influences one’s ability and/or decision to be or not to be open about one’s identity. This analysis is intended to support a discussion of new ideas and ways of viewing the experiences of public speaking and the presentation of narratives.

Public Speaking as an Exercise of Bio-power

Health promotion and education strategies are typically perceived as common means of supplying citizens with information about the ways we can avoid and/or manage illness and improve our health and the health of our families (Gastaldo, 1997). More traditional medicalization perspectives often perceive health promotion and education strategies as involving medical professionals, who possess great degrees of

power that enable them to impose certain standards of living or ways of being upon us (Lupton, 1997). We, as passive recipients of this information, agree to these standards and incorporate them into our lives (Lupton, 1997). Applying a Foucauldian analysis to these practices of health promotion and education, however, allows us to examine power dynamics within the medical system as more than one-directional. In other words, we are encouraged to acknowledge how our own agency, as patients, plays a role within such interactions. Although health promotion and education may support and reinforce particular practices and behaviours as “normal,” such as visiting the doctor regularly and adhering to medication regimes, we do not just passively adopt such practices (while refuting others) within our lives, but instead we *choose*, sometimes consciously and sometimes unconsciously, to accept and to apply such practices (Gastaldo, 1997; Foucault, 1978). Consequently, our acceptance also works to reinforce these particular activities, practices and behaviours as normal and as the “guidelines [of] how [fellow] patients should understand, regulate and experience their bodies” (Lupton, 1997, p. 99). These guidelines come to represent more than just the ways one should manage and care for one’s body, but also the “appropriate” ways one should conduct one’s self as a citizen. It is not only by disciplining citizens, but also by encouraging them to discipline their selves that strategies of health promotion and education, as mechanisms of bio-power, work to ensure certain levels of health, productivity and efficiency amongst citizens (Gastaldo, 1997). Health promotion and education is, thus:

...an educational experience that gives professionals and patients/clients elements for building up representations of what is expected from ‘healthy’ and ‘sick’ people. These social roles are reinforced by a complex system of rewards and punishments. Health education is an experience of being governed from the outside and a request for self-

discipline. From inside, health education is a constructive exercise of power that improves the medical gaze... (Gastaldo, 1997, p. 118)

It is important at this point to acknowledge that health promotion is not only a practice conducted by health care professionals, but may also involve the *voluntary participation* of citizens, who are not necessarily medical personnel (Gastaldo, 1997). Citizens, once they have gained a certain level of knowledge from professionals or have demonstrated that they have achieved a certain level of self-awareness, become capable of endorsing particular health approaches and encouraging certain changes in the lives of fellow citizens. One example of participatory health promotion by community members is *public speaking*, which involves the sharing of one's story of living with chronic illness and/or health complications. This participation is simultaneously empowering and controlling in that individuals make the conscious choice to talk about their lives and to share their experiences; however, in doing so, their narratives become shaped by the institutions in which they are expressed. For instance, a storyteller may be encouraged to deliver one's story in a particular way. William spoke to this structured execution when talking about how he narrates himself in public:

I've learned to develop a sense of humour regarding my disease, my situation, things I've learned over the years, which helps me deal. I try to portray a sense of humour when I speak to kids only because I want them to see that [living with HIV] is not all doom and gloom. I'm human. This is how I've dealt with it. And I've found that when I speak and I have a sense of humour, you know, telling funny little stories and things...it goes over well with the kids. You know, I use that as an icebreaker. (20/03/06)

Here, we can see the way in which William reshapes his story to achieve pedagogical goals and to engage an audience. The story moves away from being a transparent reflection of life with HIV towards a particular performance of HIV to secure public attention and change. William seemed to know that he could not tell a story of "doom

and gloom,” and, thus, his story of living with HIV is portrayed as having a lighter side. While not necessarily problematic, what become obscured are the moments of doom and gloom. In this way, certain aspects of one’s narrative become possible, while other aspects become impossible (Healy, 2000). The interesting effect of this inclusion of particular stories with the exclusion of others is the ways it shapes our cultural understanding of HIV/AIDS.

Similarly, another way in which one’s story may be altered by the institution within which it is occurring is if particular aspects of the storyteller’s experience are encouraged in order to achieve certain outcomes, such as the alteration of listeners’ “deviant” behaviours. When talking about her work in speaking to women at the Ottawa-Carleton Detention Centre, Barbara commented:

From the women [inmates I hear], “Well, how could you let yourself get infected?”...The first thing I say, “I’m not a drug user. I was never a prostitute. I was just a Mom and I didn’t get it through blood transfusion. I got it from sex, unprotected sex”. (09/05/06)

In reading this passage, we can identify the ways in which mainstream society’s association of intravenous drug use and of sex work with HIV/AIDS seemed to have influenced the ways in which Barbara told her story to her audience. We also hear that in re-telling her story to strangers, Barbara reported how she came to live with HIV through unprotected sex with her ex-partner without knowing of the potential for exposure and for contraction of the virus. That disclosure may have been done in such a way as to minimize the stigma and discrimination that she experienced. In telling her story in such a way, however, Barbara relied on the possibility that being exposed unknowingly to HIV through sexual engagements with one’s partner evokes different emotions than does announcing one has engaged in “risky” behaviours. It is likely that the stigma,

discrimination and oppression faced by Barbara around her lived experience and the ways in which society perceives PHAs shapes the ways she fashions herself for public consumption. While the presentation of Barbara's story challenges common perceptions of PHAs and acknowledges that many people may come to live with HIV/AIDS, it also reinforces notions of PHAs as being particular kinds of citizens who engage in particular activities, such as drug use and/or sex work. In this passage, we can also see the ways in which preventing or limiting one's exposure to HIV becomes a very individualized experience. Listeners are encouraged to be cautious of their behaviours in order to prevent the possible exposure and contraction of HIV.

Examining public speaking as a mechanism of bio-power is important in that the goals of public speaking, as a practice of health promotion and education, are to alter the behaviours and moralities of the listeners. As evidence to this point, it is important to acknowledge the types of stories that are put forward. More specifically, the four participants involved in public speaking, Barbara, Kent, Phyllis and William, are all individuals who have been living with HIV for over 10 years and identify as no longer engaging in behaviours dominant society perceives as "risky." Although their life stories are extremely valuable to the HIV/AIDS movement, the deployment of such stories demonstrates how certain narratives are used in health promotion and education strategies, while stories of individuals who may be currently partaking in activities that may be perceived as "risky," such as intravenous drug use, are not typically heard. The inclusion of particular stories and erasure of others is another demonstration of how certain narratives become possible and others impossible, particularly within this environment of health promotion and education.

Public speaking, however, is not only a technique of educating others; it is also a means of disciplining one's self through the education of fellow citizens. As written by Howson (1998):

[A]s patients become partners in medical culture...through, for instance, preventive programmes, they draw on medical discourse to articulate their experiences, and engage in a dialogue with medical culture, in ways which reinforce their recruitment to the management of their own bodies. (p. 223)

Public speaking, therefore, may represent a more complex dynamic considering that the condition, in this case HIV/AIDS, about which one is informing others is the condition with which the speaker is living. Not only does the public speaker work to encourage fellow citizens to manage their behaviours, desires and practices in particular ways, but the speaker is also persuaded by dominant notions of HIV/AIDS to reflect on their past behaviours, desires and practices and to alter and/or manage such behaviours in order to demonstrate a new self-knowledge and self-appreciation (i.e. care for the self). In order to examine this concept further, I will now suggest that public speaking also takes the shape of a *technology of the self* where the speaker must learn about and care about the self to the point that she can know and understand how to "appropriately" care about and educate (or exercise bio-power over) fellow citizens. I will also contend that through this care of the self and education of fellow community members, one not only challenges mainstream perceptions of PHAs, but also reinforces common notions of citizenship.

Public Speaking as a Technology of the Self

The Confessional Nature of Public Speaking

In this section, I will address the ways in which dominant conceptions of HIV/AIDS construct the practice of public speaking as a means of confessing one's stories in ways that demonstrate innovative understandings and knowledge of their selves that have stemmed from or been formed through personal reflection, self-awareness and care of the self.

Foucault worked to analyze the history of the ways in which people (particularly in western nations) acquire knowledge about themselves given the existence and the influence of the many institutions or human sciences, including economics, "natural" sciences, medicine, psychiatry, psychology, social work and religion (Foucault, 1988b). Foucault (1988b) regarded these various institutions and the practices they uphold as being "very specific 'truth games' related to specific techniques, or technologies, that human beings use to understand themselves" (p. 18). Even more, Foucault identified Greco-Roman philosophies and salvation religions, such as Christianity, as having played a major part in influencing the certain "truth obligations" adopted by and put forward by many modern-day institutions, particularly around ideas of how to live "appropriately" and to be *good, responsible citizens* (Foucault, 1988b). As such, Foucault encouraged people to be critical of the "knowledge" or "truths" gained from these institutions since they typically call for individuals to demonstrate that they believe in these pieces of knowledge or facts (Foucault, 1988b). This demonstration, in general, involves each individual engaging in some form of self-reflection so as to build not only on one's knowledge of one's self, but also to identify the ways in which one's self-knowledge

aligns or does not align with these specific truths and to subsequently modify and reconfigure one's ways of thinking, acting and living (Foucault, 1988b). Armed with new self-awareness, self-discipline and ways of being, one can continuously display one's care for one's self through taking time to recognize the ways one can lead a "better" life as a citizen (Foucault, 1988b). The various practices that enable one to know and to care for one's self were referred to by Foucault (1988b) as *technologies of the self*

⁶. These technologies or techniques of self-examination, as Foucault (1988b) wrote:

...permit individuals to effect by their own means or with the help of others a certain number of operations on their own bodies and souls, thoughts, conduct, and way of being, so as to transform themselves in order to attain a certain state of happiness, purity, wisdom, perfection, or immortality." (p. 18)

These technologies reveal "the history of how an individual acts upon himself [sic]" (Foucault, 1988b, p. 19) and becomes a citizen through continuous contemplation and control of one's actions. It is important to acknowledge that these technologies are not just introduced within power relationships by individuals who possess certain levels of power and are able to impose these technologies upon individuals with less power (Foucault, 1988b, 1994b). Such an imposition would generate images of power relations as being one-directional and oppressive. Furthermore, viewing power in such a way minimizes the complexity and productivity of power relations and ignores the

⁶ It should be noted that Foucault (1988b) identified three techniques as "technologies," in addition to technologies of the self. The second is considered *technologies of production*, which permit people to alter or manipulate items, for instance, within studies of the sciences (both "natural" and human) and linguistics (Foucault, 1988b). The third is referred to as *technologies of sign systems*, which allow people to employ and assign "signs, meanings, symbols, or signification," for instance, within, again, studies of science and linguistics (Foucault, 1988b, p. 18). The fourth is known as *technologies of power or domination*, which define the conduct or behaviour of individuals and make them subject to certain ends or forms of domination (Foucault, 1988b). Although technologies of the self will be the focus of the remainder of this chapter, it should be noted that these technologies do not typically work in isolation, but instead operate together (Foucault, 1988b). The foundation of each of these technologies is that they "each impl[y] certain modes of training and modification of individuals, not only in the obvious sense of acquiring certain skills but also in the sense of acquiring certain attitudes" (Foucault, 1988b, p. 18).

simultaneous interaction of professional power and individual agency that operates within such relations (Foucault, 1988b, 1994b). More specifically, whereas the state and a number of its institutions may construct and reinforce particular ways of being, acting and living as normal and acceptable, we, as subjects, recognize and regard these constructed norms as opportunities to represent ourselves as the “right” type of citizens. Therefore, technologies of the self are not just systems or practices that act upon us, but we act upon and take advantage of these technologies in order to construct particular identities of our selves. Technologies are, thus, simultaneously imposed upon and chosen by each of us.

One example of a technology of the self operating within Christian-based faiths is the *confession* which, at first glance, appears to simply involve the periodic verbalization of one’s internal thoughts to individuals or fellow citizens who are believed to hold greater or *pastoral* knowledge (Foucault, 1988b). Behind this practice, however, lies a more complex process of continuous contemplation of one’s values, beliefs and actions, which is followed by the confession. By engaging in such self-reflection, one is working to:

...know what is happening inside [oneself], to acknowledge faults, to recognize temptations, to locate desires, and...to disclose these things either to [a Higher Being] or to others in the community and hence to bear public or private witness against oneself. (Foucault, 1988b, p. 40)

Through this contemplation and subsequent declaration, an individual is left exposed. The function of the confession, particularly within Christian-based religions, becomes to “[rub] out the sin and yet [reveal] the sinner” (Foucault, 1988b, p. 42) so that one can be guided towards salvation. Through this exposure, one is believed to be able, with or without the help of citizens with expert or pastoral power, to begin to identify how one

might change one's thoughts, feelings, values, beliefs and behaviours to be in line with those constructed by mainstream society as normal, healthy and productive (Foucault, 1988b). These normal, wholesome and effective ways of living represent truth principles or norms that work to regulate and modify citizens; however, again, it is important to remember that power is not only oppressive. These norms allow us to perform particular identities and (re)produce ourselves in particular ways.

Although the confession continues to be a prominent technology of the self within salvation-based religions, this practice has spread out into various institutions of the social sciences as a means of promoting self-regulation. As written by Foucault (1988b):

From the eighteenth century to the present, the techniques of verbalization have been reinserted in a different context by the so-called human sciences in order to use them without renunciation of the self but to constitute, positively, a new self. (p. 49)

In other words, the intention of technologies of the self has shifted away from encouraging one to reject one's ("bad") self towards persuading one to vigilantly engage in self-inspection and self-regulation. These new technologies can be found in a variety of institutions and in many common practices (Foucault, 1988b; Rose, 1990). Through these new techniques, similar to the confession, one reflects upon one's thoughts, beliefs and actions and, as a means of caring for one's self, identifies the ways in which such technologies may help one to change and to (re)manufacture one's self in particular ways. Writing in a diary, journal or daily log, for instance, allows a person to document their thoughts, behaviours and even "sins." This journal acts as a mirror, "but a mirror one [holds] oneself" and, through examining one's reflection, "the self...become[s] both sinner and judge" (Rose, 1990, p. 220). In these roles, one is able to continuously monitor and adjust one's behaviour so that one can perform a particular self-image. It is

at this point that public speaking, analogous to the public confession, begins to take the shape of a technology of the self.

Public speaking, as noted above, is the sharing of one's story within a public arena. These arenas or institutions not only influence the ways we present our stories or the particular aspects of our stories that are emphasized (or neglected), but they also provide the opportunity for us to shape our selves as particular identities. As noted by Frank (1995), "The self-story is not told for the sake of description, though description may be its ostensible content. The self is *formed* in what is told" (p. 55). We, as citizens, willingly engage in these technologies so that we can experience the normalizing effects of such technologies, the privilege they may offer and/or the certainty or sense of belonging they provide.

During interviews, a number of moments arose when participants alluded to ways in which they had come to know and care for their selves through public speaking and subsequently re-imagined themselves as responsible citizens. To begin with, participants involved in public speaking referred to having a sense of *responsibility* in making presentations about health promotion and education. For instance, Kent commented:

...because I have HIV, [some people] don't want to or don't know how to accept me. And so I figures, well, this way [by making public speeches] I can get out and tell people and they'll learn. (27/04/06)

Along the same lines, William reported:

You know, there's a lot of fear-based ignorance out there...But for the most part, I can't fault people because how are people going to know about this disease unless people like myself come along to tell them all about it? Knowledge is acceptance. (20/03/06)

Here, we can see the way in which public speaking, for Kent and William, provides the opportunity to challenge the stigma, discrimination and oppression to which they are

subjected. It may also be valuable to examine how Kent and William have seemingly taken on the responsibility of educating individuals not currently living or diagnosed with HIV/AIDS. We can see the way in which citizenship is secured through the practice of teaching others by a re-telling or confessing the story of one's self (Cruikshank, 1999; Foucault, 1988b). In such a context, these publicly shared narratives become less like stories of personal experiences and more like cautionary tales of what one could become if one does not change one's behaviours.

In addition to reporting that they had a responsibility to provide public awareness around HIV/AIDS, some participants commented that public speaking, as a form of advocacy, provided them with a sense of *purpose* or a cause to champion. Phyllis reported:

[Living with HIV] has made me...I don't know how to explain it...I kind of had a purpose after I started doing AIDS work. Before that I was kind of floundering. (02/05/06)

William also made reference to finding purpose and, thus, feeling empowered:

[Living with HIV] has meant that for the first time in my entire life I have found a purpose to continue on. And over the years I've turned my life around into being a very caring person. And I actually think I would not be here today if it was not for HIV or AIDS. I probably would have died many, many, many, many, many years ago. Although I've had my ups and downs all the way through. Life's not perfect. You know, things happen. But if it wasn't for HIV or AIDS, I probably wouldn't be around today. Also, I feel for the first time in my life, ever since I started getting involved as a frontline worker and as a behind-the-scenes activist that I have a purpose in life, that I fit in...I never felt that I fit in anywhere. And I feel I have a purpose. I feel like a part of the community and it's very, very empowering. (20/03/06)

For these participants partaking in public speaking, as a form of advocacy, provided them with the opportunity to identify a "purpose" in their lives. At the same time, I wonder if it is also helpful to think about how this meaning is gained through reproducing or

replicating notions of the good citizen. The idea of public speaking providing a person with a sense of purpose or value raises an interesting question of how we come to find purpose or to have value. How has value come to be associated with one's "contribution" to society? Furthermore, in what ways does public speaking reinforce notions that citizens need to find a purpose or become active citizens? As noted in the Chapter 2, within a neo-liberal society, part of being a citizen is eagerly participating in certain endeavours, such as paid employment and/or volunteering, because to be active is to be productive and, therefore, less of a burden on the state (Cruikshank, 1999). In a capitalistic society, however, the purpose, value or worth of an individual citizen is often measured by what they economically or socially contribute to society (Foucault, 1978). By being active through publicly telling one's story of living with HIV, one is not only engaging in practices of health promotion and education, but also working towards achieving greater self-awareness of one's past thoughts, beliefs and actions; acknowledging the ways to change those perceptions and behaviours and identifying the ways such self-awareness and new ways of being can influence and be imparted on fellow citizens. It is by engaging in such efforts that one becomes a "better" citizen.

In addition, participants alluded to being able to *protect* or *save* fellow citizens from coming to live with HIV/AIDS. William, for instance, commented:

I currently am a volunteer with [an AIDS service organization (ASO) as a speaker]. I do what we call 'speaks'...And what I mean by speaks is I tell people my personal story in hopes that people will learn from my experiences and actually I have three philosophies. My first one is that if I can affect somebody in a positive way and steer them away from harms that they would have been heading towards and allow them to make proper judgment calls in their own lives when if they hit those forks in the roads, then I'll have done my job. If I can save one person through the course of my lifetime, then I'll have done my job. (20/03/06)

Within this passage, we can see how William referred to his hope that his audience would learn from his experience, which he seemed to have recognized, possibly through self-reflection, as including “harmful” behaviours and “improper” judgments. When reading this quote I am intrigued by the phrases that articulate HIV/AIDS within redemptive narratives of being saved. The opportunity to prevent others from illness appears to represent an opportunity to save oneself. Such language may reflect the internalization of stigma and dominant perceptions that to live with HIV/AIDS is to be “lost” or to have not been “saved.” This piece of narrative raises the question of what “saving” someone or one’s self looks like? Referring to another comment William made about his past may provide some clarity:

Basically I came from a middle-class family. I was well raised, well brought up, well loved. There was no addictions, not even smoking cigarettes in the immediate family. Well provided for, well loved and there was no abuse of any kind, whatsoever. My problems came when I became a teenager and I started going to high school. I got in with the wrong crowd, so I fell prey to the peer-pressure element and that led to drugs and alcohol and my life of addictions. (20/03/06)

In this way, saving someone for William seems to include warning others of the influence of peer pressure and discouraging other people from engaging in activities that are commonly perceived as negative, such as the use of recreational drugs and alcohol. In this way, the public speaker reinforces a moral universe by relying on notions of “good” versus “bad” to articulate the self. Through the practice of saving fellow citizens and one’s self from bad influences, the morality of HIV/AIDS is reproduced. Raising public awareness becomes making people conscious of all the “bad” or “dangerous” activities in the world, such as drug use (particularly intravenous), sex work and sexual activity that has been constructed as promiscuous. What is key here is that these behaviours, in and of

themselves, do not lead to a diagnosis of HIV. Rather, it is sharing used needles or having sexual intercourse without the use of protection that places people at risk of being exposed to and contracting HIV, but these distinctions are erased in this particular story. Instead the HIV/AIDS narrative focuses on behaviours that are considered to increase the potential for exposure to the virus. Through public speaking, “saving others” becomes a means to redeem one’s self from one’s past and to secure one’s position as a citizen.

Kent also spoke to this notion of saving through public speaking:

Like, there’s a lot that [PHAs] can still do for people, like...the next generation...Some of us go out and do speaks and that. If we can help one person understand, “Yeah, you have to be safe out there, but if you end up with it, don’t think you’re finished”. (27/04/06)

Here, I would argue, understanding becomes code for saving; understanding or awareness acts as the mark of change, the way to recognize the possibility of saving. There is a fine balance, however: HIV/AIDS is constructed as something to be feared yet the speaker is cautious to assert that it is not a death sentence. Later, however, Kent went on to comment:

Like, having HIV, I don’t want anybody to have it. I don’t want my worst enemy to catch this...I don’t wish this on anybody because, I don’t know, sometimes I lay in bed and I can just feel the disease in me. I know everyday that goes by I’m getting sicker and it’s like, ‘Why would I want anybody to go through this?’ (27/04/06)

Through this powerful statement, Kent’s ambivalence becomes visible. The “new” message of HIV/AIDS, articulated above, that life is changing, not ending, when one comes to live with HIV/AIDS, is contradicted by Kent’s description of his lived experience of the challenges of HIV. His disdain for the illness is clear, suggesting a struggle not only with the body, but also with one’s self-perception. Such a comment may be reflective of the internalization of dominant perceptions of persons living with

illness as “sick” or “unhealthy” and, thus, as citizens who are “lesser than.” Public speaking, however, becomes an opportunity for one to demonstrate the ways in which, despite illness, one has changed, improved and become a better, healthier citizen.

Within this section, I examined the ways in which public speaking, as a technology of the self, allows individuals to reproduce themselves as good and responsible citizens living with HIV through participation in health promotion and education. Similar to the confession, public speaking enables one to demonstrate one’s engagement in self-reflection, one’s enhancement of self-knowledge and, thus, one’s care or awareness of one’s self. At the same time as enabling individuals to make choices around how they tell their stories to others, public speaking also works to construct speakers as narrators who tell particular kinds of stories and, thus, become particular types of citizens (or selves) (Gubrium & Holstein, 2001). In the following section, I will discuss this issue further, but with a focus on the ways in which this practice of public speaking reinforces a gendered experience of HIV/AIDS.

The Gendered Nature of Public Speaking: To Confess or Not To Confess?

Within some interviews, discussion about public speaking centred on the issue of “gender.”⁷ During discussions with female and male participants involved in public

⁷ The social construction of “gender” as a binary (i.e. as only female and male), has led to the attribution of specific characteristics to women and to men. At the beginning of our lives, we are each categorized as either “female” or “male” (usually by examination and measurement of our physical genitalia) and, as a result, we each are then expected to take on characteristics that have been socially identified as feminine or as masculine (Butler, 1990). As young children, youth and eventually adults, we learn sex-appropriate preferences and behaviours that are practiced and reinforced within the patriarchal family setting and then reinforced in other social environments (Gatens, 1998). In this way, gender becomes *performative*. We are not “female” or “male” because we are biologically-predisposed to act or take on particular preferences or behaviours, but instead because such roles are imposed upon us and because we choose to perform such roles (Butler, 1990; Grosz, 1995). This is, again, the way in which power is productive and is not oppressive (Foucault, 1994b). Through adopting the gender roles that are imposed upon us, we are manufactured and we manufacture ourselves into the “gender” that we are assigned and that is expected of us. We often do so because adhering to a particular gender provides each of us with a sense of certainty in

speaking, a clear picture arose in which dominant expectations around gender were reinforced through the practice of public speaking. More specifically, the two female participants who were involved in public speaking, Barbara and Phyllis, talked about their engagement in this form of work as it existed in relation to their roles as mothers and caregivers. Both women repeatedly emphasized the need to withhold identifiable information, such as their first and/or last names, as a means of protecting the identities of their family members, particularly their children. On the other hand, the two male participants involved in public speaking, Kent and William, made reference to such a need much less frequently. Furthermore, both men reported openly providing identifiable information, such as their names, within their local communities. The discussion to follow involves an exploration of the ways in which the gender binary is reinforced through public speaking, as a technology of the self.

In our interviews, Barbara and Phyllis talked about their roles as public speakers in ways that demonstrated such roles being in conflict and/or co-existence with their roles as caregivers. For instance, Barbara reported:

I'm very protective. I don't come out in Ottawa with my real name because of my grandchildren and because of my children. I don't know who my children know. I don't know who my children have told, even though they have to ask my permission to tell anybody. (09/05/06)

Phyllis also made a similar remark, "I need to protect my daughter. I don't normally give speeches in Ottawa. I can do a workshop in Sudbury or Thunder Bay or anywhere throughout the province" (02/05/06). Withholding one's real name when making presentations within Ottawa or only making speeches outside of Ottawa enables both

our identities, presents normalizing effects, bestows privilege and offers opportunities for us to unite through what we perceive as commonalities (Lorber, 2005).

women to partake in public speaking while still maintaining the role of mother and protector of one's family.

This need to protect one's child continued to be a central focus within our interviews, particularly for Phyllis. In talking about her daughter's place of employment, Phyllis identified it as a place she did not visit when her daughter was working in order to avoid anyone recognizing that she and her daughter were related. When asked how not visiting her daughter at her place of employment made her feel, Phyllis reported:

I need to protect my daughter. I mean, yeah, she's getting old. She can very much take care of herself in the physical sense, but, you know, she doesn't need that crap...As if life isn't difficult enough and they're going to assume she's positive. (02/05/06)

Here, we, again, witness this need to care for one's child. We also begin to see the lengths Phyllis must go not only to protect the emotional well-being of her daughter, but also to shield her daughter from the stigma of being associated with HIV.

When asked about the ways she perceived stigma influenced her ability to talk about her diagnosis, Phyllis referred again to her child, "It's more to protect my daughter. Even the book...put out...did you notice that none of these women in there show their faces, but all the men did?" (02/05/06). The book to which Phyllis referred was a project begun by a community worker, who was also living with HIV, where the writings of individual PHAs were collected and put into a book, along with a picture either of each writer (displaying or hiding her or his face) or of an image that represented her or him. Phyllis seems to refer to this project as a means of highlighting the gendered nature of protecting and caring for one's loved ones.

Later on in our interview, Phyllis spoke more specifically to the gendered nature of living with HIV when she provided her insight into why she believed the voices of

women, such as those involved in the book project, might be quieted within the HIV/AIDS movement:

I think women don't get out there as much as men because, you know, we got shit going on. We [have] got family, we have jobs. You know, we are always the caregiver. We're always the last to go see a doctor. (02/05/06)

Here, we can see the ways women living with HIV/AIDS, who have family members for whom to care, are placed within the caregiver role that may restrict their HIV/AIDS activism and advocacy. Barbara also spoke to her own identity or role as a caregiver:

Researcher: By the sounds of it...you're not only living with HIV, you're also a mom, you're a partner.

Barbara: I'm a caregiver. You know? I look after people. (09/05/06)

From these two females, we can begin to see how women living with HIV/AIDS, if they choose to and are able to access the category of mothers, must place the needs of their family members, before their own needs (O'Reilly, 2006). This sense of urgency in protecting one's family members and putting their needs before one's own is consistent, in western societies, with dominant perceptions of the *good mother*, who is believed to be protective, nurturing, caring, socializing⁸, proud and organized (Guendouzi, 2005; O'Reilly, 2006). Within many western societies:

...[g]ood mothers put the needs of their children before their own, are available to their children whenever needed, and should the mother work outside the home, her children rather than her career should be at the centre of her life. (O'Reilly, 2006, p. 36)

This idealized perception of the mother as "good" and "natural" has placed pressure on women to "put their lives on hold or risk being seen as an 'irresponsible mother'"

⁸ Socializing involves teaching one's children "appropriate" or "moral" values, beliefs and behaviours (Guendouzi, 2005; O'Reilly, 2006).

(Guendouzi, 2005, p. 19). The manufacturing of the ideal or supermom obscures any prospects of one being any other type of mother and works to further fix:

...the standard for what is a “good” mother (and therefore a good woman) and what is a “bad” one. It is, therefore, the standard for women to measure themselves against, and against which others measure women. (Choi et al., 2005, p. 168)

Particular expectations have been placed on and adopted by women that oblige and compel them to care for others, often over themselves, and to be conscious of the ways in which their actions may influence or affect others (Ciambrone, 2003; O’Reilly, 2006). As a consequence, the identities of these women may become interlocked with or inseparable from those of their children, partners, parents and other loved ones. In this way, women are expected to possess and to display essential characteristics that will constitute them as good mothers.

The participants of this study, who were involved in public speaking, may be subjected to and taking up dominant notions that we all have specific roles to fill; women are required to be super-mothers, super-partners and super-housekeepers and where men are expected to be the heads of households and authority figures (Choi et al., 2005; Ciambrone, 2003; Grosz, 1995; Guendouzi, 2005). This identification of female participants’ increased sense of responsibility as mothers is not intended to dismiss the feelings Kent or William may have around their roles as fathers or as caregivers. Instead, it is to demonstrate the influence of “gender,” where female participants involved in public speaking may regard their roles as mothers as central to their identities and male participants partaking in public speaking may identify their roles as authority figures as key aspects of their identities (Weedon, 1997). In western societies, men have been constructed as individuals who gain social capital or value through involvement in

endeavours outside the family, which are perceived to possess a great deal of power, opportunity and/or knowledge (Guendouzi, 2005; Weedon, 1997). Women, on the other hand, have been manufactured as individuals who access social capital through fulfillment of their “essential” roles within the family, as spouses and mothers (Guendouzi, 2005; Weedon, 1997). As a result, men telling their stories within public arenas may be doing so as *experts* or *authorities* on the topic of HIV/AIDS, which may diminish one’s sense of personal consequence in disclosing one’s identity. Women, when presenting their narratives within the HIV/AIDS movement, may be doing so as caregiver. Their stories then may take the shape of *personal confessionals* instead of expert information, which may heighten their sense of personal consequence in disclosing their identities. Specifically, since these stories become personal depictions of their lives, these women may feel that they, along with their loved ones, will be left vulnerable and exposed if and when they provide identifiable information. In these ways, not only does the practice of public speaking, as a technology of the self, reinforce gender roles, but this practice is also used by participants to reconstruct or manage their gendered identities as good mothers/women or as authority figures. Therefore, public speaking acts as a space that individuals can transform or construct themselves into particular identities.

There are, of course, disruptions even among the members of this small group of participants. One such moment was presented by Kent, who acknowledged his concern about family members being impacted by the public disclosure of his serostatus and experiencing what Phyllis coined “guilt by association” (02/05/06). Kent commented:

Well, I got to the point where I checked with my family and my ex-partner, before...I started doing speaks, if it was okay with them because I got to think that [speaking publicly] doesn’t just affect me, it affects everybody that knows me and as soon as your name goes public. It’s like,

“Is that [Janis]’s son?” and stuff like this and then people might not want to bother with her. But my family was very cool about it, so I got to the point where it was like, ‘You know what? I’m tired of living in the shadows of this disease. It’s time to get out and let people know [me]. This is me’. (02/05/06)

He also noted, “Yeah, everyone that knows you, [your HIV-status] affects them because [no one] want[s] to be associating with or known as the person that knows that person who has [HIV/AIDS]” (p. 14). In these quotes, we can see that concern about loved ones, such as family members and friends, is a reality for this PHA, who identifies as male, given the prominence of AIDS-phobia (Herek, 1999). Quite interestingly, the presence or discussion of this concern for Kent challenges the gender binary.

Phyllis also provided a moment of disruption. When asked how making public presentations anonymously so as to protect her child made her feel, she commented:

Actually, I find it okay because it’s almost like I get to assume a different identity when I’m away. You know, kind of like the AIDS activist. Whereas when I’m at home, it’s like I’m the mom, the [paid employee] and stuff like that. So it’s like I’ve found voice outside of Ottawa. (02/05/06)

I find the presence of this desire to take on an assumed identity provides an interesting break in that one wishes to take a moment from being the mother, the spouse and the paid employee. This passage challenges the gender binary and the construction of women’s sole purpose being to mother in that public speaking provides the occasion to step away from the role of motherhood and to assume a separate character. This stepping away, however, can only take place when doing so can occur within anonymous environments and/or at a distance. In this way, the role of protective mother is heightened in the context of AIDS-phobia and may add additional burdens to women living with HIV/AIDS.

By employing the practice of public speaking, female and male participants of this study are able to access certain (yet different) degrees of citizenship. By engaging in health awareness, one is able to be active within one's community, to perform the role of the model community member living with chronic illness, to manage one's health in such a way that one is able to give speeches and, thus, to represent the responsible citizen. By reflecting on their experiences as mothers when making public presentations, the female participants involved in public speaking (re)produce themselves as particular types of citizens. Traditionally, citizenship has excluded the experiences and narratives of individuals who identify as women; Aboriginal peoples; racialized peoples; persons who identify as lesbian, gay, bisexual, transgendered, two-spirited, questioning and/or queer* (LGBTQQ*)⁹; persons living with disabilities; elderly persons and/or many more (Gatens, 1998). This exclusion has led to the construction of the white, middle-class, straight and able-bodied man as being representative of "the citizen" and, even more, the paid labourer, the provider, the authority figure and so forth (Gatens, 1998). As a result, the construction of women's role as being to care for their families has become one of the primary, if not the only ways in which women access citizenship. To become a good mother, one must be able to raise good children (or young citizens), who will grow up to be autonomous, active and efficient adult citizens. Given this context, female and male participants within this study, who were involved in public speaking, were able to use the technique of public speaking to access particular identities and citizenship.

⁹ This description and abbreviation is followed by an asterisk to denote any other sexual and/or gender identities that are not represented by the description or abbreviation.

Summary

As discussed above, public speaking, particularly around one's health, provided the opportunity for individuals to talk about their past experiences and to be involved in health promotion and education. This information is valuable for any audience. At the same time, it is important to examine the ways such a practice may also reinforce notions of citizenship and the expectations of rigid gender roles.

In the first portion of this chapter, I discussed the ways techniques of bio-power present opportunities to teach individuals how to care for their selves so that the state and its institutions do not have to do so. Public speaking around health promotion and education represents such a form of power in that a community member shares her or his story in order to encourage fellow community members to live, act and behave in particular ways so that they will become or remain particular types of citizens. This form of bio-power, however, is complicated by the narrator being a person living with the condition about which she or he is enlightening others. As a result, the institution within which a story is presented also transforms and shapes the story.

In the second section of this chapter, I moved onto explore the practice of public speaking as a technology of the self. Not only is the public speaker working to encourage fellow citizens to manage the behaviours, desires and practices in particular ways in order not to be exposed to and/or contract HIV, but in making such presentations, the speaker is encouraged by dominant notions of HIV/AIDS to reflect on her or his past behaviours, desires and practices and to alter and/or manage her or his own ways of living. This alteration and regulation, by the narrator and by the listener, reinforces particular ways of being citizens as "right." The narrator, of course, does not just blindly adopt these ways

of living that have been constructed as appropriate, but instead she or he uses the practice of public speaking to access particular degrees of citizenship.

In the final section of this chapter, I began to examine the ways in which public speaking and “gender” shapes both women and men into particular kinds of citizens, in addition to the ways in which this practice is also used by women and men to access certain levels of citizenship. Societal expectation placed on women, as citizens, may leave them to feel that they are unable to disclose identifiable information that could be linked to and affect their loved ones, while societal expectations placed on men, as citizens, may situate them in positions that require them to disclose in order to take on or maintain positions of authority. Public speaking, therefore, provides the opportunity for individuals to engage in self-reflection or self-analysis as a way of determining the type of woman (and mother) or man one wishes to be.

It is important to note that it is not the intention of this chapter to discourage anyone from becoming involved in health promotion and education and/or in the HIV/AIDS movement, but instead to be conscious of what our language, knowledge and work actively challenges and silently reinforces. As best presented by Foucault (1994c):

The conclusion would be that the political, ethical, social, philosophical problem of our days is not to try to liberate the individuals from the state, and from the state’s institutions, but to liberate us both from the state and from the type of individualization linked to the state. We have to promote new forms of subjectivity through the refusal of this kind of individuality that has been imposed on us for several centuries. (p. 336)

Applied to the issues addressed in this chapter, it is not about discouraging PHAs from participating in public speaking, but to recognize and to encourage people involved in advocacy to refuse and reject the techniques of power that attempt to mold us into particular kinds of individual citizens.

CHAPTER 6: STRUCTURING GRIEF: THE EFFECT OF NORMALIZING DISCOURSES

Introduction

Now that I have presented the various ways in which citizenship influences and is interwoven into the lives of persons living with HIV/AIDS (PHAs), in this chapter, I will analyze the ways in which a more personal intrapsychic process of grief shapes how one comes to know one's self. I will also examine the ways in which such an intrapsychic process is influenced by dominant perceptions and conceptualizations of grief.

The initial intention of this research project was to address how people who are living with a stigmatized condition, such as HIV/AIDS, are able to grieve or to come to terms with their diagnoses in environments where they are rarely provided with the space or opportunity to talk about their experiences. After talking with participants, however, I began to realize that my curiosity around grief reinforced normative discourses of bereavement. More specifically, in my question of how are PHAs able to grieve, I was upholding the mainstream perception that PHAs, along with persons living with other chronic conditions, are *expected* to grieve. Furthermore, with such a question, I was inadvertently upholding our common western criteria of "healthy" or "functional" grief being short-term, expert-guided (whether directly or indirectly), stage-driven and eventually "accepted." As a way of challenging this normative construction of grief, I transformed my line of questioning from investigating how PHAs grieve to exploring how grief is constructed in particular ways within mainstream society. Specifically, I stopped questioning *how* PHAs grieve and began asking *why* PHAs are expected to grieve the loss of "healthy" or "ideal" bodies. Through mainstream media, everyday

discussions and social practices, language and imagery are used to encourage people to mourn the loss or absence of certain attributes (Butler, 2003; Craib, 1998). For instance, we are (subtly and explicitly) persuaded to mourn the “loss” of our youth, specific physical features, certain levels of ability and so forth. For PHAs, the common expectation is that individuals living with such a condition should mourn the transformation from “healthy” bodies to ones that are living with chronic illness. This expectation of mourning denies or excludes the possibilities of us valuing and recognizing the ever-evolving nature of our bodies and subjectivities.

The direction of this chapter, therefore, has shifted towards an exploration of the ways in which dominant discourses of health and of grief have worked to socially construct the lived experiences of grief. An analysis will occur around how illness, or a compromised level of health, has been situated as a mournful experience. Discourses of health that often construct false dichotomies of “healthy” versus “unhealthy” or “normal” versus “pathological” have generated social perceptions that hold the ill body as a depressing and distressing existence and, thus, should lead to feelings of disappointment, inferiority and grief. Such feelings, however, may not be the realities of PHAs. Therefore, the intention of this chapter has been to problematize and complicate the construction of bereavement.

In order to work towards achieving this task, I will analyze the influence of normative models of bereavement and grief, such as that proposed by Kübler-Ross in 1969. I will discuss how grief, in general, has been socially constructed as an experience to follow what is perceived of as a loss. I will also address the ways in which such models are intended to control, manage and transform our understandings of mourning

(Craib, 1998). Through the establishment of bereavement models, the adaptation of these models to psychotherapy and counselling (by psychiatrists, psychologists and social workers) and the creation of diagnostic tools that distinguish between “normal” and “pathological” forms of grief, mourning has come under the control of “experts” (Craib, 1998; Foote & Frank, 1999). For instance, models established by professionals within various disciplines have defined the expression of certain emotions as appropriate following the experience of a traumatic incident, while the demonstration of other emotions as out of place (Foote & Frank, 1999). Mourning has come to be a phenomenon that society must organize and map so that individuals experiencing grief can return to their “normal” lives as soon as possible. As such, the ways individuals progress through their complex emotions is largely predetermined (Craib, 1998).

In the first section of this chapter, I will analyze the adoption of normalizing discourses of grief, particularly the language of *acceptance*. In the second section, I will discuss the ways in which the absence of grief may represent one’s resistance and/or one’s approach to accessing respectability. Finally, in the last section of this chapter I will address the ways in which the construction of HIV/AIDS as a “manageable disease” may influence the experience of grief for some participants.

The Construction of Normal Grief

Stories of Bereavement

Several participants in my study discussed the ways in which they had experienced grief following their diagnoses of HIV. Grief, for these participants, related to a number of issues, including general concerns around living with HIV/AIDS, the

possibility of dying earlier than expected, the possibility of restricted or limited sexual contact, the loss of being perceived as “normal” and the experience of discrimination. Upon identifying these experiences of grief, participants then tended to discuss ways in which they had come to *accept* their diagnoses of HIV. The question that will be raised here is: How do such discussions of grief and of acceptance reinforce and recreate normalizing discourses around the phenomenon of mourning? In order to be able to examine the influence of and replication of this discourse, a discussion of participants’ experiences of this phenomenon is vital.

To begin with, when asked about her feelings and the possibility of experiencing grief following her initial diagnosis of HIV/AIDS, Joanne commented:

Yeah, I was pretty depressed. I isolate[d] myself big time. Big time. I isolate[d] myself for six months, I think. [It] took me over a year to come to [this AIDS service organization (ASO)]...It was weird. I was scared. I was scared shitless because I think [coming to this organization] was setting in reality for [me]. (27/04/06)

Here, we can see the ways in which Joanne’s grief slipped into depression, isolation and fear. Accessing services through an ASO frightened Joanne in the way that it solidified the reality of her diagnosis of HIV. In this way, grief can be isolating and can create a barrier to receiving services (Sherr, 1995). For Joanne, if she were living with a less stigmatized disease, accessing services may have been less daunting sooner than later. Given this experience, the idea that one should, “get on with one’s life” and accept one’s situation, which is often put forward by bereavement models and research, is problematic because it does not speak to the broad, social-political context in which people live. The social-political context of HIV/AIDS is very different from the social-political context of

another illness. Therefore, in terms of understanding grief, context needs to be recognized.

When asked if she experienced any grief or bereavement following her diagnosis, Sandra reported:

I grieved big time. I thought, "Oh, my God, I'm dying! No!" I thought there was no more sexual contact with anybody because I thought if I breath[ed] on him or if I touch[ed] him then [he would be exposed to HIV]. Because there's all these things, "Oh, you can catch it [because] that person has it," and I thought, "Oh, oh, no!" and it scared the hell out of me. (25/04/06)

Here, we see the ways in which the experience of grief is tied to concerns around the potential loss of physical and sexual contact. We also witness how mainstream myths of HIV/AIDS have influenced this initial reaction and concern around exposing fellow community members to the virus through basic interactions, such as touching and breathing.

When asked if he had experienced any form of grief following his diagnosis of HIV, Kent discussed his experience of having suicidal thoughts and facing what he referred to as the "poor me's":

I ended up, after thinking of [suicide], for a while [I thought about] the "poor me's." They were killing me because I felt sorry for myself and I'd say, "Why did this happen to me? I'm not gay. It shouldn't happen to me, but I'm an IV drug user." In my mind it's like, "No, no, that HIV is just a 'gay disease', it's not a 'straight disease.'" So for years I went, "Poor me." And it was hard to get out of that, too, because I had a lot of suicidal [thoughts] then, too, because it was, like, "Well, as soon as people think I'm gay, I'm finished in my world, the drug world or the straight community." (27/04/06)

Here, we witness how despair, grief and the "poor me's" centred around the ways in which Kent may be labeled with a particular identity and subsequently ostracized from his community once people discovered his HIV-status. Kent later talked about the ways

he came to recognize how HIV/AIDS was not a “gay man’s disease;” however, it is still valuable to recognize the ways in which this initial concerns of being stereotyped works to reinforce HIV/AIDS as a “gay man’s disease.”

One participant talked about her experience of grief in terms of bereavement models. More specifically, when asked if she was able to initially talk about her diagnosis with her loved ones, including family members and friends, Alana mentioned:

No. No. I believe you go through the five states of grief when you become HIV-positive. My first was denial. I didn’t tell anyone [about my HIV-status] for six months. I was afraid of their reaction... (04/05/06)

Here, we see a more overt adoption of bereavement models as a means of explaining one individual’s experience of grief. In addition, we glimpse the ways in which denial, another common stage of bereavement models, has been constructed as the factor leading to Alana withholding her HIV-status from her family members and friends. It may also be beneficial to consider the ways in which stigma and discrimination may influence Alana’s ability to talk about her diagnosis.

When asked about his reaction to his initial diagnosis, William reported feeling:

Despair, uncertainty, depression...severe anxiety, the whole gamut. I mourned that I knew it was the end of my life as I knew it. And I mourned that for many years before I came to grips with my situation. (20/03/06)

In this quote, William’s experience of mourning centred around the perception of a particular lifestyle or way of living coming to an end following his diagnosis of HIV/AIDS and his movement away from grief involved him working to come to terms with that diagnosis. Loss of one’s way of life could take many shapes for an individual, such as limited or no contact with family members, friends and fellow community members; increased health complications and elevated anxieties around sexual contact, to

name just a few. Although we did not explore this sense of loss further within the interview, from this passage, it is clear that following these initial feelings of grief there was a “coming to grips with” or even acceptance of one’s situation for William. It is the complexity of this language of acceptance and other aspects of normalized grief that will now be discussed.

Features of Normalized Bereavement

Through the quotes noted above, we begin to hear the diverse ways in which participants spoke about grief. Even with this variety within our interviews, each participant, in their own ways, came to a similar place which involved taking on a narrative of *acceptance* and of coming to terms with their diagnoses in one way or another. This language of acceptance has been a key component in the normalizing construction of grief. Writers such as Kübler-Ross (1969), suggest that an individual experiencing grief, particularly the mourning of one’s imminent death, move through a specific number of stages until one reaches the final stage, which is generally referred to as acceptance. More specifically, the grieving individual is believed to:

...ha[ve] had enough time (i.e., not a sudden, unexpected death) and has been given some help in working through the previously described stages [i.e. denial and isolation, anger, bargaining and depression], he [sic] will reach a stage during which he is neither depressed nor angry about his ‘fate.’ He will have been able to express his previous feelings, his envy for the living and the healthy, his anger at those who do not have to face their end so soon. He will have mourned the impending loss of so many meaningful people and places and he will contemplate his coming end with a certain degree of quiet expectation. (Kübler-Ross, 1969, p. 99)

Within this quote, the grieving individual is constructed in particular ways. To begin with, the mourning individual is defined as “unhealthy,” which reinforces common

perceptions that there exists some ideal, healthy body to which we should all strive and for which we should mourn if we cannot attain it. This unhealthy person living with illness is believed to be envious of individuals who are “healthy” and to be suffering from her or his lack of healthiness. Moreover, the construction of this dichotomy reinforces notions of not only normal grieving, but also notions of citizenship. As noted in Chapter 3, healthy bodies are generally envisaged to belong to citizens who have been able to manage their health “properly” and, thus, not to come to live with illnesses. For individuals who are living with illnesses, there is the expectation that, as citizens, they will work to manage their lives in ways that will help them to maintain their health. Quite interestingly, William discussed his experience of acceptance in ways that centred around this expectation of one working to sustain a particular level of health:

Now, you know, I've accepted my situation. It doesn't bother me. I'm healthy. I try to stay healthy as I possibly can. It's not always easy and, you know, nobody can ever be 100 per cent. You know, it's just impossible to be totally strict in your life. You know, but I try to do the best I can. I try to do the best I can. I think I do a pretty good job of it. You know, I've come to terms with my disease. (20/03/06)

Within this passage, William discussed the challenges of being completely strict in the management of his health, but also emphasized his strong will to do so. We can see how coming to terms with his diagnosis, for William, highlighted being open to accepting the challenge of maintaining a certain level of health. This dedication to monitoring one's health and accepting one's responsibility to do so is characteristic of the self-regulatory and independent nature of the neo-liberal citizen. More importantly, this commitment and acceptance reduces the burden one places on the state and its institutions by individualizing the experience of living with illness and of living with grief. I would argue that suggesting one must grieve a compromised level of health reinforces the

expectation that one should work to manage one's health to the best of one's ability so as to demonstrate one's dedication to being an proficient, well-managed citizen.

Another way in which grief is shaped by the Kübler-Ross model is that the grieving person is expected to reflect on her or his pending death and move towards acceptance through "quiet expectation." Episodes of mourning are imagined to be respectable, dignified and contained (Craib, 1998; Foote & Frank, 1999; Kübler-Ross, 1969). In western nations, citizens, particularly women, are expected to remain composed, elegant and quiet when enduring challenges (Butler, 1990; Ciambrone, 2003; Foote & Frank, 1999; Stacey, 1997). Joanne spoke to this issue of silent, yet persistent tolerance, "I [have] accepted [my diagnosis of HIV] in my own heart now. I accept it. I know I have to keep on living with this. I can't change the page. I can't close the [book]" (27/04/06). In this passage, the sheer intensity of acceptance is quite clear, as if Joanne is talking herself into acceptance. Through this emphasis, I would suggest one becomes able to build up personal strength so that one can endure the experience of living with HIV/AIDS. Quite interestingly, at other points within our interview, Joanne spoke of experiences of discrimination that made such silent courage difficult. When asked about specific experiences of discrimination, Joanne commented:

I was walking down the street with my niece one day and this was in [an eastern Canadian province] and [there was] this other person that I knew and they knew that I had HIV. The other person started laughing, so my little niece look[ed] at me and she [said], "Aunt [Joanne], what are you going to do?" I [said], "You know what we're going to do? We're going to look high up in the air and we're going to keep on going. It's like they're not even there because why should I upset myself?" "But, Aunt [Joanne], you're not feeling good?" I [said], "No, I'm not feeling good, but I'm not going to waste my energy on them." Like you have to carry on, but then sometimes you can only take so much. You can live by [discrimination] everyday, two to three days, four times a day [of]

somebody sitting there putting you down and laughing. You know what? When it boils right down to it, [there's] their true colours. (27/04/06)

And, when asked how being discriminated against or judged felt, Joanne reported:

It shuts me down. It locks me up. It puts me in my depression. I don't like that feeling and I don't think I should have to feel this towards the public. But when you're looking at the cultures out there and the different personalities of people, I guess it tells us in the Bible we have to accept the good, we have to accept the bad, so there's no reason for me [to] judge these people. I mean, if they want to laugh at me because I have this and they want to put me down, well, at least they're not bothering the next [PHA]. Like, what am I supposed to do? I'm supposed to wash my hands every time. (27/04/06)

Within these passages, we see the way Joanne's quiet resilience is a means of accessing respectability through turning the other cheek and enduring the discrimination (Fellow and Razack, 1998). Such quiet persistence without contest also makes accessible a sense of righteousness and dignity. The western construction of dignity is often perceived as resisting the urge to fight back. This perseverance, however, means locking in a great deal of pain and sorrow, which may place strain on an individual. At the same time, one might question the number of options that are available to Joanne within normalizing discourses of mourning. In the case of Joanne, we see the narratives of anger, frustration and depression are restricted to the point that she felt unable to speak out about her experiences of discrimination to her assailants and instead believed she had to be reserved and composed.

Although very powerful, the language of acceptance represents only one normalizing narrative of grief that has been incorporated into models of bereavement and into the language of mainstream society. There are other key narratives that are interwoven into perceptions of "healthy" forms of grief. Another common contemporary perception of normal or appropriate grief is that mourning is an experience that one has to

overcome by oneself through engagement with various *technologies of the self* (Craib, 1998; Foote & Frank, 1999; Kübler-Ross, 1969). By engaging in these various techniques or technologies, one is believed to be able to overcome one's grief and to become the "appropriate" grieving subject. As noted in previous chapters, technologies of the self assist and encourage one to "look inward," to engage in self-reflection, to recognize one's responsibility in identifying the ways of achieving change (or, in this case, acceptance) in one's life and to execute such changes (Foucault, 1988b). These technologies can take many concrete forms, such as self-help books, exercise programs, meditation activities and therapy sessions (Foote & Frank, 1999). These technologies, however, can also take more subtle shapes, including the particular ways one presents one's self and engages with others. Kent, for instance, discussed the ways that he used humour to help him reach and demonstrate acceptance about his diagnosis of HIV/AIDS:

And the thing is that I joke a lot about the HIV. I like bugging people because I think years ago that's how I accepted it. Like, if I'm going to have it, I'm going to bug people till the day I'm gone...And that's my way of accepting it. So I love bugging people. (27/04/06)

Here, for Kent, appearing jovial and engaging with fellow community members in humorous and mischievous ways becomes a way of demonstrating his acceptance of his condition. It may also be helpful to think about the ways in which a sense of humour represents a technology of the self in that it can help to create a particular self-image and achieves expected outcomes. By appearing good-humored, one becomes the citizen who is healthy, happy and well-adapted.

Another example was presented by Sandra, who, when discussing how her feelings had changed since her initial diagnosis, referred to another less obvious technology of the self: seeking out community.

I mean, I'm more positive about [my HIV-status] because I know we're all going to end up being oil, you know what I mean? We're all going to end up dying. Like, I noticed this [poster] on the bus, too, that really made me think...[It said,] "Dying...is [natural], but dying [alone is] unnatural." And I looked and it really made me think, "Okay, I have friends...and I know I won't die alone, which is good. But before, living in the closet [about my HIV-status] and then thinking, "Oh, my God, I don't want nobody knowing," and this and that, I would have died alone...But now that I know that there are places like this [ASO], I feel better...I started finding people that had [HIV] and they were opening up...and I thought, "Well, why am I [hiding?]" and [so] no [hiding], not anymore".
(25/04/06)

Here, we witness the ways in which a sense of community or of belonging has helped Sandra to reach acceptance. For Sandra, the possibility of dying became tolerable or manageable upon her recognition that she was not alone in such an experience. In her words, there was some comfort in being able to share the experience of living with HIV with fellow PHAs. Such connections helped to draw Sandra out of hiding about her HIV-status. A sense of self seemed to develop or grow from the interactions of one's self with others. Such interactions enabled Sandra to reflect on cues in her environment that refer to death and to identify the ways such indicators relate to her own experience. In this way, we can rethink finding of community as a technology of the self. Locating community members who share the same experience allows one to reflect on one's experience, to realize that one is not alone and to achieve acceptance of one's situation.

One final feature of normalized grief that will be noted here is the non-linear movement of an individual between the various stages of a bereavement model. This particular kind of movement has more recently been identified as a feature of such models (Kübler-Ross, 1987; Showalter, 1997). When asked to describe her specific experience of grief, Alana made reference to this non-linear progression:

It was like the five states of grief described in...Kübler-Ross. It was like that. And you go through the stages and you go through them again. You don't go through them in order. You can revisit them several times. I think I've reached acceptance, in a certain way, most of the time, but, occasionally, I'll feel total despair and distress and depression because of the fact I'm terminally ill and I could get sick and die. And that's depressing and sad. It makes me a bit angry and makes me wonder what happens [after we die] and all that shit. (04/05/06)

Here, we see Alana's identifying with the stage of acceptance being layered with despair, distress and depression. Whereas this less structured progression through such models has been encouraged by researchers of bereavement, it is still anticipated that one's grief will end with acceptance (Kübler-Ross, 1987). For Alana, however, this movement has not stopped, but instead continues even after acceptance has been reached. This reference to the model proposed by Kübler-Ross (1969) speaks to the way in which bereavement models have shaped grief to such a degree that lay people explicitly use them as ways of making sense of their own experiences. While this incorporation of such models can be helpful, these models may become the commonsense approach to grief, which normalize one particular grief experience.

The questions one may now ask are: How has grief been constructed in our contemporary, western society as a process that involves progressing through various stages with the help of technologies of the self until one reaches acceptance? What is the purpose of such a construction? Foucault (1988b) provides one point of clarity on this issue by suggesting that subjects are shaped and shape themselves through governmentality and bio-power to be particular types of citizens. Considering these concepts, it becomes possible that mainstream notions supporting the practice of grieving individuals proceeding systematically through stages, within a structured period of time, until they reach acceptance may be upheld by the neo-liberal expectation that citizens

should be maintained and should maintain themselves as productive economic units at all times (Foucault, 1978; Foucault, 1994a). When we experience grief after the loss of someone and/or some aspects of our lives, our productivity and efficiency often declines (Craib, 1998). This waning may affect our abilities to engage in paid employment, to provide for ourselves and our families and to manage our selves and the lives of our family members. For instance, a person experiencing mourning may take time off from paid employment, may lose interest in working at home (i.e. caring for children and partners) and may discontinue other activities that support the values of the neo-liberal society. If, however, such an individual can be directed towards a quick acceptance, then she or he will be able to continue to regulate the various aspects of her or his life, so that the state and institutions do not have to do so. In this way, “[t]he job [of bereavement counselling] becomes getting the machine back on the road” (Craib, 1998, p. 164). The focus becomes redirecting us, the grieving individuals, back to our “functional selves” as soon as possible so that there will be minimal disruption to the economic activity of our capitalistic society (Foucault, 1978).

A second point of clarity in the construction of normalized grief is that people in our western society are uncomfortable around mourning. Grieving has been constructed as an occasion when emotions are in excess and uncontrollable (Foote & Frank, 1999). If an individual can be guided towards controlling her or his emotions and to accept such instances of grief, then everyone (not experiencing grief) around her or him can feel more comfortable. The intention of regulating one’s emotions is often to make the entire experience easier for fellow citizens, who will no longer have to witness the expression of such uncontrollable emotions. How, then, do we regulate our own emotions to make

others feel comfortable? One way for PHAs may be not to disclose their serostatuses. Alana provided an example of this monitoring of one's disclosure, which was discussed in Chapter 4 on page 92. In this passage, Alana spoke of her weariness in disclosing her serostatus to family members, friends and fellow community members because she did not want to make the people around her feel bad or uncomfortable about her HIV-status. Managing the experiences of grief for citizens may not only be to ensure the goals of neo-liberal, capitalist societies are achieved and maintained, but also to ensure that citizens are not made to feel uncomfortable.

Within this section, I reviewed the features of normalized grief and the ways in which they are simultaneously imposed upon and adopted by us. In the following section, I will describe the experiences and responses of some participants that challenge the various notions of normalized bereavement.

Absence of Grief as Resistance and/or Respectability

Although some participants spoke of experiences of grief that seemed to be in line with bereavement models, others told stories that did not fit into the experiences prescribed by such models and research. In this way, these stories represented interesting fissures, where there was almost an *absence* of grief for some participants. These participants, instead of discussing their past or present experiences of grief, moved on to talk about how they did not grieve. This lack of grief overtime began to take the shape as disruptions to mainstream perceptions of living with HIV/AIDS. For the purpose of this thesis, I will take two approaches to unpack this issue. In the first approach, I will follow the direction of Foote and Frank (1999) and will argue that the absence of grief represents a form of *resistance*. In the second approach, I will take guidance from Fellows and

Razack (1998) and will maintain that the absence of grief reflects a desire to shore up *respectability*.

As noted above, normalizing discourses of grief situate mourning as a short-term experience, where grieving for too long or even too short a period of time is considered to be *complicated* grief (Craib, 1998; Foote & Frank, 1999; Kübler-Ross, 1969). Demonstrations of “appropriate” grieving are, thus, forfeited by mourning that persists beyond or that is not “healed” within a “reasonable” amount of time (Foote & Frank, 1999). Furthermore, “[e]ven during the most intense periods of grieving, mourners are expected to restrain their displays of grieving to appropriate times and places” (Foote & Frank, 1999, p. 172). In order to challenge these normalizing notions, Foote and Frank (1999) regard complicated mourning as forms of *resistance*. More specifically, they:

...propose to understand complicated mourning as one instance of such a *physical* radicalness. People engaged in complicated mourning present no countertheory of their condition. Instead, these people use their bodies to disrupt normal expectations, including emotional restraint, diet, sexuality, and work. Unlike the dominant discourse, those who resist ‘lay down no law,’ but in their embodied refusal of what the dominant discourse demands, the ‘challenge what is.’ (Foote & Frank, 1999, p. 175)

Talking with participants, experiences of challenging such dominant notions of grief arose. When asked whether or not he experienced grief, John commented:

Yes, but that was so long ago, I can’t even remember what [grieving] was like...I got a lot of grief when it first came down. I told one friend of mine and he went out and told somebody so he could get drugs. So that was my first experience with what potentially could happen if I didn’t keep my emotions and thoughts to myself. (01/05/06)

Here, we see the reference to grief, not so much in the sense of sorrow, but more of distress and frustration with the individual who disclosed John’s HIV-status without his consent. From this experience of unauthorized disclosure, John learned to keep any

feelings and concerns he had around his diagnosis to himself. Later in our interview when asked how not talking about his diagnosis had or had not affected his experience of mourning, John commented:

I didn't do a lot of grieving [following my diagnosis of HIV]. There's nothing to grieve about. It happened to me. It happens to lots of people. It's not like I'm the only one in the world, you know? So I just do my thing and try and relax. (01/05/06)

Here, we can see an insistence of a minimal experience of grief and the identification of the diagnosis of HIV as being an experience not to be grieved. This response from John, who self-identifies as a black, straight man living with HIV for 14 years, goes against the experiences that are typically constructed by bereavement models and research. For instance, the results of one research project conducted by Sikkema, Kochman, DiFranceisco, Kelly and Hoffman (2003) around AIDS-related grief have been interpreted as indicating that the experience of grief was more severe among racialized individuals. Given such research, one would believe that such a man within Canada would have a different experience of grieving a clear heterosexual, masculine identity. The fact that he asserts an experience of non-grief is very interesting. I do not have an explanation for this exceptionally telling experience, but it does speak to the ways in which people do exceed models and expectations, often acting in ways that are completely contradictory to what may be deemed by "scientific" research as "the norm."

In response to a question regarding whether or not stigma influenced his experience of grief, Mark commented:

Yeah, I mean, [stigma] did [influence my experience of grief]. It took me a while to find out that, "You know what? [Living with HIV] is okay. I can grieve about it or I can get on with my life." And I decided not to waste my life sitting here in a dark corner crying my eyes out, you know? Open the door and walk out. (28/04/06)

What is useful in looking at this quote is the way it subverts and reproduces normalized notions of grief. These ways of narrating one's life can be empowering and important for that person who is alone, not seeking services and feeling grief. It is important to narrate one's self as having agency within the experience of HIV/AIDS. This narrative is very useful in reclaiming one's sense of control over one's life. At the same time, the question that it raises for me as a researcher is: If narratives similar to this one are ones that we celebrate, that we respect, that we put out and make into public speeches, then does it make it harder to have a different experience of grief? Does it de-legitimize the possibility that a PHA will live the rest of her or his life with parts of every day struggling with this lived experience? Furthermore, is there a way we can actually broaden this spectrum of narratives that we have so that a multitude of experiences are possible? Although this idea did not get unpacked in my interview with Mark, it leaves us with some interesting questions to explore in future research.

Phyllis also discussed her resentment towards the idea of feeling badly for herself:

I don't need to be sitting around saying, "Woe is me, I have HIV." I don't need to be in that space and, you know, for some people that works for them and they'll stay in that space forever. (02/05/06)

When asked how being able or not being able to talk about her diagnosis of HIV/AIDS influenced her experience of anticipatory grief, Phyllis also commented:

It's something that I've kind of gotten used to. I choose to tell, when to tell, however I tell. I think at this point in my life, I really don't care what other people think or what they don't think. It's not like I'm still in my twenties and everybody else's opinion in the world matters. Do I care if this person doesn't like my haircuts? No. I feel kind of silly using that example, but I'm almost 40. I've been around a while...So what someone else thinks of me or doesn't think of me really makes no difference to my world. I know that I have a job, I have housing, I have a child, a husband. This is my life. If someone doesn't like it or they have something to say

about it, they can say it. It's not going to make a whole lot of difference to me. (02/05/06)

In these two quotes, we witness the reclaiming of one's choice about how one will disclose or not disclose one's HIV-status and of not allowing fellow community members to make one feel negative about one's diagnosis, which, again, is quite empowering. At the same time, it may be valuable to examine how this idea or these feelings are ways of securing a toehold of respectability (Fellow and Razack, 1998). In our competitive, capitalist society, respectability is not distributed evenly and is not accessible to everyone. As a consequence, we must demonstrate how we deserve such respect by showing how we pick ourselves up and carry on. In this way, Phyllis may be trying to access a respectable experience of HIV, which is difficult to do given mainstream perceptions. By demonstrating her ability to move beyond any self-pity or sorrow, Phyllis's identity can be celebrated because she is trying to get on with her life.

Taken together, these points of disruptions or fractures can be read as resistance towards mainstream society's construction of HIV/AIDS as an illness to be mourned. By refusing to allow people who are judgmental to enter their spaces, PHAs may be resisting within power relations the influence of dominant conceptualizations of the healthy/ill body.

HIV/AIDS as a Manageable Disease

The third and final topic that will be addressed within this chapter is the issue of HIV/AIDS being reconceptualized from an acute infection to a manageable disease, a discussion that began in Chapter 3. Alana spoke specifically to her experience of trying to negotiate her diagnosis of HIV as a manageable disease when such a

reconceptualization denied her the ability to think about, to articulate and to feel her experience of grief. As HIV/AIDS is reconstituted, persons living with this condition have to put their feelings in line with the new vision of illness or else if they have different understandings and experiences of living with this condition, they become marginalized and silenced. As noted by Alana:

People I know, even counsellors I have, I say I need help dealing with the issues of death and dying. [Counsellors I have worked with] seem to act like HIV is a “manageable disease.” That’s their mantra. “Its just like diabetes.” I think they forget that it’s always terminal and there’s no cure. So they’ll say stuff like, “Oh, well, I could die tomorrow, too”...You know, but people seem to think now that it’s no big deal having HIV, whereas it’s very hard to live with. (04/05/06)

Here, we see the anguish of having counsellors and community members dismiss the experience of living with HIV as being resolved because of its new reclassification as a manageable disease.

When asked what she believed counsellors, medical personnel and other professions classifying HIV/AIDS as a “manageable disease” might not be considering in labeling HIV/AIDS in such a way, Alana commented:

I think they’re denying my right to be indignant, angry. I mean, I don’t want to be that way all the time, but there’s going to be times in my life, you know, I’m going to sit down and say, “Man, that’s a shitty trip. I got a bad deal.” I feel like I should be allowed to have those feelings and I feel like these “manageable disease” people are...minimizing my emotions and my condition. (04/05/06)

And:

People act like [living with HIV has] changed. It’s not a death sentence anymore. It’s a “manageable disease,” which I don’t find makes me feel very comfortable. But that’s the perception people have and that’s the reaction I get now that. “Oh, lots of people are dying,” kind of deal. Which I find minimizes my feelings of fear of dying. And they’re like, “Well, everybody’s dying. You could get hit by a bus tomorrow.” Would you say that to a guy with a cancerous tumor sticking out of their

forehead? Would you say that to a guy on death row? Would you say that to a guy hanging from a noose? “Oh, everyone’s going to die. You could be killed tomorrow.” You know? It doesn’t make sense and I find that what’s peoples’ reactions. I feel that it minimizes my legitimate feelings of despair. I’m not saying I should be despaired all the time but, you know, if it hits me that way, I have a right to feel that way. (04/05/06)

In these passages, we witness feelings of fear and despair around the potential for one’s life to be shortened due to HIV/AIDS-related complications. These feelings conflict with mainstream notions that living with HIV/AIDS is controllable. The detached attitudes or responses of community members seem to restrict the opportunity for Alana to express these feelings around death and dying. Quite interestingly, Alana seems to know that she should not be in despair all the time.

Considering these passages, the construction of HIV/AIDS as a “manageable disease,” for the purpose of this thesis, reveals the effects of dominant discourses of health and of medicine, where illness is viewed as a result of dysfunctional cells that need to be “corrected” or managed through various treatments, medications and the knowledge of professionals. More specifically, with the advancements of highly active antiretroviral therapies (HAARTS), HIV/AIDS has been a condition that can be handled by one taking care of the self and abiding by one’s medical regime. This reconceptualization not only challenges an individual’s physical experience of living with HIV/AIDS, but also affects how one emotionally experiences living with the virus. Since HIV/AIDS is now viewed as an illness that can be controlled with the right medication cocktail and a dedication to such medicine, one is expected to get over any sort of complex feelings one may have about a diagnosis of HIV. As commented by Alana:

Before [people not currently living or diagnosed with HIV/AIDS] were horrified and now it’s more like nothing, you know, “Oh, what are you

worried about?” You know? “Shape up and ship out. Put on a happy face. Pull up your socks.” (04/05/06)

Here, as discussed in Chapters 2 and 3, we see the ways in which the concept of manageable illness supports a particular illness narrative that involves the expression of controlled, composed and limited emotions, while ignoring or denying others narratives where one might express concern or distress about one’s diagnosis. In this respect, illness narratives are expected by mainstream society to come across as happy and to convey a sense of strength within the individual; one who has “shaped up” and “moved on” following one’s diagnosis. The expectation, however, behind promoting particular narratives, leaves some voices silenced, unable to express the distress they may be experiencing.

Summary

In this chapter, I explored how grief has been socially constructed vis-à-vis bereavement models, such as the one proposed by Kübler-Ross in 1969. As the feedback from participants has demonstrated, experiences of grief are complicated. Many people feel complex emotions following difficult or traumatic experiences in their lives and, thus, they may turn to models of bereavement. For these individuals, bereavement models may provide structure and clarity to help them address their feelings. It is important at the same time to recognize that such experiences may be re-structured or even pre-structured through such models. For instance, “normal” mourning is typically considered to occur in stages, to be short-term and to conclude with acceptance. This construction of normal or healthy grief should not be classified as good or bad, but instead should be recognized as making other experiences of mourning impossible.

Some participants in this study demonstrated that their experiences of or lack of grief challenge mainstream perceptions. These participants presented experiences that represented fissures in these mainstream ways of talking about and experiencing grief. These experiences were also complicated, however, by strives towards acquiring respectability.

It is important to emphasize here that I am not trying to disprove bereavement models or devalue the work of researchers and/or counsellors specializing in bereavement. Instead, I want to encourage each of us to alter and challenge our common views and ideas around mourning and to see how the ways in which we mourn are shaped by the social-political contexts in which we live.

CHAPTER 7: CONCLUSION

Pulling It All Together

Throughout this thesis I have explored the ways in which stigma, neo-liberal citizenship and grief are interwoven in the lives of persons living with HIV/AIDS (PHAs). This exploration is valuable in that it contributes to existing bodies of literatures that address these topics. The work of authors such as Gregory M. Herek (1999), Arvind Singhal and Everett M. Rogers (2003) and Robb Travers (2006) have and will continue to provide insight and awareness into the experience of stigma for PHAs. In addition, authors such as Deborah Lupton (1997), Sarah Nettleton (1997), Alexandra Howson (1998), Eric Oddvar Eriksen & Jarle Weigård (2000), Mark Philp (2000) and Ashley Currier (2003) offer valuable research and literature that enhance dialogues around the construction of citizenship, in particular as it relates to health. While each piece of work noted above contributes to discussions of HIV/AIDS, stigma and/or identity construction, there is no analysis of grief in these works. These pieces of literature often leave the connection between stigma and citizenship, in addition to the connection between stigma, citizenship and grief unexplored. Within this paper, one of my intentions has been to examine how grief operates in particular, structured ways, specifically around loss and illness, and how perceptions of grief manufacture a particular kind of citizenship, one that is without self-pity and sorrow. Therefore, the goal of this thesis has been to bring these pieces together within one body of work and begin a discussion on the ways that we are subjected to discrimination, encouraged to be certain types of citizens and expected to grieve in structured ways. Quite interestingly, at the beginning of this project, grief, not citizenship, was the primary focus. As my work unfolded, however, the focus of this

study and of interviews shifted away from grief towards citizenship, specifically the ways citizenship intersected with so many aspects of participants' lives, including their health and their private and public disclosures.

In conducting this research project, I chose to use a qualitative, poststructural analysis because it provided the opportunity to listen to, hear and examine the content, complexity and layers of participants' stories. Unlike quantitative research, the purpose of this study was not to seek out statistical significance, but instead to partake in an exploration of the experiences of how the lives of a small number of participants living with HIV were interwoven with mainstream notions of citizenship and of mourning. Such an analysis has enabled me to examine how our personal narratives reinforce certain ways of living.

Each chapter had a specific focus in addressing the role that citizenship played in the lives of participants. Chapter 2, to begin with, laid the foundation for the entire paper by discussing the ways we are constructed and construct our selves as citizens. In this chapter, I examined how systems do not just exercise power over each of us to maintain order, but instead work to encourage our compliance in ordering ourselves. For the participants of this project, various styles of citizenship were shored up through the management of one's self with respect to health, finances, ambitions and goals. Through the reinforcement and emphasis of these particular characteristics, a dichotomy of "good" versus "bad" citizenship was reproduced. It is important to note that to be shaped and/or to shape one's self as a citizen is a collective, morally charged task. To do so is complicated and textured by the many issues at play in our lives.

In Chapter 3, I talked about the ways the bodies of participants were disciplined by both mainstream society and by the individuals through the use of various technologies of the self as means of “staying healthy.” Through these disciplinary processes, participants, along with the rest of us, are taught how to care for our selves so that the state and its institutions do not have to do so. For participants, this expectation to care for the self has been intensified through the reconceptualization of HIV/AIDS as a “manageable disease.” With this reconstruction, HIV/AIDS has become a chronic condition that can be “controlled” as long as one lives the “right” life. This reconceptualization ignores the many social determinants of health such as poverty and oppression that influence one’s life. Ruptures did occur, where participants challenged this notion of the manageable disease and the right practices of life. This dynamic of reinforcing and of challenging mainstream perceptions, values and beliefs demonstrate the complex interaction of expert power and individual autonomy.

In this chapter, I also discussed the ways in which participants perceived HIV/AIDS and cancer as comprising different lived experiences. I analyzed the role that contagion and causality play in reinforcing this perception. I also examined the ways this dichotomy or hierarchy works to divide people and to disguise the various ways we reproduce the oppression of others in our own attempts to gain respectability.

In Chapter 4 and Chapter 5, I discussed the different ways we employ forms of *talk* to share our narratives and the ways such talk reinforces ideas around citizenship. In Chapter 4, specifically, I interrogated the different factors that affect how one talks about or discloses one’s HIV-status in one’s private life. I initially focused on particular experiences of stigma, discrimination and oppression as they reinforced particular

degrees of citizenship for participants. Specifically, I explored experiences of discrimination within the medical and justice systems, as well as in paid employment and/or volunteer opportunities and everyday life that affixed particular degrees of citizenship to participants. In the medical and justice systems, for instance, participants were at times made to feel that they were “untouchable” and, thus, dangerous in some way. These experiences spoke to the construction of HIV-positive bodies as “lesser than” citizens who compromised the safety of “innocent” citizens. In this chapter, I also discussed the ways in which such experiences of discrimination, along with other factors such as the need to protect oneself, to care for one’s family members and friends and/or to challenge or resist common perceptions surrounding HIV/AIDS, may affect where, when and to whom participants disclosed or did not disclose their serostatuses. From dialogues with participants, it became apparent that disclosures and non-disclosures were quite textured.

In Chapter 5, I unpacked the ways public speaking as a technique of bio-power and as a technology of the self. Public speaking, as an exercise of bio-power, worked to promote the morality of citizens by supporting and endorsing particular behaviours as “safe” and “healthy.” Simultaneously, public speaking, as a technology of the self, strived to ensure the morality and the “healthy” lifestyle of the public speaker. This practice of the self is not only forced upon the public speaker, but instead is taken up by her or him as a means of shoring up citizenship. In this same way, participants involved in public speaking also worked to sustain their particular gendered citizenship, where female participants partaking in public speaking were able to uphold their “roles” as mothers and male participants were able to sustain their “roles” as authority figures.

Finally, in Chapter 6, I examined the ways the language of participants was consistent with that of bereavement models, which have come to influence societal perceptions and constructions of the experience of grief (Craib, 1998; Foote & Frank, 1999). As noted above, prior to beginning this project, I had intended to address the ways in which I hypothesized stigma might influence or affect the experiences of (or lack of) grief for participants given what I perceived as a limited quantity and quality of spaces where PHAs are able to talk about their experiences of bereavement. As my work unfolded, however, I began to shift my questioning towards examining the ways in which PHAs are *expected* to grieve their diagnoses of HIV/AIDS. Participants provided rich details of their experiences, where some individuals supported common perceptions of bereavement, while other participants challenged such ideas. The important point of this chapter was that dominant perceptions and constructions of bereavement and certain ways of grieving are regarded as respectable, while others are classified as out of place and inappropriate. While bereavement models are valuable to many, the importance of challenging our ideas of bereavement cannot be overstated. The intention of this discussion was not to persuade people from turning to bereavement models to reflect on their own complex feelings or those of others. Many people find such models valuable given their normalizing effects. Instead the idea is to question *how* and *why* we come to value particular forms or expressions of grief, specific ways of addressing one's mourning and certain ways of managing one's grief that are frequently presented in bereavement models. Furthermore, it may also be beneficial to contemplate why we value the use of bereavement models, what structure such models offer and how such models construct the grieving citizen. Through this rethinking of our experiences of

grief, we may begin to see the ways this emotion has come to be structured and manufactured so that it becomes (or appears) less “messy” and disruptive to our contemporary society in which we are expected to be citizens who are self-controlled and without self-pity so that we can be active, productive and efficient in all that we do.

Future Research

Given the results and outcomes of this research project, some future research areas can be identified. To begin with, future research exploring the effects of stigma on experiences of mourning the loss of fellow community members living with HIV/AIDS would be valuable. In addition, although not addressed in this thesis, future research unpacking the influence of culture, as well as (re)colonization, on a small group of PHAs’ experiences of grief would also provide an interesting and useful analysis.

Rethinking Citizenship

In analyzing my interviews with a small group of PHAs, my intention was to encourage the reader to think about how we each are constructed and construct our selves as citizens. This construction, again, is not necessarily good or bad, but is instead a complex dynamic. Furthermore, within this dynamic, we may not be constructing our selves so as to meet our own agendas, but instead to meet the agendas of the contemporary state and its institutions. It is important to remember that the state and its institutions, “act only to strengthen the moral capacities of individuals, to make it possible for them to restrain themselves, never to determine their ends” (Cruikshank, 1999, p. 47). By giving individuals specific choices or options that are constructed as

being reflective of one's level of morality, the state promotes citizens to make "ethical" choices, but it does not determine or define the moral course of action (Cruikshank, 1999). As part of this dynamic, we decide or choose to partake in it through one means or another. It is in this way that power is productive. Through power relations occurring between ourselves, the state, its institutions and fellow community members, we learn the rules of engagement or the "appropriate" ways of thinking, talking, acting and being (Cruikshank, 1999; Mills, 2003). Although these power relations work to establish and to reinforce certain ways of behaving that represent societal norms, we are each *free to choose* to adopt (and to reinforce) particular ways of living, while rejecting others (Mills, 2003; Rose, 1990). For instance, in contemporary society, people are considered to be free to choose how they live with HIV/AIDS. It is vital to remember, however, these choices are located within a moral, regulatory framework and are influenced by the variety of social determinants that affect our lives.

While the notion of citizen reconstruction is quite abstract and removed from everyday life, the results of this research suggest that there is a need to reflect upon how our language and practices regulate normality. Through the language we use, the knowledge we adopt and the practices in which we engage (i.e. regulated freedom), we may be avoiding the idea of being anything other than "the citizen" because of the potential negative reactions we may receive from others, including family members, friends, health care professionals and many others. At some level, interrogating our own investments in seeing our own selves as normal may open up the possibility to become the citizens that we each *want* to be, not that we are *expected* to be.

Relevance to Social Work: A Personal Reflection

Prior to and during the work of this thesis, I had certain ideas about the roles of social workers as advocates, case managers and community developers with PHAs. Having moved on to work in the field just prior to the completion of this thesis, I have begun to see the role social workers play in regulating populations so as to produce *responsible citizens* (Currier, 2003). As I witness and partake in this system, I frequently think of and turn to authors such as Craib (1998), who warns us that:

...unless we are careful, our insights become caught up in a process of social control in which our work is geared, without our knowing it, less to healing, to the integration of the whole individual, or to freeing the individual to make his or her own decisions than to producing the sort of personality that is most suitable to contemporary society. (p. 158)

Our desires to ensure that the individuals with whom we work are exercising their individual autonomy are often challenged by the mandates and expectations of our agencies and our funding bodies. Although I would like to believe that I am continually challenging my own practice and the idea of socially controlling individuals, I witness myself slipping into the practice of manufacturing citizens and am anxious of how I will escape it. Although I cannot begin to provide a step-by-step process to achieving “freedom” from this system because no such process exists and because, even if such a process did exist, it would inevitably somehow reinforce and manufacture citizens in other ways, I can remind myself and the people with whom I engage of the importance of continuously challenging what we say, think and do. Otherwise, despite our greatest hopes to be critical thinkers, actors and social workers, who “help” and “empower” the individuals with whom we work, we will only be reinforcing, replicating and contributing to the oppression these individuals face.

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APPENDIX A: PROFILES OF PARTICIPANTS

Alana identified as a white, heterosexual female in her early forties. At the time of our interview, Alana had been living with HIV for almost 10 years.

Barbara identified as a white, heterosexual female in her late fifties. At the time of our interview, Barbara had been living with HIV for more than 10 years.

Joanne identified as a white, French-Canadian, bisexual female in her mid-thirties. At the time of our interview, Joanne had been living with HIV for less than five years.

John identified as a black, heterosexual male in his late forties. At the time of our interview, John had been living with HIV for more than 10 years.

Joseph identified as a white, French-Canadian, gay male in his mid-forties. At the time of our interview, Joseph had been living with HIV for more than 15 years.

Kent identified as a white, heterosexual male in his mid-forties. At the time of our interview, Kent had been living with HIV for more than 10 years.

Mark identified as an Aboriginal, gay male in his mid-twenties. At the time of our interview, Mark had been living with HIV for less than five years.

Phyllis identified as a white, bisexual female in her late thirties. At the time of our interview, Phyllis had been living with HIV for more than 15 years.

Sandra identified as an Aboriginal, transgendered person (male-to-female) in her late thirties. At the time of our interview, Sandra had been living with HIV for almost 10 years.

William identified as a white, heterosexual male in his mid-forties. At the time of our interview, William had been living with HIV for over 20 years.

APPENDIX B: RECRUITMENT POSTER

(Reduced in size)



Are you living with
HIV/AIDS and
interested in
talking about your
experience?

If you are interested, please contact **Marie** at **520-2600 (ext. 0264)** to leave a message and I will return your call. To keep your identity confidential, please provide only your *first* name.

An honorarium will be provided to individuals willing to talk about their experiences. These experiences will contribute to a research project.

Thank you for your interest. I look forward to talking with you soon!

** This research project has been approved by the Carleton University Research Ethics Committee.*

APPENDIX C: INTERVIEW GUIDE

Demographic Information

1. What is your age?
2. How would you define your sexual identity?
3. How would you define your ethnicity? What culture do you feel most connect with?
4. What is your education level?
5. What is your source of income?

First Rank Questions

6. Can you tell me a bit about what it has been like to live with HIV/AIDS?
7. What does living with HIV/AIDS mean for you?
8. Do you believe this diagnosis has changed/alterd how you see yourself (i.e. your identity)? Do you feel different? If so, in what ways?
9. Do you find that your feelings about yourself (i.e. your identity), particularly related to your HIV status, change with time? If so, in what ways?
10. Have you been able to talk about this diagnosis with loved ones (i.e. partners, family members, friends and so forth)? What has made doing so difficult or so comfortable?
11. Has being able or not being able to talk about your diagnosis changed your relationships with family members? Friends? Partners? If so, in what ways?
12. If changes have occurred in your relationships, have such changes impacted your perception of yourself or how you feel about yourself (i.e. your identity)?
13. In your own words, considering your own experience, what do you think are the primary reasons you have been able to tell or not tell everyone or some people in your support network, including partners, family members and friends, about your diagnosis?
14. Do you experience *stigma* (i.e. discrimination, the inability to talk about your diagnosis, fear of rejection and so forth) as a result of your HIV status?
 - *i.e. Some people define stigma as discrimination, the inability to talk about one's diagnosis, fear of rejection and so forth.*
15. What does stigma mean or look like to you? Can you give me examples?
16. Do you feel that stigma has influenced your ability to talk about your diagnosis?

17. How has being able or not being able to talk openly about your diagnosis made you feel about yourself (i.e. your identity)?
18. If you feeling comfortable talking about this, what were some of your feelings following your diagnosis?
19. Do you feel you experienced grief following your diagnosis? If so, how would you describe it?
20. *Considering these feelings*, do you feel that stigma influenced your experience of grief or your ability to come to terms with your diagnosis? If so, in what ways?
21. How has being able or not being able to talk openly about your diagnosis influenced your ability to grieve or come to terms with your diagnosis, if you have done so?
 - *i.e. Does it make you feel sad? Do you feel as if you have lost something?*

Second Rank Questions

- 1) If you feel comfortable discussing this, can you describe to me any moments or situations when you have felt socially stigmatized or discriminated against? How do you get through such moments? (i.e. How do you cope?)
- 2) *In the work that I have done, I have witnessed some persons living with HIV/AIDS experience stigma and discrimination in their sex lives, particularly in disclosing to partners.* Has your diagnosis influenced your sex life? If yes, in what ways?
- 3) Has your diagnosis influenced the ways that you see yourself as a sexual being? If yes, in what ways?
- 4) *You talked or did not talk about the uncertainty experienced when disclosing to loved ones*, what does that uncertainty of not knowing how loved ones will react if/when you tell them about your diagnosis look like? Can you describe that experience?
- 5) Have you experienced any uncertainty of how acquaintances and other community members (i.e. persons who are not your partners, family members or friends) will react if/when you tell them about your diagnosis? How would you describe that experience? Is it a different experience than when considering telling a loved one? If so, in what ways?
- 6) Did being able or not being able to talk *then* (i.e. the past) about your diagnosis openly with others, such as partners, family members and friends, influence feelings you have about yourself?
- 7) Has being able or not being able to talk *now* (i.e. at the present time) about your diagnosis openly with others continued to influence feelings you have about yourself?

APPENDIX D: LETTER OF INFORMATION

The Lived Experience of HIV/AIDS: The Impact of Stigmatization on the Grief and the Self-Identity of Persons Living with HIV/AIDS¹⁰

Greetings!

My name is Marie Baffoe and I am a second-year graduate student at the Carleton University School of Social Work. I am currently conducting a research project that will look at the impact of stigma on the grief and self-perception of persons living with HIV/AIDS. In other words, I am interested in talking with persons living with HIV/AIDS, like yourself, in order to discuss your thoughts and feelings about the ways that you believe stigma and discrimination has impacted the ways you have addressed your feelings about your diagnoses and the ways that you see or feel about yourself.

What does being a research participant for this study mean?

If you are interested in taking part in this research project, you are asked to withhold any identifiable information (i.e. your last name, mailing address and so forth) from the research. For instance, when contacting the researcher, you are asked to provide only your *first* name. Such a request is made to help to ensure your identity remains confidential. Unfortunately, if identifiable information (for instance, your last name) is provided, your experiences and personal knowledge will not be used in this research project.

Participation in this study includes taking part in a 60-90 minute interview to discuss your experiences of living with HIV/AIDS. The interview will consist of open-ended questions. These questions can be found on the interview guide provided. Although this guide will offer some themes that we would touch upon, our interview would also be influenced and directed by your personal experience and the issues you consider important. At any time in the interview, you can decide not to respond to any questions that you do not feel comfortable with answering.

Interviews will be recorded and later transcribed by a privately hired transcriber. Although the transcriber will be listening to our recorded session in order to transcribe it, he or she, similar to myself, will not have access to any information that would identify you. In addition, the transcriber will be required to sign a confidentiality agreement. I will also use a numbering system to label the cassette tape in order to ensure your identity remains confidential. A copy of this transcribed document will be available to you upon request and you will be able to ask to have information added or deleted. All research materials, such as the interview cassette tape and transcribed notes, will be placed in a locked filing cabinet in my home and only I will have access to that cabinet. Once this study has been completed, which will be in approximately October 2006, all such information will be destroyed.

¹⁰ The title of this thesis was later changed to "The Lived Experience: A Poststructural Analysis of the Impact of Stigmatization on the Identity Constructions and the Experiences of Grief for Persons Living with HIV" in order to better reflect the purpose of the thesis.

If you decide to participate, once you have contacted me, we would arrange a day, time and place to meet to hold our interview. The location where we would meet would be your choice. Meeting in a location other than the agency where you obtained information about this project would help to ensure that your identity is kept confidential; however, the choice is yours. Alternative locations we could meet at include a private room on the Carleton University campus or any other neutral location within the community. I am willing to meet with you wherever you feel comfortable.

The findings from the interviews with participants will be used to support the written portion, or thesis, of this research project. As a result, direct quotes may be used. In addition, the findings of this study may also be included in future publications and conference presentations.

Benefits & Risks of being a research participant

It is hoped that the results of this study may benefit other persons living with HIV/AIDS who may be able to identify with the experiences and the feelings of the participants of this study. It is also hoped that you, as a participant, will directly benefit from this research project in that you will be able to share your stories and experiences, which will contribute to existing knowledge and literature on HIV/AIDS. Finally, it is hoped that this project, through your testimonies, will contribute to the existing literature that addresses the influence social stigma may have on the experience of grief and the identity construction of persons living with HIV/AIDS.

Although the personal risks for all participants will be small due to the protection of your identities, when discussing your diagnosis of HIV/AIDS, there is the possibility that you will experience a variety of feelings, including discomfort and sadness. I will offer support to address these feelings and to minimize this risk during our interview. I will also offer you information about supportive and/or counselling services in the Ottawa area so that you can, if you want, access such services following our interview.

Ensuring your well-being

Due to the serious and sensitive nature of this research topic, sad and uncomfortable feelings may arise for you during or after our interview is complete. In order to ensure your well-being, we can discuss these feelings if you would like throughout the interview and/or at the end of it. You can also contact me at anytime to discuss these feelings if they persist. In addition, as noted above, a list of the contact information for various counselling services within the Ottawa area will be provided to you.

My Responsibilities

As a social work student, I am obligated to abide by the Canadian Association of Social Workers Code of Ethics. This Code of Ethics ensures that, as the researcher in this project, I keep your identity and any identifying personal information anonymous and confidential. In addition, due to the limits of confidentiality, it is also my responsibility to report any situation that I am made aware of or observe that places a participant at risk of harming him- or herself and/or other persons.

Your rights as a research participant

As a participant in this study, you have the right not to only chose to participate in this study, but to also withdraw from this study at any time, if you do not feel comfortable in being part of it, without receiving any type of penalty. If there is a time that you have questions and concerns, or that you do not feel comfortable with being part of this research project, you can contact me at (613) 520-2600, extension 0264, or my supervisor, Sarah Todd, an Assistant Professor at the Carleton University School of Social Work, at 520-2600, extension 4498. If you have any questions about being a research participant, in general, you can also contact the Carleton University Research Ethics Committee Chair, Professor Antonio Gualtieri, at (613) 520-2517 or at ethics@carleton.ca. You do not need to provide your name or any other personal information to the Ethics Committee Chair when asking questions about your rights.

Access to results

You, the other participants of this study and the general public will have access to final written research paper, or thesis, which will be located in the MacOdrum Library at Carleton University. In addition, I will ensure that both the AIDS Committee of Ottawa and Bruce House receive a copy of the thesis.

Ethics

This research project has been viewed and approved by both the Department of Social Work and the Research Ethics Committee at Carleton University. If you have any questions or concerns about the conduct of this research project, please contact, again, the Carleton University Research Ethics Committee Chair, Professor Antonio Gualtieri, at (613) 520-2517 or at ethics@carleton.ca.

Providing Consent

If you are interested in participating in this research project, please read and complete the attached Informed Consent Form. Thank you for your interest in this project. I look forward to working with you in the future.

Sincerely,

Marie Baffoe

APPENDIX E: INFORMED CONSENT FORM

Researcher:

Marie Baffoe
Carleton University Masters of Social Work Student
Ottawa, Ontario
(613) 520-2600 (ext. 0264)

Invitation to Participate:

You are invited to participate in the research project The Lived Experience of HIV/AIDS: The Impact of Stigmatization on the Grief and the Self-Identity of Persons Living with HIV/AIDS¹¹ conducted by Marie Baffoe, Carleton University Masters of Social Work student, under the supervision of Sarah Todd, Carleton University Assistant Professor (School of Social Work).

Intention of Study:

I am currently conducting a research project that will look at the impact of stigmatization on the grief and self-perception of persons living with HIV/AIDS. In other words, I am interested in talking with persons living with HIV/AIDS, like yourself, in order to learn more about your thoughts and feelings about how you believe stigma (i.e. discrimination, the inability to talk about one's diagnosis, fear of rejection and so forth) and discrimination has affected the ways you have addressed your feelings about your diagnoses and the ways that you see or feel about yourself.

Confidentiality: Explanation of Procedures and Data Management

Within this research project, you are asked to withhold any identifiable information (i.e. your last name, mailing address and so forth) from the research. For instance, when contacting the researcher, you are asked to provide only your *first* name. Such a request is made to help to ensure your identity remains confidential. Unfortunately, if identifiable information (for instance, your last name) is provided, your experience and personal knowledge will not be used in this research project.

Your personal identity will remain confidential. In other words, no personal and identifiable information will be attached to your interview responses, but instead in the written portion of this project, a pseudonym, or made-up name, will be used and assigned to your information. Interviews will be recorded and later transcribed. A numbering system will be used to label the interview cassette tape. All research materials, including cassette tapes and transcribed information, will be kept in a locked filing cabinet to which only I will have access. Any information collected in this research project that is published or presented [at conferences] at the present time or in the future will not identify you by name. All necessary precautions will be taken to protect your identity.

¹¹ Again, the title of this thesis was later changed to "The Lived Experience: A Poststructural Analysis of the Impact of Stigmatization on the Identity Constructions and the Experiences of Grief for Persons Living with HIV" in order to better reflect the purpose of the thesis.

Due to the limits of confidentiality, I am responsible for reporting any situations that I am made aware of or observe that involves a participant being at risk of harming him- or herself and/or other persons.

Potential Benefits:

The results of this study may benefit other persons living with HIV/AIDS who may be able to identify with the experiences and the feelings of the participants in this study. It is also hoped that you, as a participant, will directly benefit from this research project in that you will be able to share your stories and experiences, which will contribute to existing knowledge and literature on HIV/AIDS. Finally, it is hoped that this project, through your testimonies, will contribute to the existing literature that addresses the influence social stigma and discrimination may have on the experiences of grief and the identity construction of persons living with HIV/AIDS.

Potential Risks:

Although the personal risks for participants will be minimal due to the protection of your identities, when discussing your diagnosis of HIV/AIDS, there is the possibility that you will experience a variety of feelings, including discomfort and sadness. I will offer support to address these feelings and to minimize this risk during our interview. In addition, I will provide you with information about supportive and/or counselling resources in the Ottawa area so that you can, if you want, access such services following our interview.

Contact People:

If you have any questions about this research study and your participation in it, please contact Marie Baffoe at the number provided above. If you have any questions about your rights as a research participant, please contact the Carleton University Research Ethics Committee Chair, Professor Antonio Gualtieri, at (613) 520-2517 or at ethics@carleton.ca. You do not need to provide your name or any other personal information to the Ethics Committee Chair when asking questions about your rights.

Voluntary Participation and Withdrawal:

Your participation in this study is voluntary. You may end the interview at anytime or completely withdraw from the study. If you do chose to withdraw, please notify me by June 1, 2006, so that your information can be removed from the data analysis. Also, if you do decide to participate, but do not feel comfortable in answering certain questions, you can decline from answering such questions. Finally, once the interview has been transcribed, a copy of this transcribed document will be available to you upon request (please see below) and you will be able to ask to have information added or removed.

Signature:

I, _____, have read the above Informed Consent Form and agree to taking part in the research project The Lived Experience of HIV/AIDS: The Impact of Stigmatization on the Grief and the Self-Identity of Persons Living with HIV/AIDS conducted Marie Baffoe, Carleton University Master of Social

Work student, under the supervision of Sarah Todd, Carleton University Assistant Professor (School of Social Work). I agree to the use of the information obtained from this research project in future publications and conference presentations on the condition that my identity remains confidential.

Signature of Participant:

Date:

Researcher:

Date:

Please provide me with a copy of the transcribed notes from our interview.

* A copy of this Consent Form will be provided for you to keep.

APPENDIX F: SUPPORT SERVICES OF OTTAWA HAND-OUT

Support Services in Ottawa

Crisis Intervention / Telephone Support

Ottawa Distress Centre – (613) 238-3311 [English]

Tel-Aide Outaouais – (613) 741-6433 [French]

Counselling Services for Individuals, Couples and Families

AIDS Committee of Ottawa – (613) 238-5014

AIDS Committee of Ottawa, The Living Room – (613) 238-3425

Centre for Counselling and Pastoral Services – (613) 782-3022

Centre for Psychological Services – (613) 562-5289

CentrepoinTE House – (613) 224-8688

Family Service Centre of Ottawa-Carleton – (613) 725-3601

House of Hope and Healing – (613) 722-4847

Jewish Family Services of Ottawa-Carleton – (613) 722-2225

Ottawa Pastoral Counselling Centre – (613) 235-2516

Pink Triangle Services – (613) 563-4818

Source – (613) 789-1552

Ottawa Community Health Centres

Carlington Community Health Centre – (613) 722-4000

Centretown Community Health Centre – (613) 233-4443

Orleans-Cumberland Resource Centre – (613) 830-4357

Eastern Ottawa Resource Centre – (613) 741-7029

Hunt Club-Riverside Community Health Centre – (613) 247-1600

Lowertown Community Health Centre – (613) 789-3930

Nepean Community Resource Centre – (613) 596-5626

Overbrook-Forbes Community Resource Centre – (613) 745-0073

Pinecrest-Queensway Health & Community – (613) 820-4922

Sandy Hill Community Health Centre – (613) 789-1500

Somerset West Community Health Centre – (613) 238-8210

South East Ottawa Centre for a Healthy Community – (613) 737-5115

Vanier Community Services Centre – (613) 744-2892

Western Ottawa Community Resource Centre – (613) 591-3686