# “Victim and Vector”:

# The Affective Life of People with HIV Through the Epidemic Eras

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## Abstract

This dissertation explores the criminalization of HIV nondisclosure through the lens of the sociology of health and illness, critical victimology, affect theory, and narrative theory. It situates participants' stories within different historical periods—ranging from the HIV/AIDS crisis era (1981–1995), through the era of treatment and HIV normalization (1996–present)—to demonstrate how these epochs shape the affective life of people living with HIV (PLWH) as they make sense of their diagnosis, disclosure and nondisclosure, and their sense of self in the present. Drawing on the works of Margaret Wetherell, Sara Ahmed, Ann Cvetkovich, Arthur Frank, and Paul Ricoeur it develops the concept of the affective narrative self to understand how individuals construct and make sense of their identities through the interplay of emotions and storytelling. The dissertation explores how the affective narratives of HIV are historically contingent, such that how people feel and narrate their experiences of living with HIV and their sense of self is shaped by the dominant cultural and medical logics of their time. Methodologically, it employs a feminist affective epistemology (Hemmings, 2012) and a theoretical narrative analysis (Riessman, 2008) to analyze semi-structured interviews with 44 participants—43 PLWH and one HIV-negative person whose partner did not disclose their serostatus prior to sex—as well as lifeline drawings that visually depict their experiences.

There are three substantive analysis chapters which discuss the findings of this study. The analysis reveals that HIV nondisclosure is experienced through competing affective narratives of victimhood. While some participants described nondisclosure as a betrayal that elicited anger and sometimes a desire for legal recognition, others resisted the victim label, citing personal responsibility for sexual health. PLWH articulated their experiences of diagnosis through different registers of grief and as a form of biographical disruption, marked by narratives of the loss of one's sense of self, the loss of one's healthy body, the death of friends and family, and social death. The study further identifies the undetectable self as an affective narrative self, wherein undetectability functions as both an empowering and disciplining force. Ultimately, this research challenges punitive approaches to HIV nondisclosure and advocates for transformative justice frameworks that move beyond legal retribution to address the structural inequalities shaping PLWH's lives.



**Keywords**: HIV Nondisclosure; Criminalization; Victimology; Affect Theory; Narrative Identity; Health and Illness; Lifelines

*I dedicate this dissertation to the people living with HIV who so graciously offered their time to speak with me, to all people living with HIV, and to all people who struggle with their own victim-survivor identities*

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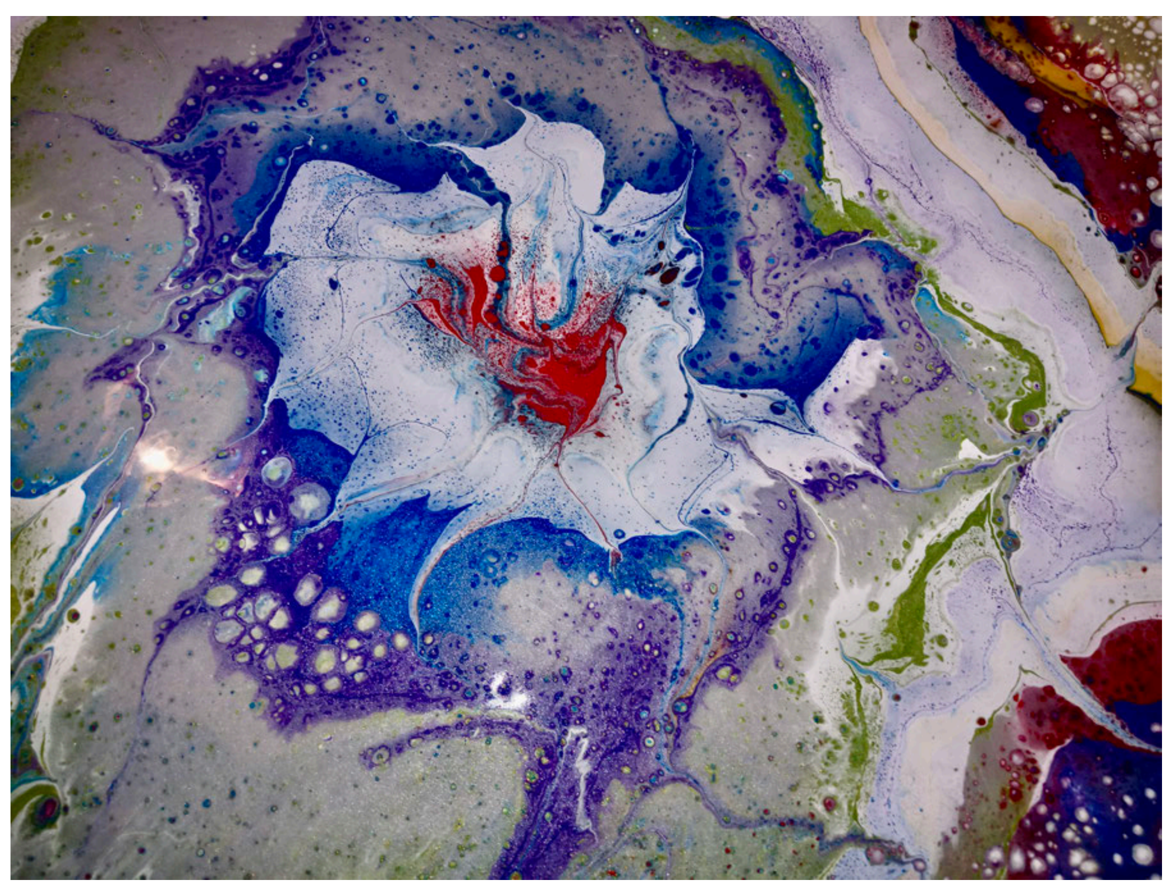
## List of Acronyms

| | |
|---|---|
| ART | Antiretroviral Therapy |
| ARV | Antiretroviral |
| ASO | AIDS Service Organization |
| BCCFE | British Columbia Centre for Excellence in HIV/AIDS |
| CCRHC | Canadian Coalition to Reform HIV Criminalization |
| HAART | Highly Active Antiretroviral Therapy |
| HALCO | HIV/AIDS Legal Clinic Ontario |
| HJN | HIV Justice Network |
| HPPA | Health Promotion and Protection Act |
| PASAN | Prisoners HIV/AIDS Support Action Network |
| PEP | Post-Exposure Prophylaxis |
| PHAC | Public Health Agency of Canada |
| PLWH | People Living with HIV/AIDS |
| PrEP | Pre-Exposure Prophylaxis |
| STOP HIV/AIDS | Seek and Treat for Optimal Prevention of HIV/AIDS |
| TasP | Treatment as Prevention |
| U=U | Undetectable equals Untransmittable |



**Victoria's Artist Statement**

My journey began [just after the advent of HAART]. "You are HIV Positive." I couldn't find the words to speak. First, I was shocked, then scared and felt very alone. It`s been 24yrs now. It feels so long ago. And surprised and thankful that I'm still here. When I was told I had four years to live. Boy did I prove him wrong. My painting represents so many emotions that came along like waves. It's a picture of me. My canvas is always changing every day. Everything paints a pretty picture on the outside. However, on the inside there was and is sadness, loneliness, rejection, depression and not being accepted. Because of a little word HIV, that I disclosed to someone I felt close too. I wasn't going to let this identify who I am. I became a strong woman, who got involved within 6 months of my diagnosis. I wanted to make a difference and have women's voices heard. I'm now an advocate, mentor and leader in my community. With much passion and compassion for others who also live with this virus. I believe in maintaining a positive attitude. It's all in the mind, not my body. My faith and hope has taught me to stay positive. I remain to be strong and thrive to survive!!

# Chapter 1.

# Introduction

Emotions permeate our everyday interactions, senses of self, friendships, and relationships. The painting above and Victoria's artist statement exemplify how people come to understand their sense of self through their emotions and by telling personal stories. Victoria discusses how "her canvas," what I take to understand as her sense of self, is always evolving, suggesting that even the story she told to me in the interview and via this painting could be different, had we spoken today. As we move about our lives, new insights are gleaned and diverse narratives are taken up that help us to understand and give meaning to our experiences in different ways (Frank, 2010; Ricoeur, 1983/1990). Victoria writes about "painting a pretty picture on the outside." This expression evokes Goffman's (1963) discussion of the presentation of self in everyday life: the picture on the outside is contrasted by Victoria with her feelings of sadness, loneliness, rejection, and depression "on the inside." She ends her artist statement by converting 'bad feelings' into 'good feelings', giving herself a sense of purpose. She speaks about being hopeful and positive to help keep her healthy and "thriving to survive." Victoria's story of living with HIV is narrated through tales of grief at the loss of her sense of self and the person she once knew, as well as the feelings of hope and optimism she has about the future.

Victoria was diagnosed early in the epidemic in North America, a period of time that I am identifying as the era of the HIV/AIDS crisis, or what historians of AIDS cultural productions have dubbed "the first silence" from 1981 to 1987 and "HIV/AIDS Crisis Culture"

from 1987 to 1996 (Juhasz & Kerr, 2022).[1,2] The first silence is characterized by political inaction to deal with HIV and the isolated work of medical staff and impacted people who began to take action against a mysterious illness (Juhasz & Kerr, 2022). The HIV/AIDS Crisis Culture era is a time marked by "mass cultural production and discourse about HIV/AIDS leading to social, political, and medical breakthroughs" (p. xiii).

Victoria's diagnosis overlaps with the beginning of the era Juhasz and Kerr (2022) call the "second silence." The period from 1996-2008 was characterized by the advent of highly active antiretroviral therapy (HAART) which led to better health outcomes for People Living with HIV (PLWH), even though many, including Victoria, suffered debilitating side effects from these early medications (discussed in more detail in chapter 5) (Ariss, 1997; Juhasz & Kerr, 2022). These drugs contributed to transforming HIV into a chronic but manageable illness, which resulted in HIV taking up less space in public discourse (Juhasz & Kerr, 2022) and gave PLWH a sense of hope that the epidemic was nearing its end. The second silence therefore reflects an era of HIV/AIDS normalization (2008 to the present) in which, as Squire (2010) argues, the "particularities" of living with HIV (i.e. the challenges and differences in how HIV is experienced based on race, gender, sexual orientation, age, and class) have become hidden as PLWH are expected to act as self-regulating citizens responsible for managing their own health,

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[1] While I map out these eras in a linear fashion, I follow Juhasz and Kerr's (2022) assertion that "time is not a line. We offer this timeline to be helpful, not prescriptive. AIDS is not over" (p. xiii). As such, the eras I outline here may not be how someone else might portray the history of HIV/AIDS and certainly, there are no clear boundaries when one era starts and another ends. I make these borders to delineate, methodologically, when participants were diagnosed with HIV to frame the analysis and to showcase how historical HIV narratives operate in the present.

[2] The timeline I identify here and throughout the dissertation is centered around the events that transpired in North America. Certainly, the epidemic was and is experienced differently across the world and the timeline of HIV across the globe could be very different than the one I present in this dissertation. For the purposes of this analysis, because all participants were, at the time, living in Canada and obtaining treatment in their respective provinces, I did not dive into an analysis of regional differences. In addition, most participants were at least diagnosed in Canada (N=31) or the US (N=5) while 6 were diagnosed in Africa and one person I am unsure of where they were diagnosed since I did not explicitly ask where they were diagnosed.

pursuing wellbeing, and taking their medications regularly. These later eras in the history of HIV are characterized by hopeful biomedical narratives of scientific innovation and intervention that create new HIV subjectivities along virological lines (Lloyd, 2018; Race, 2001).

Several narratives, saturated with emotions of all kinds, emerged during this era to tell the tale of HIV/AIDS. There are stories that tell the tale of the origins of HIV,[3] scientific innovation,[4] community stories of political organizing, resistance, and resilience,[5] personal narratives of death and surviving,[6] and other stories about the racist and homophobic

[3] The most well-known story of the origins of HIV in the United States (U.S.) is that of Gaëtan Dugas, who was a gay Canadian flight attendant thought to have brought the virus to the US. Dugas was incorrectly identified as patient zero by Randy Shilts in his book *And the Band Played On*, about the AIDS crisis in the early 1980s. A subsequent movie of the same title was filmed in 1993. Dugas became the symbol of the AIDS monster (magazines and newspapers printed horrifying stories about Dugas with titles such as "The Appalling Saga of Patient Zero" in Time magazine; "Patient Zero: The Man Who Brought AIDS to California" in California Magazine; "The Man Who Gave Us AIDS" in the New York Post; "The Monster who Gave Us AIDS" in the Star tabloid; and "The Columbus of AIDS" in the National Review). He was vindicated much later after his death when it was discovered that Shilts distorted the story of Dugas in his book and that HIV was introduced to the US in about 1969 via Haiti, where it was thought people slaughtered chimpanzees for meat at which point the virus was transmitted to humans (Babineau, 2007). Patient zero never actually referred to the first person to acquire HIV and thus spread the virus to everyone else, but a cluster of gay men with AIDS who had sex with each other, in an epidemiological study conducted early in the epidemic by the Centers for Disease Control (CDC) in the US to trace the sexual contacts of this group. This was before anyone knew that AIDS was caused by a virus or realized that it had already been spreading for the last decade, if not decades before that (Babineau, 2007). A recent documentary titled *Killing Patient Zero* tells this tale of vindication.
[4] See for example: Lieberson, J. (1983). Anatomy of an Epidemic. *New York Review of Books*. Available from: https://www.nybooks.com/articles/1983/08/18/anatomy-of-an-epidemic/.
[5] Movies such as *The Normal Heart* and books like *Moving Politics: Emotion and ACT UP's Fight Against AIDS* by Deborah Gould (2009) document the activism of gay men and organizations during the emergence of HIV in the 1980s.
[6] Death is present in any story about HIV, particularly those that were told in the early days of the epidemic. See for example the recent edited collection by Matilda Bernstein Sycamore (2021) *Between Certain Death and a Possible Future: Queer Writing on Growing Up with the AIDS Crisis*.

underpinnings of the response to the HIV/AIDS crisis, including criminalization, stigma, and political inaction[7], to name but a few. [8]

Each of these narratives are imbued with meaning(s) that permeate both HIV positive and HIV negative[9] people's understandings of the virus and our relations to it and those who carry it (Treichler, 1999; Watney, 1987). In other words, these narratives (among others) constitute the stock of knowledge from which PLWH construct what it means to live with HIV, who they are, and how others make sense of HIV and those who live with the virus. Such configurations include who is seen as 'risky' or 'at risk', 'good' or 'bad', responsible or irresponsible, and worthy of compassion and sympathy. Narratives are powerful tools that help to disseminate what I describe in chapter 2 as the diffuse medical, legal, and moral modes of regulation. In so doing, narratives signal who and what behaviours are considered respectable and moral, and thus which

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[7] Most notably, Alexander McClelland's (2024) recent book *Criminalized Lives: HIV and Legal Violence* in which he tells us about the stories of 16 people who were criminalized for allegedly not disclosing their HIV status to their sexual partners before engaging in sex in Canada. For discussions about the ways in which PLWH were constructed during the height of the epidemic and the discourses that pervade our understandings of HIV and PLWH see: Paula A. Treichler. (1987/1991). AIDS, Homophobia, and Biomedical Discourse: An Epidemic of Signification. In Douglas Crimp. (ed.) *AIDS: Cultural Analysis, Cultural Activism*. (pp. 31-70) Cambridge, MA: MIT Press; Cindy Patton (1990). *Inventing AIDS*. New York: Routledge; Simon Watney. (1987). The Spectacle of AIDS. In Douglas Crimp. (ed.) *AIDS: Cultural Analysis, Cultural Activism*. (pp. 70-86) Cambridge, MA: MIT Press; Douglas Crimp. (1991). *AIDS: Cultural Analysis, Cultural Activism*. Cambridge, MA: MIT Press.

[8] Indeed, there are too many stories of HIV to document here because they encompass not only academic stories from the "hard" sciences to the social sciences but movies, plays, fiction and non-fiction novels, artistic works such as paintings and public art, and personal narratives of surviving. See for example, Alexandra Juhasz and Theodore Kerr (2022) who, in their recent book *We Are Having this Conversation Now: The Times of AIDS Cultural Production,* trace the multiple timelines and stories of the epidemic through the artistic products generated from the epidemic. For a detailed personal narrative of living with HIV since the onset of the epidemic, see David Caron (2014). *The Nearness of Others: Searching for Tact and Contact in the Age of HIV*. Minneapolis: University of Minnesota Press.

[9] Throughout the dissertation I use the terms "person living with HIV" to refer to people who have been diagnosed with HIV. I do this as it places the person ahead of the illness to recognize that PLWH are people first and foremost with complex selves and lives that go beyond HIV. However, in the methodology and at certain points in the dissertation I use the terms "HIV-positive" and "HIV-negative" in a general sense to differentiate those who have been diagnosed with HIV and those who have not, as many studies in the field of HIV research similarly do. I recognize that these terms are socio-technical in nature and do not use them to describe specific participants unless they refer to themselves in this way. Nonetheless, as the methodology mobilizes these binary distinctions, I acknowledge that they prefigure the dissertation, serving as a kind of metanarrative in the way that I take these to be a neutral or natural fact in the set-up of my methods. Yet, despite my methodological decision to use these binary categories, my theorization of the affective narrative self and my participant's words complicate the idea that these categories are neutral or natural. For example, in chapter 7 I discuss how participants are crafting a different identity, which I have termed the undetectable self, to fight the stigma associated with "HIV positive."

segments of the 'public' should be subject to increased forms of punishment, surveillance, and exclusion – namely those condemned as 'unruly' (e.g. sex workers, gay men, people who use drugs, Haitians, Africans, and other people of colour) people who threaten the health and safety of others (Kinsman, 2024).[10]

The criminalization of HIV nondisclosure with other punitive public health practices,[11] operated throughout the HIV/AIDS crisis and continues today in the era of HIV/AIDS normalization. The criminalization of HIV nondisclosure, is, I contend, an effect of and shaped by the affective narrative (a concept I develop in chapter 3) configurations that emerge(d) from these epochs. These configurations frame conceptions of what it means to not disclose one's HIV status and inscribe victim/perpetrator and undetectable/detectable subjectivities through the interlocking systems of law, public health, and medicine. Together, these affective narratives shape how one *should* live their life with HIV and who should be punished for transgressing the moral bounds of good HIV citizenship, today marked by the practices of taking one's medications diligently, keeping a low viral load, disclosing, and keeping up with medical appointments (Bryant et al., 2023; Lloyd, 2018; Mykhalovskiy, McCoy, Bresalier, 2004; Race, 2001).

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[10] I am invoking Kinsman's (2024) critique of public health as being implicated within broader mechanisms of regulation and social surveillance that strive to impose white-middle class ways of life onto racialized, poor, working-class people. Kinsman (2024) urges us to consider "which public and which health is being defended" when we speak of public health (p. 265).

[11] I am referring here specifically to Hastings et al.'s (2021) use of "carceral public health" to capture how "coercive public health interventions … use tools, technologies, and forms of reasoning from the realm of criminal law to respond to public health issues" (p. 1253). For example, Medical Officers of Health regularly issued Section 22 orders under the Ontario Health Protection and Promotion Act (HPPA) to "instruct designated persons who have, or may have, communicable diseases to take, or refrain from taking, specific actions to diminish communicable disease transmission" such as proscribing unprotected sex (O'Byrne & Bryan, 2013, p. 43). If people fail to abide by the order, the Medical Officer of Health can apply to a judge of the Ontario Court of Justice and request that the court prohibit the contravention of the order. If the judge keeps the order, section 102 subsection 2.1 of the HPPA states that the order may be enforced in the same way that any other judgement or order made by the Superior Court of Justice is imposed.

To make these arguments, chapter 2 situates this project in the sociology of health and illness and critical victimology literatures. I examine the ways in which health is productive through the intersection of medical, moral, and legal forms of regulation. I review the literature on the public health and moral regulation of HIV and mobilize the notion of biographical disruption to describe how PLWH experience life with HIV in the era of 'Treatment as Prevention' (TasP). This body of work helps me show how medical, moral, and legal modes of regulation create narratives of what it means to be a 'good' HIV citizen, thereby simultaneously establishing the 'bad' HIV citizen. In section 2.3, I present the victimology literature, describing its history to show how victims are normalized within the law such that the law is productive of victimhood. I then review the literature on how people experience victimhood as it relates to gender-based violence and sexual assault, including how people might resist or take up this identity. This allows me to frame participant's stories as existing at the intersection of medical, moral and legal modes of regulation imposed upon PLWH in the name of public health and the politics of victimhood enacted in feminist organizing to recognize gender-based violence and the HIV community's rejection of this label.

To ground the analysis, in chapter 3 I review the theoretical literature that describes key differences and similarities between affect, feeling, and emotion. I bring into conversation Margaret Wetherell's (2012) concept of affective practices and Sara Ahmed's (2004) description of affects as sticky and her notion of 'impression' to conceptualize affect not just as something that flows in the atmosphere or that is pre-conscious, but also as something that is actively practiced and produced within the psychosocial field as we make judgements, make sense of, negotiate, and act in the world. I then consider Paul Ricoeur's and Arthur Frank's articulations of narrative as that which allows us to understand and give meaning to our experiences. I

specifically use Ricoeur's (1985/1990) conception of narrative identity to articulate how we construct our sense of self through the stories we tell about our lives. This construction is made through, what Ricoeur (1983/1990) describes as the hermeneutic spiral of mimesis comprising the prefigured (pre-narrative) field of action and experience, the act of configuring these experiences into a narrative that connects individual events or incidents, and the refiguration or interpretation of that narrative by the listener/reader such that the practice of "emplotting" (Ricoeur, 1983/1990, pp. 31-51) events into a narrative, transforms them "into experience that has meaning" (Frank, 2010, p. 136). The narratives that develop from this hermeneutic spiral are shaped by social, cultural and historical contexts and thus serve as the stock of knowledge from which individuals make sense of their daily lives and how they define their senses of self. With this conception of affect, narrative, and identity in mind, I develop the notion of the affective narrative self in section 3.2.2. I use this concept to describe how people define themselves and others through narratives (historical, mythological, fictional, biographical, cultural, familial, traditional, modern, political, medical, legal, etc.) that become affectively charged, what I call affective narratives. I contend that narratives are saturated with affect as they circulate through and within time, as they are mobilized to tell one's story, and as they are interpreted through the reception of that telling.

To understand which affective narratives structure people's HIV stories, how PLWH make sense of their diagnosis, treatment, and nondisclosure, and whether they think of themselves as victims, I conducted semi-structured interviews with a total of 44 people, 43 of whom are living with HIV and one person who was HIV negative but who was not disclosed to by their partner prior to sex. I interviewed both people who are living with HIV and people who are HIV negative because I wanted to understand how people make sense of not being disclosed

to in the context of the law on HIV nondisclosure in which over 60% (Hastings et al., 2022) of cases result in no transmission of HIV. I also asked participants to draw lifelines (N=25) which depict the important moments of their HIV story to complement the interviews and provide deeper insight into their emotions and feelings about living with HIV, disclosure and nondisclosure, and treatment (see section 4.2.3). To analyze the interviews and lifelines, I engaged in a thematic narrative analysis looking at the content of people's stories (Riessman, 2008) rather than the structure of their narratives to glean insight into the "storied nature of the self" (Skjelsbaek, 2006, pp. 376-377). I detail my positionality and specific methodological process in more detail in chapter 4. This methodological process and theoretical framework allowed me to analyze participant's stories by situating them within the eras of HIV and the prefigured affective narratives that tell the tale(s) of HIV and PLWH. I contend, that these affective narratives form the structures of meaning-making by which PLWH come to understand their sense of self, in relation to (non)disclosure, victimhood, their diagnosis, living with HIV, and treatment.

In Chapter 5, I specifically explore how participants felt about their partner's nondisclosure, including how they make sense of victimhood and their responsibilities around sexual health. I propose a framing of nondisclosure as an affective practice configured through the prefigured narratives of legal and victim-feminist constructions of victims as always-already innocent and the affective narratives of the HIV/AIDS crisis that emphasized an empowered sense of shared responsibility for sexual health and the rejection of victimhood. These affective narratives give way to interpretations of HIV nondisclosure by some participants as a victimizing event through their anger while others read nondisclosure as a moment of shame for their failure to engage in safe sex. Anger and shame are thus some of the emotions that work to configure

participant’s affective narrative selves and that factor into whether participants understood themselves as victims of nondisclosure.

In Chapter 6, I argue that participant’s stories of their diagnosis form a melancholic narrative, such that “the past is brought to bear witness to the present” (Eng & Kazanjian, 2003, p. 5), thus complicating the hopeful biomedical narratives that define the era of HIV/AIDS normalization. Such narratives work in the present to disappear the “particularities” of living with a socially stigmatizing illness (Squire, 2010) and the modes of regulation that continue to be enacted, drawing strict boundaries between the ‘good’ and the ‘bad’ HIV citizen. The melancholic narratives addressed in this chapter thus represent a kind of complaint that life with HIV is anything but normal as people live with the traumatic legacies of the past and as they come up against HIV stigma. In this chapter, I engage with the queer and HIV activist and scholarly writings that remember the traumatic losses (i.e., the death of friends and lovers, the loss of sexual freedom experienced after the emergence of HIV, loss of employment and housing, the loss of relationships with family and friends, and the loss of self) sustained during the age of HIV/AIDS crisis and work to demonstrate how these losses continue to be felt in the present amidst the silencing effects of the advent of treatment (Juhasz & Kerr, 2022; Sycamore, 2021; Westengard, 2019). This is the “second silence” (Juhasz & Kerr, 2022) that internalizes people’s grief and makes absent the ways in which living with HIV means living alongside grief; a melancholic life that makes one’s Otherness stand out. I show this through a discussion of the stories of death and loss that PLWH told me, including the loss of one’s sense of self and social identity, and the loss of one’s healthy body.

In Chapter 7, I juxtapose these melancholic narratives with the hopeful narratives brought on by biomedical advances that have normalized HIV and that participants mobilize to configure

their stories into a new technoscientific identity (Gagliolo, 2021; Lloyd, 2018; Persson, 2013; Race, 2001; Squire, 2010). As such, I end the dissertation with a discussion of hope, albeit one that is critical of the hopeful narratives that have emerged in the normalization era. I argue that participants configure the undetectable self (an affective narrative) through the affective practices of maintaining a suppressed viral load. The undetectable self is configured as someone one who is healthy, responsible, and safe and stands in opposition to the detectable Other – a 'hope alien' who refuses to buy into the optimistic narratives offered by science.

In the concluding chapter, I suggest the importance of developing an affective victimology which takes seriously the emotions felt by people who have experienced harm and what these can tell us about people's motivations, desires, actions, and subjectivities. An affective victimology would also consider the ways in which emotions operate in the politics of victimhood to justify punitive laws and policies by examining how sympathy binds to notions of 'innocence' to demarcate ideal from non-ideal victims. The conclusion also offers a discussion of the limitations and contributions of this research, including suggestions for how to move forward in our efforts to reform HIV criminalization in Canada. Specifically, I urge readers to create spaces in which PLWH might feel safer to disclose and I advocate for approaches to HIV nondisclosure rooted in transformative and restorative justice rather than the criminal legal system.

Before diving into the literature review in the next chapter, I first discuss the legal framework that makes HIV nondisclosure a criminal matter in Canada and the consequences of using criminal law as a public health technology. I do this to show how the institutions of criminal law and medicine intersect to regulate the lives of PLWH; to make clear the legal intricacies of how the law evolved and how it shapes who we deem victims and perpetrators; and

to document the harmful effects of the law on the lives of PLWH, including living in constant fear of prosecution, reduced willingness to get tested, and a mistrust of one's medical team.

## 1.1. HIV Nondisclosure in Context

Broadly, the existing literature on HIV nondisclosure centres around critiquing the legal framing of consent, sexual autonomy, and risk in HIV nondisclosure cases in Canada (Buchanon, 2015; Grant, 2013; Klein, 2016; Mackinnon & Crompton, 2012; Mathen & Plaxton, 2011); documenting the impact of criminalization on public health policy (Elliott, 2002; Hindmarch, Orsini, & Gagnon, 2018; Mykhalovskiy, 2011; Weait, 2007) and on services offered by AIDS service organizations (Kilty & Orsini, 2017; Kilty & Orsini, 2019a, b); and conducting media analyses that reveal how sensational media coverage frames Black men as hypersexualized predators, racialized 'Others' and AIDS monsters (Kilty & Bogosavljevic, 2019; Kilty, 2014; McKay et al., 2011; Miller, 2005; Mykhalovskiy et al., 2016; Persson & Newman, 2008; Shevory, 2004; Worth et al., 2005, Worth, 2002). To date, just one study has explored the ways in which people living with HIV/AIDS (PLWH) experience criminalization in Canada (McClelland, 2019a, 2019b, 2024), one has explored the construction of victimhood in law and advocacy around HIV nondisclosure (Speakman, 2019), and one that has examined the construction of complainants in HIV nondisclosure cases in the media (Aguinaldo & Greenspan, 2024).

We know that at least 206 people have faced criminal charges relating to HIV nondisclosure in 224 cases in Canada from 1989-2020 (Hastings et al., 2022). The majority of these cases occurred between 2004 and 2014 with a decrease in cases in 2018, 2019, and 2020 likely because of ongoing advocacy efforts across Canada that are critical of how the law is applied (Hastings et al., 2022). Between 1989 and 2020, 113 of the 224 cases occurred in Ontario

and 33% involve white defendants, 22% Black defendants, 7% Indigenous, 1% East Asian, 2% South Asian, and 2% Latin American (Hastings et al., 2022). Men account for 89% of all defendants and women 9% (Hastings et al., 2022). Most cases occur in the context of heterosexual sex with all female defendants and 63% of male defendants having faced charges related to HIV nondisclosure after engaging in heterosexual sex, while 25% of cases in which the gender of the defendant is known, involve male defendants and male complainants (Hastings et al., 2022). In the next sections, I offer an overview of the criminalization of HIV nondisclosure in Canada, detailing the evolution of law and the consequences of criminalizing HIV nondisclosure.

### 1.1.1. The legal landscape in Canada

According to the HIV Justice Network (HJN) (2022), 81 countries have taken various approaches to criminalizing HIV, typically using either HIV or disease-specific laws or general criminal offences against the person to prosecute (Elliott, 2002, HJN, 2022; Weait, 2016). Some countries require proof of intent and transmission of HIV in order to prosecute (e.g., the United Kingdom), while others, like Canada, hold PLWH criminally liable for exposing someone to the risk of infection even where there was no transmission or intent to transmit (Grant, 2011; Grant, Shaffer, & Symington, 2013; Klein, 2016; Weait, 2016; Wolf & Vezina, 2004). In instances where there is transmission, courts need to prove fault, which may come in the form of intent, recklessness, or negligence – each of these terms have different legal definitions depending on

the jurisdiction (Weait, 2016).[12] Not requiring intent or transmission widens the net in terms of who may be criminalized (Grant, 2011). For example, of the cases that resulted in conviction of at least one charge related to HIV nondisclosure in Canada from 1989-2020, 64% did not result in the transmission of HIV; of the 187/224 cases in which the outcome is known, 70% (130/187) ended in conviction on at least one of the charges and of those convictions, 64% (83/130) were the result of a guilty plea (Hastings et al., 2022). Internationally, Canada is known to be overzealous in prosecuting HIV nondisclosure (HJN, 2022).

Canada does not have a specific HIV law; instead, the obligation to disclose in some circumstances was established by the courts who use existing criminal code legislation to hold criminally liable PLWH who have failed to disclose their HIV-positive status to their sexual partners (HIV/AIDS Legal Network, 2019; Dej & Kilty, 2012). The most common charges are aggravated sexual assault, assault, or aggravated assault (Dej & Kilty, 2012; Grant, 2008). Notably, 70% of cases result in a conviction of at least one charge (HIV/AIDS Legal Network, 2019; Hastings et al., 2022; Mykhalovskiy et al, 2016; Mykhalovskiy, Betteridge, & McKay, 2010) compared to a 42% conviction rate for non-HIV related sexual assault cases in Canada

[12] In Canada, fault or *mens rea* is particularly confusing given that "Parliament has not clearly and consistently defined fault elements such as "purposely," "knowingly," "recklessly," or "negligently" or specified what particular fault element applies for each offence" (Roach, 2022, p. 192). As such, the courts are left to infer the fault elements from the legislative definition of each individual offence (Roach, 2022). Canadian common law generally uses two types of *mens rea*; namely, subjective in which the crown must prove that the "accused subjectively had the required guilty knowledge" pertaining to the specific circumstances or consequences of the prohibited act and objective or that a "reasonable person in the accused's position would have had the required guilty knowledge or would have acted differently" (Roach, 2022, p. 195-196). Under subjective *mens rea* there are four elements: intent/purpose/willfulness, knowledge, willful blindness, and recklessness with intent representing the highest form of subjective *mens rea* and recklessness the lowest. For sexual assault, Roach (2022) argues that the fault element teeters between recklessness and negligence. In Canadian HIV nondisclosure cases, the courts have focused predominantly on the issue of consent and whether it was obtained fraudulently (Shaffer, 2013; Symington, 2012) and does not *require* intent to transmit the virus but rather knowledge that one is HIV positive and thus that the sex engaged in posed a "significant risk of serious bodily harm" (*R. v. C.,* 1998) where there was a "realistic possibility of transmission" (*R. v. M.*, 2012; CCRHC, 2017; Dej & Kilty, 2012; Grant, 2013). Clarifying what the SCC meant by this legal test in *R. v. M.*, the judges stated that a person is not required to disclose their HIV status if they engage in consensual sex with a condom *and* have a low viral load (200 copies of the virus per ml of blood).

(Department of Justice Canada, 2019). As such, Canadian law centres on whether consent to sexual activity was obtained fraudulently since the person consenting did not have all requisite information to make an informed decision (Grant, 2008). Specifically, the Supreme Court of Canada (SCC) ruling in R. v. C. (1998)[13] changed our understanding of consent for sexual assault charges by stating that failure to disclose one's HIV positive status constitutes fraud, which vitiates consent.

C was living with HIV and was advised by public health officials that there was a high risk of transmitting HIV to others if engaging in unprotected sex and that he was to inform all sexual partners of his status. C did not disclose his status to the two complainants and had unprotected sex with them. Both complainants consented to unprotected sex but testified at trial that if they knew he was living with HIV, they would not have done so. At the time of the trial, the complainants had not tested positive for HIV. As a result, in November 1994, C was charged with two counts of aggravated assault under s.265 and 268 of the *Canadian Criminal Code*. The B.C. trial court acquitted C, finding that the charge of aggravated assault could not be made because there was no evidence that the two women had not provided valid consent to sex with C (R. v. C., 1996).[14] The case was brought to the BC Court of Appeal in 1996, where the court upheld the acquittal and dismissed the appeal on the grounds that,

> There is no recognized duty, enforceable through the criminal law power of the state, which requires a person to provide full disclosure of all known risks associated with sexual intercourse to his or her sexual partner as a condition precedent to the partner giving an effective consent to sexual intercourse. The criminal law of assault is, indeed, an unusual instrument for attempting to ensure safe sex. I share the trial judge's reluctance to have recourse to concepts of

[13] Many of the complainants in these cases can retain their privacy through a publication ban. As such, I use abbreviations of the defendant's name when referring to different cases of HIV nondisclosure to refrain from outing the defendants further. I subscribe to the notion that everyone has the right to be forgotten and therefore do not want to reproduce their names in this dissertation and instead choose to protect their privacy.
[14] Information about the original case from the BC trial court is taken from the BCCA and SCC decision. The original trial in the BC Supreme Court is not digitized and accessible without going directly to the court to obtain a physical copy of the decision.

> informed consent developed in civil proceedings in circumstances such as those confronting us here. (*R. v. C.,* 1996, para. 60).

Nonetheless, the Supreme Court of Canada (SCC) ruling on this case overturned the appeal court's decision, stating that,

> …a complainant's consent to sexual intercourse can properly be found to be vitiated by fraud under s.265 if the accused's failure to disclose his HIV positive status is dishonest and results in deprivation by putting the complainant at a significant risk of suffering serious bodily harm (*R. v. C.,* 1998, p.373).

In their decision, the SCC's majority ruling outlined three tests that the prosecution must provide to establish that fraud occurred:

1. An act by the accused that a reasonable person would see as dishonest;
2. A harm, or a risk of harm, to the complainant as a result of that dishonesty; and
3. The complainant would not have consented but for the dishonesty by the accused (Elliott, 1999, p. 12; *R. v. C*, 1998, p. 372).

To detail what the court meant by harm, the justices determined that the "harm in question must constitute a *significant risk of serious bodily harm*" (Grant, 2008, p. 135, emphasis added). Therefore, when a PLWH fails to disclose their HIV positive status, their nondisclosure constitutes a significant risk of serious bodily harm and positions consent as fraudulently obtained (Grant, 2008).

The ambiguity of the legal test in *R. v. C.* (1998) is evidenced by the vast inconsistencies in how the lower courts have applied the precedent and the lack of clear parameters for determining what constitutes a significant risk (Grant, 2020). For example, lower courts have interpreted the significant risk of different sexual activities – including those considered to be low risk, such as oral sex and protected sex – in a variety of different ways (Symington, 2009). The use of condoms and the risk posed by unprotected versus protected sex has also been used as a determining factor in some cases. In *R. v. NG.* (2010) the courts decided that if condoms were used at all times there was no legal duty to disclose (Dej & Kilty, 2012; Mykhalovskiy et al.,

2010; Symington, 2009), while in the original trial court decision in *R. v. M.* (2009), the judge determined that vaginal sex with a condom and without disclosure still constituted a significant risk of harm and found the defendant guilty of aggravated sexual assault (Grant, 2011; Mykhalovskiy et al., 2010).

In 2012, the SCC heard a second case of HIV nondisclosure that advocates hoped would clarify the legal test in *R. v. C*. In *R. v. M*, the accused had sexual relations with nine female teenage complainants with whom he would inconsistently use condoms. While he did not disclose, he was compliant with antiretroviral therapy, except for one instance in which he failed to take his medication. He maintained an undetectable viral load, thereby making it impossible[15] to transmit the virus to his sexual partner regardless of whether he was wearing a condom. The trial judge found M guilty of six counts of aggravated sexual assault, sentenced him to 14 years of incarceration, and ruled to have him deported (Grant, 2020). Problematically, the trial justice argued that both conditions had to be met because M had endangered the life of the complainant regardless of whether a condom was used (Grant, 2009). Such a decision defies scientific

[15] Viral load simply means the amount of virus in a person's bodily fluids and is usually measured as copies of the virus per millilitre of blood. There are three terms that describe the level of viral load in a person's bodily fluids; namely, undetectable, suppressed, and low. *Undetectable viral load* means that a person's viral load is so low that HIV does not appear on most common types of viral load tests and a person cannot transmit HIV to sexual partners. This number is usually around 50 copies of HIV per milillitre of blood, depending on which test is used. A *suppressed viral load* generally refers to having under 200 copies of HIV per millilitre of blood which means that a PLWH cannot transmit HIV to their sexual partners. Currently, this is the standard that is being used as a legal benchmark in some Canadian provinces although it could change as new scientific information comes out (HIV/AIDS Legal Network, 2024). This standard was developed by the Public Health Agency of Canada who conducted research for the Department of Justice, examining levels of risk of transmission based on varying degrees of viral load a person might have and condom use (LeMessurier et al., 2018). They found that sexual activity with a person who adheres to treatment and maintains a suppressed viral load for four to six months, poses a negligible risk of transmission (LeMessurier et al., 2018). Recently, the World Health Organization (2023) found that a viral load of 1000 copies per millilitre of blood or less poses negligible, or no risk of transmission. It is unclear whether this benchmark will be adopted by legal actors in Canada (HIV/AIDS Legal Network, 2024). Lastly, a *low viral load* for the purposes of the criminal law in Canada, means having under 1,500 copies of HIV per millilitre of blood (HIV/AIDS Legal Network, 2024) – this was the standard applied in R. v. M. in 2012. The HIV/AIDS Legal Network (2024) advises that if a person has a low viral load but not enough to be considered suppressed or undetectable, they could be at a heightened risk of prosecution and should disclose their status to partners.

evidence that when condoms are used correctly, their effectiveness at preventing the transmission of HIV is approximately 98% (Hartford, 2014; Mykhalovskiy et al., 2010).

The Court of Appeal in Manitoba overturned this decision and held that either the careful use of a condom *or* an undetectable viral load could negate the significance of the risk (Grant, 2020). The Supreme Court justices eventually ruled to acquit M for instances in which he used a condom *and* had a low viral load thereby changing the significant risk test to the more stringent "*realistic possibility of transmission of HIV*" (*R. v. M.*, 2012, para 84, emphasis added). In other words, the decision in *R. v. M* clarified that nondisclosure still poses a significant risk of bodily harm as set out in *R. v. C* unless the accused had a low viral load *and* used a condom (Dej & Kilty, 2012). *R. v. M* was an important case as it was the first to consider scientific evidence on viral load (Dej & Kilty, 2012) particularly because PLWH who consistently adhere to antiretroviral therapy can have an undetectable viral load and therefore pose a negligible risk of transmitting HIV sexually (UNAIDS, 2018). Critics argue that the decision in *M* did little to clarify the decision in *C*, instead doubling down such that a "realistic possibility appears to mean a risk that is *not negligible* and *not speculative*" (Grant, 2020, p. 56, emphasis in original), which suggests that the Supreme Court requires virtually no risk of transmission (Grant, 2020).

Since the decision in R. v. M., the Canadian government has made important strides in its efforts to reduce the number of prosecutions for HIV nondisclosure in Canada. For example, on World AIDS Day 2016, the former Minister of Justice and Attorney General, the Honourable Jody Wilson Raybould recognized the "problem of overcriminalization" and a year later released a report titled Criminal Justice System's Response to the Non-Disclosure of HIV. This report made essential recommendations to limit the number of prosecutions against people living with HIV (Department of Justice, 2017). The report concluded that the law should not apply to cases

of HIV nondisclosure before sex where the person maintained a suppressed viral load because it does not meet the realistic possibility of transmission test (Department of Justice, 2017). It further concludes that the law should “generally” not apply to people living with HIV who are on treatment, are not on treatment but use condoms, or engage only in oral sex (Department of Justice, 2017). Importantly, the report was the first to consider what the complainants in these cases experience. The document states that complainants described feeling a range of emotions, including fear, guilt, anger, stress, embarrassment, and anxiety, which have detrimental psychological impacts (Department of Justice, 2017, p. 27). These effects were particularly felt as people waited for test results. Moreover, victim impact statements revealed that they felt betrayed and that some even attempted suicide and self-harm (Department of Justice, 2017). In those cases where transmission occurred, complainants reported significant harms including increased stress and stigma associated with being HIV positive. Many complainants also stated that they were treated like liars by the criminal justice system, felt hardships from having to testify at trial, and from having their medical records disclosed (Department of Justice, 2017).

A year after the report, the Honourable Jody Wilson Raybould issued a federal directive regarding HIV nondisclosure to serve as a guide for federal prosecutors. The directive states, among other things, that the Director of Public Prosecutions will not prosecute HIV nondisclosure cases where: the PLWH maintained a suppressed viral load of under 200 copies per millilitre of blood because there is no realistic possibility of transmission; the person did not maintain a suppressed viral load but used a condom or only engaged in oral sex. They will prosecute HIV nondisclosure cases with non-sexual offence categories where non-sexual offences more appropriately reflect the wrongdoing. They will also consider if public health authorities offered services to a PLWH “who has not disclosed their HIV status prior to sexual

activity when determining whether it is in the public interest to pursue a prosecution against that person" (The Honourable Jody Wilson Raybould, 2018).[16] While laudable, these directives only apply to federal prosecutors and thus govern Criminal Code prosecutions in the three territories (Yukon, Northwest Territories, and Nunavut) (Canadian HIV/AIDS Legal Network, 2019).[17] The 10 provinces are under the jurisdiction of their provincial Attorneys General; since 2019 only three provinces, British Columbia, Ontario and Alberta, have made their own directives stating that a person living with HIV will not be prosecuted for nondisclosure if they are taking their medications and have a suppressed or undetectable viral load for a minimum period, between four to six months, before sex takes place (HIV/AIDS Legal Network, 2024).

Nonetheless, it is important to acknowledge that the lower courts have been using the scientific evidence on viral load in recent cases. For example, several people who did not use condoms but had undetectable viral loads at the time they had sex, have been acquitted by the courts, while others have had their charges dropped by prosecutors (Canadian HIV/AIDS Legal Network, 2019). For example, in one case, (R. v. R., 2022) the Ontario Court of Appeal decided that a person who is considered an "elite controller," someone whose body can naturally suppress HIV in their blood without being on treatment, did not pose a realistic possibility of transmission when they engaged in sex without a condom (HIV/AIDS Legal Network, 2024). In R. v. Mu (2022), the court decided that the accused's actions did not pose a realistic possibility of transmission because she was taking her medications and had a suppressed viral load at the time she had sex without a condom (HIV/AIDS Legal Network, 2024). There has yet to be a SCC case which explicitly states that having a suppressed viral load is enough to avoid

[16] See: The Honourable Jody Wilson Raybould (2018, December 8). *5.12 Prosecutions Involving Non-Disclosure of HIV Status.* https://www.ppsc-sppc.gc.ca/eng/pub/fpsd-sfpg/fps-sfp/tpd/p5/ch12.html
[17] In 2020, the Canadian HIV/AIDS Legal Network changed its name to the HIV/AIDS Legal Network. All sources before this will be cited with their older name throughout this dissertation.

prosecution which would apply across Canada. On the other hand, there is still much debate in the courts about whether using a condom without a suppressed viral load requires disclosure. For example, in Nova Scotia, the courts determined that regardless of the HIV positive person's viral load, sex with a condom does not pose a "realistic possibility of HIV transmission" (R. v. T., 2018); in Ontario, however, a lower court held a young man criminally liable for not disclosing his HIV positive status to his sexual partner because he did not have a suppressed viral load even though he used a condom (R. v. G., 2017). The HIV/AIDS Legal Network (2019) explicitly advises that "nowhere in Canada is there a clear legal protection that states using a condom will be enough to prevent [a person] from being prosecuted or convicted for non-disclosure if you don't also have a low, suppressed, or undetectable viral load" (p. 10).

The community has also been quite active in its advocacy to transform the criminal law. The Canadian Coalition to Reform HIV Criminalization (herein called 'the Coalition'), of which I am a steering committee member, was formed in 2016 to change discriminatory and unjust criminal and public health laws and practices that criminalize and regulate people living with HIV. The coalition consists of people living with HIV, community organizations, lawyers, and researchers working to challenge and change the law to limit the number of people who are charged for and convicted of HIV nondisclosure. In 2017 the coalition released a community consensus statement after consultations with community members about ending unjust HIV criminalization. This statement was endorsed by more than 170 community organizations from every part of Canada. In 2022, they released the second version of this statement which calls for: criminal prosecutions to be used as a last resort in cases where this is actual and intentional transmission of HIV; Federal and Provincial Attorney Generals to develop sound prosecutorial guidelines to prevent unjust HIV prosecution; sexual assault charges to stop being used to

prosecute allegations of nondisclosure, exposure, or transmission of HIV; the end of deportation of non-citizens following conviction; all Governments to support the development of resources and training for judges, police, Crown prosecutors, and prison staff to address HIV related stigma and fear; and all past convictions to be reviewed so as to remove PLWH from the sex offender registry list (CCRHC, 2022). These calls were echoed in a technical memo drafted in 2022 by legal experts on the coalition that details several proposed amendments to the law on HIV nondisclosure in Canada. This technical memo was sent to the Minister of Justice's office and Justice Canada to aid in discussions about legislative reform when Coalition members met with former Justice Minister Lametti, former Justice Minister Virani, and Department of Justice policy advisors.

In 2022, the Government of Canada undertook their own consultations with Canadians about the criminal justice response to HIV nondisclosure. The Canadian public was invited to share their views through an online survey about the various criminal law reforms related to HIV nondisclosure that the government was considering at the time (Department of Justice, 2023). The survey had a total of 980 respondents, 907 of which were independent individuals with the remaining 73 representing organizations (e.g., non-governmental organizations, health services, legal, and academic research centres and groups (Department of Justice, 2023). The results of these consultations were published in a report titled *HIV Non-Disclosure Public Consultation: What We Heard* (2023), which notes that 85% of respondents agreed that sexual assault law should not be used to prosecute cases where the only issue is nondisclosure. About half of the individual participants and almost three-quarters of organizational representatives agreed that intent to transmit the virus should be required for criminal prosecution and 43% of all respondents thought that the criminal law should be limited to cases involving transmission. Just

under two-thirds (61%) of respondents (60% of individuals and 78% of organizations) favoured amendments to the Criminal Code that would preclude PLWH from criminalization if they take reasonable precautions to protect their sexual partners by taking anti-retroviral therapy, using condoms, and/or limiting sexual activity to oral sex. Lastly, more than half of respondents (59%) agreed that there should not be a new HIV, sexually transmitted infection, or infectious disease-specific offence created in the Criminal Code (Department of Justice, 2023). Some respondents also stated that there should be a total decriminalization of HIV (Department of Justice, 2023). While these findings are largely positive, any movement with regard to legislative change has stalled with the most recent cabinet shuffle and the looming 2025 federal election (Akarasewi, 2024; Gallant, 2024; CPAC, 2024). Indeed, the government informed Coalition members that "there is no longer a path forward" on law reform before the next federal election (CCRHC, 2024).

### 1.1.2. Consequences and Impact of Criminalizing HIV Nondisclosure

The consequences and impacts of criminalization are well documented in the literature on HIV nondisclosure (Adam, 2005; Adam, Elliott, Husbands et al., 2008, 2014; Allard et al., 2013; Bogosavljević & Kilty, 2023; Csete et al., 2023; Elliott, 2002; Galletly & Pinkerton, 2006; Hastings et al., 2023; Kilty & Mott, 2022; LEAF, 2019; Michaud et al., 2021; Symington, 2009; Weait, 2001).[18] The criminal law has disrupted years of HIV prevention campaigns that strived to establish and reinforce norms emphasizing shared responsibility for HIV prevention, instead individualizing prevention by responsibilizing PLWH for disclosing their serostatus to potential partners regardless of the possible consequences for PLWH (Adam, Elliott, Corriveau et al.,

[18] There are more sources that discuss the consequences and impacts of criminalizing HIV nondisclosure, which I use throughout this section, than there is space to document here.

2014; Galletly & Pinkerton, 2006; Weait, 2001). The law may subsequently create a false sense of security amongst HIV-negative people who may believe that it will force disclosure and thus that they are not obliged to practice safe sex (Adam et al., 2008, 2014; Elliott, 2002; Galletly & Pinkerton, 2006; Kilty & Mott, 2022). By framing disclosure as the moral thing to do, criminalization fails to recognize that in certain situations nondisclosure is the 'right' thing to do (Bogosavljevic & Kilty, 2021). In other words, individualizing sexual safety in such a way,

> …constructs human actors as rational, adult, contract making individuals in a free market of options. It does not account for the much more complex motivators and vulnerabilities that characterize real human interaction and it denies the vulnerabilities, emotions, and tough dilemmas faced by people in their everyday lives (Adam, 2005, p. 344).

The criminal law is an improper tool for HIV prevention because it cannot recognize the complexity of disclosure (Allard et al., 2013; Bogosavljevic & Kilty, 2021). Indeed, as McClelland (2024) argues, "the blunt violence of the criminal law flattens complexity and nuance, which limits our collective understanding of how these cases came about in the first place" (p. 3).

That the law aims to force disclosure neglects the reality that disclosing can be dangerous, especially for vulnerable individuals such as women, low-income people, sex workers, immigrants, and the homeless or precariously housed (Allard et al., 2013; Kilty & Orsini, 2017, 2019a; Siegal et al., 2005; Symington, 2009). People living with HIV/AIDS also speak about not disclosing their serostatus to loved ones to protect them from emotional distress (Rouleau et al., 2012). Others make decisions around disclosure to cope with their diagnosis and because they fear rejection (Adam, Corriveau et al., 2015) or because disclosure would be tantamount to a crime (Drummond, 2011; Elliott, 2002; Klein, 2009). In some cases, HIV

negative partners have used the law as a coercive tool to blackmail their HIV-positive partners (Allard et al., 2013). It is therefore no surprise that some people might choose not to disclose.

The criminal law on HIV nondisclosure has also created confusion amongst health care providers who, because of the courts' failure to clarify what constitutes significant risk, often provide contradictory counselling advice (Mykhalovskiy, 2011). For example, counsellors expressed that the law has created an environment in which clients no longer want to discuss the challenges they face around disclosure (Mykhalovskiy et al., 2010). One way that ASOs try to counter the effects of the law is by understanding the "structural and interpersonal barriers" to disclosure that each client faces; however, using confession to "build trust with and to elicit similar reflexive confessional from service users, […] positions the ASO worker as an authority figure in the support relationship and for some, as a model of a neoliberal sexual citizenship" (Kilty & Orsini, 2017, p. 9).

Further eroding the relationship between PLWH and medical professionals, the introduction of phylogenetic analysis, more commonly termed molecular surveillance, uses the blood routinely given by PLWH in the context of their medical care to identify 'clusters' of certain strains of HIV (McClelland et al., 2019). Critics argue that this practice violates the privacy and consent of PLWH whose "health data are being repurposed for use in surveillance which disproportionately targets marginalized people already experiencing over-policing and criminalization" (McClelland et al., 2019, p. 3). There is widespread fear that phylogenetic analysis can be used to prosecute PLWH in cases of HIV nondisclosure even though the CDC has stated that molecular surveillance cannot indicate transmission directionality (McClelland et al., 2019). In short, the intrusion of law into the counselling relationship has undermined the confidence PLWH have with service providers, which may affect people's willingness to seek

treatment (Elliott, 2002). The law thereby weakens effective public health initiatives, increases stigma and discrimination, violates the rights of PLWH, and spreads problematic information about HIV (Elliott, 2002; Global Commission on HIV and the Law, 2012; UNAIDS, 2012; McClelland, 2019a, 2019b).

Adam, Elliott, et al. (2014) document that PLWH face significant problems in starting and maintaining romantic relationships, including increased apprehensiveness, a heightened sense of anxiety and vulnerability about how to behave in a way that avoids the risk of prosecution, negative reactions to disclosure, and the loss of confidentiality from secondary disclosures of their serostatus. McClelland (2019b) argues that the convergence of knowledges about HIV and PLWH from the media, press releases, court documents, institutional directives, expert opinions, medical files, and social media "reinforces and amplifies legal forms of violence" (p. 133) such that people criminalized for HIV nondisclosure and PLWH more broadly live in a "negative relation" to the law and are therefore subject to a "wide range of extralegal violence, discrimination, and invasive surveillance that exists in legal grey areas" (p. 133). Criminalization and the convergence of different flows of information about those who are convicted results in "physical and psychological violence, shunning, social exclusion, loss of autonomy, and the means to realize safety and security" (McClelland, 2019b, p. 142; McClelland, 2019a).

Given that, in Canada, people criminalized for HIV nondisclosure are predominantly charged and convicted of aggravated sexual assault, they must register as sexual offenders under the federal *Sex Offender Information Registration Act*, SC 2004, c.10 (SOIRA). As a result, their designation as a sex offender and the charges for which they were convicted are often circulated and disseminated through police press releases and media reporting (Michaud et al., (2021). This

increases HIV-related stigma and the forms of legal and extra-legal violence McClelland (2019a, 2019b) outlines. Criminalization disproportionately impacts Black, Indigenous, and other racialized and marginalized groups, media representations of which tend to emphasize historically racist tropes about Black men's immigrant criminality, virility, and the 'monsterization' of Black men's sexuality (Persson & Newman, 2008; Kilty & Bogosavljevic, 2019; Mykhalovskiy, Sanders et al., 2021, 2016; Hastings, Mykhalovskiy et al., 2020). Manning (2019) argues that analysis of HIV criminalization in Canada must go beyond thinking about the overrepresentation of racialized people, instead, we must focus on,

> … how colonialism and racism intersect in the Canadian criminal justice system, which serves to maintain a dominant and subordinate relationship between the colonial-settler state, Indigenous people and Black people: by marking Indigenous bodies as human waste and Black bodies as monstrous, and by marking white bodies as controlled and civil, the naturally superior race who is entrusted with creating the racial hierarchy and maintaining law and order. I argue that we urgently need to pay attention to and address the material and bodily consequences of such colonial and white supremacist relations. (n.p)

She contends that if we understand the criminal legal system as part of an ongoing colonial project, we can comprehend the overrepresentation of racialized people as a symptom produced by that system (Manning, 2019).

A much less explored topic in the literature on the criminalization of HIV nondisclosure is how people experience nondisclosure and how they navigate victimhood, if they do at all, as a consequence of nondisclosure. The only study to consider victims in these cases analyzed how advocates for the reform and abolition of the criminalization of HIV nondisclosure neutralize the victim in their arguments. Speakman (2019) found that such messaging constructs victims as individuals who share the responsibility with "non-disclosers' for any harm they may have suffered", what she terms the 'it takes two to tango' argument. They do this by:

> Asserting that: (a) these individuals knew (or should have known) about the risks connected to having unprotected sex; (b) they exercised agency in making a series of decisions that contributes to their predicament; and (c) some individuals in this predicament will themselves reject the victim label and concede that they bear some responsibility for the outcome. (Speakman, 2019, p. 47)

Speakman (2019) problematizes the efforts of those who oppose the criminalization of HIV nondisclosure when those efforts attempt to counter the construction of PLWH who do not disclose as villains by undermining the portrayal of their partners as victims.

To the best of my knowledge, no study has talked to PLWH and people who are HIV negative about how they make sense of HIV nondisclosure before sex in the context of criminalization. This fact raises several important unanswered questions that interest me and that represent the *research questions* I explore in this dissertation. Specifically, I am curious about how people define their identities in relation to their partner's nondisclosure and their HIV diagnosis. Do people identify as victims? If so, in what ways? If they do not, how do they make sense of their experiences? What emotions and narratives structure these identifications? How do narratives of victimhood get taken up or rejected as people narrate their stories about living with HIV? How does nondisclosure fit within the broader narrative of people's lives? What does it mean to live with HIV in the era of HIV/AIDS normalization where criminalization paradoxically marks the virus as exceptional?

To answer these questions, I move between different scales of analysis, exploring both the subjective material experiences of living with HIV and the socially, culturally, and temporally produced affective narratives that shape those experiences, and that people mobilize to configure their affective narrative selves. While the emotions of grief, hope, anger, and shame that I explore directly in the analysis chapters are not necessarily new emotions to be considered in relation to of what it means to live with HIV (see for example Caron, 2014; Cvetkovich, 2003;

Gould, 2009), what is novel is my temporal framing of these emotions within a series of HIV eras to showcase how they are felt or suppressed over time and thus how they are articulated through shifting social, cultural, medical, and legal affective narratives about HIV.

I argue that the criminalization of HIV nondisclosure has (re)ignited a disease specific politics of victimhood, one that has always been contentious within the HIV/AIDS community. Notably, the Denver Principles (1983) declaration that PLWH are not victims continues to be the position taken up by many ASOs and PLWH. This dissertation shows how the HIV community's creation of a public culture during the HIV/AIDS crisis era that rejected defining their HIV related traumas in the language of victimization, continues to shape how PLWH configure their affective narrative selves today. In the current context of criminalization, I argue that this public culture works to further entrench modes of governance that responsibilize individuals regarding their own sexual health, safety, and practices rather than making visible the ways in which systemic forces work to vulnerabilize, marginalize, and punish PLWH who cannot engage in the moral imperatives of 'good' sexual citizenship. While nondisclosure may produce harm for some people, I also consider how narratives of victimization are useful in framing the harmful effects of oppressive structural forces that aim to regulate the behaviours of PLWH, including the criminalization of HIV nondisclosure and seemingly benign public health policies, that individualize, medicalize, and professionalize both sexual and broader health practices in ways that further promote that neoliberal model of sexual health and healthy citizenship (Kinsman, 2024).

My dissertation generated as many questions as it did thoughtful theoretical insights. It thus only touches the surface of a much-needed broader exploration of the politics of victimhood in the criminalization of HIV nondisclosure and in the HIV/AIDS community. I now turn to a

review of the literature on the sociology of health and illness and critical victimology to situate this project.

# Chapter 2.

# Situating the Project: The Literature Review

This chapter is divided into two main sections. In the first half, I discuss the meaning of health and explore the range of actions deployed in the name of health – actions which include criminalization as is the case for people living with HIV who allegedly[19] do not disclose their serostatus to their sexual partners. First, in section 2.1 I offer a brief overview of some literature in the sociology of health to situate myself in this field. I am specifically interested in the work that critically explores the intersection of medical, moral, and legal modes of regulation, the relationship between health, morality, and law, and the emergence of new HIV identities under the increasing biomedicalization of everyday life and contemporary seropolitics. The second part of this chapter (section 2.2) reviews the emergence and evolution of victimology, situating this project within the critical victimology literature. I specifically consider the scholarship that addresses how victims have been normalized within law and psychiatry, with a focus on how victimhood and survivorhood are experienced, resisted, constructed and ascribed.

Taken together, I show how different modes of regulation are enacted in the name of health and harm and how harm and illness are shaped by evolving institutional, cultural, social, political, legal, and psychological narratives that offer important interpretive frameworks for understanding these experiences. Most importantly, by bringing into conversation these two

[19] While in the context of the law, the issue is about not disclosing, I use the term "allegedly" to denote how messy disclosure is in practice. For example, some people have been criminalized for nondisclosure because they failed to disclose the first time they engaged in sexual intercourse with their partner but later disclosed their status. The use of the word "allegedly" is also common practice among scholars writing and researching the criminalization of HIV nondisclosure.

bodies of literature I explore how harm, illness, and health are inextricably linked as pain, trauma, injury, and disease can lead to changes in how one feels about and configures the self.

In the next section, I explore how health is productive of new identities and subjectivities by reviewing the literature on medical, moral, and legal modes of regulation.

## 2.1. Health as Productive: On Medical, Moral, and Legal Regulation

The sociology of health and illness is a wide ranging field.[20] Generally, and this is not an exhaustive list, scholars working in the sociology of health and illness have explored issues such as the social patterning of health and illness (Snow, 2012; Syme & Berkman, 2012) including the commodification of health care (Henderson & Petersen, 2002); analysis of medical knowledge and in particular the power/knowledge nexus as it relates to medicine (Foucault 1963/2003; Rabinow & Rose, 2006; Turner, 1995); the experience of health and illness including issues around biographical disruption or how illness interrupts or shifts notions of self (Bury, 1982; Charmaz, 1983; Crawford, 1994; Sontag, 1978); social and cultural aspects of the body (Turner, 1992; Shilling, 1993/2003) including work that critically analyses notions of obesity and fatness (Berlant, 2011; Lupton, 2018; Orsini, 2020) and disability (Patsavas, 2014; Titchkosky, 2011; Garland-Thomson, 2013; McRuer, 2006) in contemporary public health campaigns, politics, and social systems and institutions; and the social organization of health care and public health (Lupton, 1995; 2003) including the relationship between public health and the formation of the state (Adams, 1993; Porter, 1999).

[20] See Cockerham, W.C. (2021). *Sociological Theories of Health and Illness*. New York: Routledge; Nettleton, S. (2006). *The Sociology of Health and Illness, 2nd edition*. Cambridge: Polity Press; Conrad, P. and Leiter, V. (2012). *The Sociology of health and Illness: Critical Perspectives, 9th edition*. New York: Worth Publishers; Strohschein, L. and Weitz, R. (2013). *The Sociology of Health, Illness, and Health Care in Canada: A Critical Approach*. Toronto: Nelson Education; Mykhalovskiy, E., Choiniere, J., Armstrong, P., and Armstrong, H. (2020). *Health Matters: Evidence, Critical Social Science, and Health Care in Canada*. Toronto: University of Toronto Press.

Scholars have also examined the concept of health and its associated discourses, structures, and institutions from various theoretical perspectives including functionalism[21], political economy[22], and interactionist.[23,24] These theoretical approaches in medical sociology are rooted in enlightenment thinking, "a philosophical movement emphasized by the systematic application of reason as a means of understanding the world" (Bradby, 2012, p. 33). These scholars were interested in understanding modernity, and the effects of a shifting relationship between individual and society with the rise of industrial capitalism (Bradby, 2012). Post-structuralist theories on the other hand, hone in on the power of language and knowledge systems in centring certain notions of health and illness. Specifically, "post-structuralist thinking […] rejected the idea that there are central unifying rules operating as deep structures in society organizing language and social phenomena into stable systems, meanings, and relationships"

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[21] The functionalist approach defines the role of the medical profession as "moral guardian[s] of society" ensuring that social order is maintained by controlling the potentially disruptive nature of illness (Lupton, 2003, p. 7). One of the leading scholars of this approach was American sociologist Talcott Parsons whose work on the function of the sick role, its implications for the doctor-patient relationship, and critique of the social aspects of medicine as a profession was instrumental in the development of medical sociology in the 1950s and 1960s (Timmermans & Haas, 2008). Parsons defined sickness as a deviant social status and those who are sick as in need of care from physicians to recover because they are unable to care for themselves (Cockerham, 2020; Lupton, 2003). As such, "medical practice in this context is a mechanism by which a social system seeks to control the illnesses of its deviant sick by returning them to as normal a state of functioning as possible" (Cockerham, 2020, p. 49). Parsons' work has been critiqued for failing to explain how patients experience long-term pain, how conflicts and differences in interests between doctor and patient are negotiated, for failing to distinguish between a patient role and a sick role, and for not conceptualizing the process patients undergo to seek medical help (Turner, 1995). Today functionalism is critiqued for not considering conflict as a form of social change and for placing individuals in passive roles with little regard for people's agency and creativity (Cockerham, 2020; Lupton, 2003).

[22] Political economy approaches explore how medicine is entangled with capitalist and neoliberal rationalities to produce health inequalities (Cockerham, 2021). Medicine is understood as a mechanism to keep the population healthy enough to be active capitalist citizens, contributing to the production and consumption of commodities (Bradby, 2012; Lupton, 2003). All those who are not able to do so, those who are ill, ageing, or living with a physical disability are marginalized and cast off (Cockerham, 2021; Lupton, 2003). Conflict and inequality thus become central to social processes and the organization of social systems, which Cockerham (2021) criticizes because "conflict is not common in most health situations. Cooperation is typically the norm in care-giving environments" (p. 107).

[23] Interactionist approaches are rooted in the work of Erving Goffman, George Herbert Mead, and Charles Cooley, among others (Bradby, 2012; Cockerham, 2021). This body of work posits that medicine has the power to ascribe and validate a health status and that through the interactions between healthcare providers and patients, different meanings of health are created (Bradby, 2012).

[24] For a comprehensive review of the theories in the field of sociology of health and illness see Cockerham, W.C. (2021). *Sociological Theories of Health and Illness*. New York: Routledge.

(Cockerham, 2021, p. 151). These scholars challenged the idea that humans are sacred, metaphysical beings within which lie meanings and value, instead arguing that we are culturally and symbolically constructed subjects where meaning is constituted by difference (Bradby, 2012). For example, the works of Foucault (1963/2003) and Rose (1996, 2007) critically examine the role of power, medical knowledge, and social institutions in constituting our understanding and experiences of health and illness.

One of the more influential approaches in the sociology of health and illness is social constructionism. Scholars working from this perspective understand truth to be the product of power relations, and study how medico-scientific and lay medical knowledge and practices act as mechanisms of social control to "reinforce the position of powerful interests to the exclusion of others" (Lupton, 2003, p. 13). Social constructionists therefore interpret experiences of illness and disease via social and other power relations (Bury, 1986; Cockerham, 2021; Conrad & Barker, 2010; Lupton, 2003). This body of work has been instrumental in deconstructing commonly shared norms about sexuality, race, disability, and age by understanding these categories as socially constructed "through highly partial value judgements being promoted as neutral, often with the support of medical authority" (Bradby, 2012, p. 36). This area of medical sociology led to important conceptual distinctions between disease as "a physiological process" and illness "as a social experience of that disease" (Frank, 1995/2013, p. 223). Illness therefore is understood as being "shaped by social interactions, shared cultural traditions, shifting frameworks of knowledge, and relations of power" (Conrad & Barker, 2010). Social constructionist thinking also produced concepts such as medicalization (Conrad, 1992, 2005; Conrad & Schneider, 1992) and the more contemporary biomedicalization (Clarke et al, 2003, 2010). Social control theories take up these concepts to understand how aspects of life not

previously under the medical gaze come to be constituted as medical and biomedical problems and are sometimes merged with the study of crime to examine the medico-legal borderland (Timmermans & Gabe, 2002).

This dissertation fits within the post-structuralist and social constructionist fields of sociology of health and illness. This section draws on some of this literature to critically explore the uses and meanings of health and illness and the relationship between health, law, and moral regulation. Following such scholars as Lupton, Metzl and Crawford, I understand health to be a productive force, meaning that in the name of health, people are responsibilized and disciplined to be 'proper' citizens; those who fail to conform to standards of respectability are deemed deviant, criminal, unstable, and in need of discipline, regulation, reform, and/or punishment.

The concept of health itself is riddled with multiple meanings. For example, health can be defined as stigmatizing rhetoric in which understandings of our own health depend on the recognition and creation of the spoiled health of others (Blaxter, 2010; Metzl, 2010). In reviewing the work of philosopher Ivan Illich, Metzl (2010) argues that health is a colonizing rhetoric in that American society and arguably the West more broadly promotes an idealized version of health that is unattainable and that does not allow for suffering, aging, dying, and other natural processes of human life. Similarly, reading the work of Talcott Parsons, Irving Zola, and Michel Foucault, health can be understood as a normativizing rhetoric (Metzl, 2010). For example, Foucault's (1978) notion of biopower as a power to "*foster* life or *disallow* it to the point of death" coexists with juridical forms of sovereign power or the right of a ruler to "*take* life or *let* live" (p. 138). In other words, biopower

> …serves to bring into view a field comprised of more or less rationalized attempts to intervene upon the vital characteristics of human existence. The vital characteristics of human beings, as living creatures who are born, mature, inhabit a body that can be trained and augmented, and then sicken and die. And the vital

> characteristics of collectivities or populations composed of such living beings (Rabinow & Rose, 2006, pp. 196–197).

Through biopower, institutions tasked with protecting the health of populations produce certain kinds of 'healthy' and 'innocent' subjects to the exclusion of unhealthy others (Lupton, 1995). As such, Metzl (2010) argues that health can be understood as a discourse of power.

This discourse of power is found in definitions of health by the World Health Organization (1948) and the Government of Canada (2008) who understand health as being more than the 'absence of disease', but they also present health as a universal good to which we should all strive.[25] Critical health scholars complicate such notions[26]; for example, Metzl (2010) argues that health is not a fixed entity and is "replete with value judgements, hierarchies and blind assumptions that speak as much about power and privilege as they do about well-being. Health is a desired state, but it is also a prescribed state and an ideological position" (pp. 1–2). In other words, health is a physical state, but it is also used to make moral judgements about oneself and others. For example, when I say "I was bad with my eating today" I attach a certain moral code to food and to myself. What I might mean, is that I am a bad person for eating that doughnut. Or when others meet a fat person, they might say, 'obesity is bad for your health', the underlying connotation being that this person is lazy or weak-minded (Metzl, 2010). As Berlant (2010) argues, "obesity [is] an effect of people's *attachment to life*" in that eating offers us a "kind of rest for the exhausted self, an interruption of being good, conscious, and intentional that feels like a relief" (p. 26). That health is individualized removes it from broader social contexts in

[25] The World Health Organization (1948) defines health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (n.p.). The Government of Canada (2008) reaffirms this definition adding that "health is seen as a resource or an asset that helps us lead our everyday lives. Health is seen as a positive concept that emphasizes social and personal resources, as well as physical capacities" (n.p).

[26] See for example Richard Klein's *Eat Fat* (1996) and *Cigarettes are Sublime* (1993) in which the author challenges common understandings of fatness and cigarettes as 'bad' for one's health.

favour of understandings that emphasize lifestyle ‘choices’ (Lupton, 2003). As such, Metzl (2010) contends that we should examine the *uses* of health in our daily lives to disrupt common assumptions about health as a transparent and universal good. By questioning how health is used in everyday life, we begin to uncover “how the term is used to make moral judgements, convey prejudice, sell products, or even to exclude whole groups of persons form health care” (Metzl, 2010, p. 2).

I align with Crawford’s (1994) understanding of health as “a primary means of signification by which borders are maintained, threats specified, and internal weaknesses shored up. The imagined identity of the ‘diseased’ other serves as a boundary-reinforcing device” (p. 2). In other words, health draws the boundaries between the Self and Other, creates moral and social categories and reinforces binary oppositions between man/woman, rich/poor, gay/straight, Black/white and so on. As Lupton (1995) argues, health is more than a medical condition, disease, or the absence of disease; it “comprises a group of knowledges used to assess different populations for different governmental strategies. These knowledges are developed and deployed not only by medical doctors and health promoters, but by teachers, social workers, bureaucrats, parents, economic advisors and so on” (p. 70). As such, health is productive, in the sense that it is not just a physical state of being without illness but that *in the name* of health, populations are regulated and governed[27] in particular ways.

This project is situated, in the medico-legal borderland (Timmermans & Gabe, 2002) – the space in which medical and legal knowledges converge not only for the purpose of social

[27] I refer to Foucault’s (1982) definition that goes beyond understandings of government as only political structures or the management of states but as designating “the way in which the conduct of individuals or of groups might be directed: the government of children, of souls, of communities, of families, of the sick. It did not only cover the legitimately constituted forms of politic or economic subjection but also modes of action, more or less considered or calculated, which were destined to act upon the possibilities of action of other people. To govern, in this sense, is to structure the possible field of action of others” (p. 790).

control but also to define what is normal/deviant, healthy/unhealthy, and right/wrong. I align with Hunt's (1993) argument that favours "constitutive practices" or the "positive practices that play some part in creating, constituting, or directing some social practice" (pp. 311-312). Following Hunt (1993), I conceptualize law as a constitutive mode of regulation or the,

> …institutional ensemble and set of practices and norms that function to secure social reproduction despite the unstable and contradictory character of capitalist relations. The regulation approach thus focuses attention on social ordering as the outcome of the interaction between multiple modes of regulation. (p. 320)

Hunt (1993) argues that law itself is one set of social relations that intersects and works with other forms. Regulation involves the "suppression, marginalization, or repudiation of alternative ways of being, while 'encouraging' other realities" (Hunt, 1993, p. 314). In this way, regulation is productive in that certain forms of social relations are actively encouraged while others are discouraged. The law, therefore, rarely functions on its own, but rather in connection and combination with other regulatory mechanisms (Hunt, 1993). Indeed, Valverde (1991) contends that "the distinction between different modes of regulation (moral vs. economic vs. political) is not found ready-made but is constantly produced, in varying ways, by agents located outside as well as inside the state" (p. 166). The intersection of these different modes of regulation can most readily be seen in and through the medico-legal borderland where medical and legal knowledge link up to produce new forms of social control and legal/medical subjects (Mykhalovskiy, 2011). As such, I use the term medico-legal borderland to examine how the law intersects with other modes of regulation such as medicine and public health and notions of morality to act as a "form of power which subjugates [people] and makes [people] subjects to" this form of power (Foucault, 1982, p. 781).

Moral regulation involves the mobilization of moral discourses "which construct a moralised subject and an object or target which is acted upon by means of moralising practices.

Moral discourses seek to act on conduct that is deemed to be intrinsically bad or wrong" (Hunt, 1999a, pp. 6-7). Judgments about what is moral or immoral are attached to utilitarian claims about the personal or social harms that arise from the wrong committed (Hunt, 1999a). Harm consists of both a specific harm, which can include the physical harm that arises from a wrongful act against a person, and a symbolic harm that may impact the broader community and/or body politic (Hunt, 1999a). Through the production of accepted and encouraged behaviours, moral regulation "depress[es], repress[es], and suppress[es] alternative forms [of behaviour] which portray contrasting moralities" (Corrigan, 1981/2006, p. 327). In other words, the techniques, discourses, and practices of moral regulation make dominant ways of being, desirable and legitimate while delegitimizing others as immoral (Adams, 1993).

Moral regulation is an important mechanism for ruling relations as it reinforces and (re)produces differences among class, gender, racial and sexual lines and individual consciousness such that it legitimizes particular institutions and discourses like the patriarchal nuclear family and racist immigration policies (Valverde, 1991). This process is worked on from the point of view of morality as "a mode of regulating social and individual life generally, not pretagged moral issues" (Valverde, 1991, p. 167). Indeed, modes of regulation are as much about the intersection of medical, moral, and legal knowledges as they are about racism, nationalism, homophobia, patriarchy, and other interlocking systems of oppression (Collins, 2016, 2019).[28] In other words, patriarchal, misogynistic, colonial, racist, and white supremacist ideals are deeply embedded in modes of regulation such that a "dominant and subordinate relationship between

[28] Although patriarchy, homophobia, nationalism, racism, and colonialism can be said to be artefacts of systems of oppression, Collins (2019) conceptualizes these as systems of power throughout her most recent book *Intersectionality as Critical Social Inquiry*.

the colonial-settler state, Indigenous people and Black people" is maintained and reinforced (Manning, 2019, n.p.).

In Victorian society as today, women's identity occupied a dual position in which they were regarded as "moral housekeepers" and "moral guardians of the male soul" and thus a moral standard compared to men, but also as weaker and more fragile and vulnerable than men (Hunt, 1999a; Lupton, 1995; Gavigan & Chunn, 2010). This duality is obvious in discourses that hold up true womanhood as exemplified by the chaste, respectable mother, while sex workers are represented as the "radical other" against which true womanhood is demarcated (Hunt, 1999a). This dichotomy is clearly present in early discourses about venereal disease in which loyal, respectable (white) wives were cast as innocent victims of husbands corrupted by sex workers who were the 'true' spreaders of disease – sex workers subsequently became the prime target of venereal disease campaigns and laws precisely because they doubly "transcended societal mores […] by not only 'doing it' but 'doing it' for money" (McGinnis, 1990, p. 62; Chunn, 2000; Mawani, 2002; Valverde, 1991). These binary oppositions, or what Foucault (1982) calls "dividing practices," not only reinforce each other (neither side of the binary works without the other) but also fortify and justify diffuse modes of regulation.

Medical, moral, and legal modes of regulation are a central feature of modern liberal modes of government, what Rose (1993) calls advanced liberal government which "entails the adoption of a range of devices that seek to recreate the distance between the decisions of formal political institutions and other social actors, and to act upon these actors in new ways, through shaping and utilizing their freedom" (p. 295). Rose (1993) articulates how modern systems of governance have shifted mentalities of rule, truth-telling practices, and procedures of expertise

from 19th century liberalism through the welfare state to what he terms "advanced liberal forms of rule" (p. 285). This is a new,

> …autonomizing and pluralizing formula of rule, […] dependent upon the proliferation of little regulatory instances across a territory and their multiplication, at a 'molecular' level, through the interstices of our present experience. It is dependent, too, upon a particular relation between political subjects and expertise, in which the injuctions of the experts merge with our own projects for self-mastery and the enhancement of our lives. (Rose, 1993, p. 298)

In other words, advanced liberalism is characterized by modes of regulation that operate like capillaries to diffuse notions of individual and personal responsibility for managing risk and our own health and well-being. All differences and inequalities that occur as a result of "a regime of responsible risk taking" are a matter of choice, making inequality inevitable (Ericson et al., 2000, pp. 532-533).

Rose (1993) situates neoliberalism as one aspect of an advanced liberal form of rule arguing that it did not just criticize welfare systems for being costly, bureaucratic, paternalistic, and inequitable, but that it transformed these into problems to be solved through "techniques such as monetarization, marketization, enhancement of the powers of the consumer, financial accountability and audit" (p. 294). As Rose (1993) and others (Ayo, 2012; Brown, 2015; Ericson et al., 2000; Wacquant, 2001, 2004/2009) make clear, neoliberalism is not simply an economic and political concept but is also deeply social and moral in its philosophy. It operates under, what Wacquant (2004/2009) identifies as four institutional logics that overlap with Rose's conception of advanced liberal forms of rule: "economic deregulation" which promotes market fundamentalism; the minimization of government intervention through the decentralization, withdrawl, and re-composition of the welfare state; "the cultural trope of individual responsibility"; and the expansion and intrusion of a proactive penal apparatus to manage those who cannot self-govern and be responsible (p. 307). Focusing on neoliberalism's social and

moral characteristics, I emphasize the ways in which we are increasingly being fashioned "as market actors" who must invest in themselves (Brown, 2015, p. 31). Self-investment is but one aspect of responsibilization, which Wendy Brown (2015) describes as moving from,

> …a substance-based adjective to a process-based transitive verb, shifting […] from an individual capacity to a governance project. Responsibilization signals a regime in which the singular human capacity for responsibility is deployed to constitute and govern subjects and through which their conduct is organized and measured, remaking and reorientating them for a neoliberal order." (p. 133)

Responsibilization thus operates as a neoliberal governance strategy by way of "an external moral injunction—through demands emanating from an invisible elsewhere" (Brown, 2015, p.133).

This transformation of subjects into market actors signals the shift away from 'self-control' to a more positive concern for 'self-formation' (Hunt, 1999a). Rose (1999) contends that people are conceived as entrepreneurial selves "who [are] *active* in making choices in order to further their own interests and those of their family: they [are] thus potentially active in their own government" (p. 142). The state's role was also transformed such that its powers were now directed at empowering "entrepreneurial subjects of choice in their quest for self-realization" (p. 142). Foucault (1988) terms this transformation as the "care of the self" or the "intensification of the relation to oneself by which one constituted oneself as the subject of one's acts" (p. 41). This is exemplified in colloquial sayings such as 'self-care' in which we might take a hot bath, read fiction, sit for hours binging Netflix or whatever method of inward self-reflection and relaxation we may choose. Such 'self-care' practices shift reliance on medical professionals to the individual who is responsibilized for their own health (Armstrong, 2014; Crawford, 1980; Petersen, 2015; Petrakaki et al., 2018) even though medical professionals still dictate what *is* healthy and unhealthy.

Crawford (1980) names this shift in the new health consciousness movement as healthism, or the "preoccupation with personal health as a primary—often *the* primary—focus for the definition and achievement of well-being; a goal which is to be attained primarily through the modification of lifestyles, with or without therapeutic help" (p. 368). In particular, the ideology of 'self-care' emphasizes individual responsibility for health status (Armstrong, 2014; Crawford 1980, 1984; Petersen, 2015; Petrakaki et al., 2018) such that the person can be both victim and vector – victim to the illness yet responsible for their ill health (Battin et al., 2009). In other words, healthism urges "mastery over simple pleasures in the name of health and longevity" (Hunt, 1993, p. 3) where those who are not able to master their impulses are judged as immoral and in need of stricter forms of regulation such as punishment via criminal law (Hoppe, 2018). As Ayo (2012) asserts,

> The consequences for those who fail to conform to the prescribed mandate as to what constitutes a healthy lifestyle are real. Such include among other things, public disdain and reproach for being a part of societal problems rather than a part of the solution, gazes of repulsion due to one's failure to manifest the symbolic metaphors of neoliberal citizenship, such as the self-governing individual or the capitalistic hard work ethic, embodied in the taut, refined and fit body, and admonitions from both health experts and loved ones alike. (p. 104)

Health as productive, therefore entails medical, moral, and legal modes of regulation and shows the ways in which regulation does not just come from above (through state institutions and the law) but from a multitude of social locations, including our everyday interactions, media, social media, school, family, and various organizations such as churches, charities, and other non-profits.

In her important work on moral regulation, Valverde (1991) shows how the project of social purity in Canada from 1885-1925 was largely undertaken by private organizations, although supported by the state and ruling class. Thus, alliances are created between different

regulatory agents, evidence that governing is not a hierarchical project with ruling elites controlling the population like puppets on a string, and that medical, moral, and legal modes of regulation are more insidious (Hunt, 1993, 1999a, 1999b; Lupton, 1995; Valverde, 1991). They specifically work by encouraging individuals to choose to follow the rules determined by public health and to, therefore, change their own behaviours and actions accordingly (Ayo, 2012). In other words, the techniques, practices, and discourses of regulation work within us so that we become agents and subjects of medical, moral, legal modes of regulation. We are both *regulators* policing the boundaries between acceptable and unacceptable behaviour as set out by dominant interests and *regulated* working on ourselves to stay within the boundary so that we are not marked with the scarlet letter or to use Goffman's (1963) term a "spoiled identity."

This imperative to be self-regulating and responsible citizens is most obvious in the competing conceptions of safe sex during the HIV/AIDS crisis and beyond. Responsibility for oneself and others has long been the communal ethos among gay men as they mobilized around each other, creating community organizations that became involved in city politics to fight for their rights and offer basic counselling, legal and medical services through peer-operated phone lines that provided non-judgemental, confidential, and compassionate care (Adam, 1992). This framework of care and compassion for each other laid down the foundation for the earliest response to the HIV/AIDS crisis (1981-1986) when government, public health, and social service agencies ignored the impending epidemic or created prevention and education campaigns removed from the lived reality of those most affected (Adam, 1992; Crimp, 1987; Patton, 1989, 1996). In response, lesbians, gay men, friends and partners of PLWH, community activists, sympathetic medical professionals, and PLWH themselves banded together to provide services and care to people who were dying and ill and to resist the narrative by public health that HIV

was a problem of specific ‘risk groups’ (Gould, 2009; Kinsman, 2024). Instead, HIV/AIDS activists argued that there were risky activities that anyone can engage in but no groups were inherently risky (Gould, 2009; Kinsman, 2024).

The HIV/AIDS community developed practices to reduce the risk of transmission such as emphasizing the use of condoms or only engaging in certain sex acts which carry less risk of transmission (Adam, 1992; Kippax & Race, 2003; Race, 2018; Patton, 1989, 1996). One of the most notable safer sex messaging to come from those impacted by HIV/AIDS was Michael Callen and Richard Burkowitz’s *How to Have Sex in an Epidemic* published in 1983. In this pamphlet they write about the responsibility and ethics of everyone engaging in sex, stating that “since we are a community, taking responsibility for our own health during sex ultimately requires that we protect our partners health as well as our own” (Callen & Berkowitz, 1983, p. 15). These community members were pioneers of safe sex practices (Gould, 2009; Patton, 1989, 1996) and “gave a different social context to the notion of responsibility, associating it with forms of community and mutual-responsibility regarding safe sex, relying on grass-roots education and not coercive measures” (Kinsman, 2024, p. 397).

Regardless of their efforts, while safe sex campaigns within gay communities played a crucial role in helping individuals prevent HIV transmission,

> …in the long run they failed to challenge the problematic split between ‘normal’ and ‘deviant’ sex, bringing the latter more explicitly under the long arm of the state. Gay men’s and sex workers’ sexualities and sexual vernacular were soon barely separable from the descriptions of them by state epidemiology. Programs varied in gay-positiveness and in their capacity to enable resistance to the social oppression that contributed to the failure to take up "safe sex." Most projects targeted individual competence and left unchallenged the social and political climate that influenced individuals' understanding of their sexuality.” (Patton, 1996, p. 98)

In other words, the narratives of safer sex transformed over time as these messages became more institutionalized within medicine, public health, and law. Today, safe sex is understood within a

hierarchy of risk where certain sexual and other activities are associated with a higher or lower transmission of HIV (Mykhalovskiy, 2016). People are thus encouraged to "govern themselves by adjusting their conduct in relation to public health knowledge" and if they fail to do so they are punished by way of public health orders and criminalization (Mykhalovskiy, 2016, p. 155). As Mykhalovskiy (2016) argues, criminal law "treats the presence of HIV in the human body as a basis for new legal norms of sexual conduct and new medico-legal ways of classifying human beings" (p. 156). In the era of TasP and in the law on nondisclosure, PLWH are *made* to be the only party responsible for HIV prevention and transmission (Adam, 2005; Race, 2001, 2012; Weait, 2001, 2007). This is the new heterosexualized and coercive safe sex ethic that fails to "expand our concept of sex, to increase the discussion of pleasurable possibilities, and to eroticize measures that reduce transmission of *all* sexually transmitted diseases" (Patton, 1996, p. 250).

When people negotiate safe sex in this era of normalization under which TasP and criminalization operate, a "multiplicity of responsibilities" emerges that "can work with and against each other, sometimes reinforcing neoliberal responsibilisation, and at other times existing alongside or undercutting it" (Trnka & Trundle, 2014, p. 150). This multiplicity of responsibilities and moral reasoning is evident in Adam's (2005) study of bareback culture in Toronto, Canada. Adam (2005) describes that people engaging in bareback sex justify unsafe sex through the rhetoric of neoliberal responsibilization when men blame themselves for acquiring HIV and when they assume that everyone takes care of their own health, thereby negating their responsibility to protect their partners. Yet, his interviews also show how the moral reasoning that people take up when they engage in intimate encounters and after, can disrupt these logics by "…combin[ing] together notions of informed consent, contractual interaction, free market

choice, and responsibility [to] create a platform for constructing unprotected sex as a ‘‘responsible’’ choice among adult men” (p. 344). Trnka and Trundle’s (2014) concept of a multiplicity of responsibilities and Adam’s (2005) study demonstrates the ways in which people negotiate, mobilize, and/or reject responsibilization practices inherent in contemporary medical, legal, and moral modes of regulation within their daily lives.

Next, I discuss the ways in which HIV and PLWH become objects of medical, moral, and legal modes of regulation, first by reviewing research on the purity and hygiene movements of the late 19th and 20th centuries, then by discussing how these modes of regulation are enacted through the criminalization of HIV nondisclosure and shifting HIV identities.

### 2.1.1. The Victim/Vector Duality: Regulation Through Law and Public Health

HIV and PLWH become objects of regulation through the alignment of medical, moral, and legal discourses and knowledges that create normative standards of being and behaviour.[29] Indeed, we can think back to the purity and social hygiene movements of the late 19th and early 20th centuries in which legislation was created to regulate venereal diseases in the name of public health (Adams, 1993; Buckley & McGinnis, 1982; Hunt, 1991a, 199b; Mawani, 2006, Valverde, 1991). For instance, after the first world war, Canada passed Criminal Code legislation that punished people for transmitting venereal diseases with a fine of $500, a sentence of six months imprisonment, or both (McGinnis, 1990). The moralism that underpinned these social hygiene/sexual purity campaigns included class, race, and gender-based assumptions about who was an innocent victim in need of protection and who was the guilty vector of disease (Chunn,

[29] Using Foucault’s conception of government, Rose (1999) articulates this concept as “all endeavours to shape, guide, direct the conduct of others…[that] also embraces the ways in which one might be urged and educated to bridle one’s own passions, to control one’s own instincts, to govern oneself” (p. 3). In other words, it entails the various schemes, programmes, techniques, and devices that shape people’s conduct to achieve a particular end (Rose, 1999).

2000). White, affluent women stood in place for respectability and thus the figure of the innocent victim to be protected because they represented "the reproductive insurance of the nation" (Chunn, 2000, p. 79). Women who did not occupy this position, as well as immigrants, racialized people, and people with low socioeconomic status were deemed undeserving and thus legitimate targets of the different modes of regulation (Buckley & McGinnis, 1982; Chunn, 2000; Mawani, 2006; Hoppe, 2018). However, as Mawani (2006) reminds us, efforts to control the spread of venereal disease were directed at all Canadians with 'deviant' populations –'foreigners', 'prostitutes', young single women, and working-class men – receiving harsher punishments aimed at eradicating the diseases. While there were considerable legal efforts made to reform 'deviants', public health and state officials invested in non-legal forms of intervention through education, "endeavouring to constitute 'moral subjects' who were white, middle class, able bodied, monogamous, and heterosexual" (Mawani, 2006, p. 171). These non-legal forms were predominantly targeted at the 'respectable' classes and aimed to "construct normative heterosexualities for men as well as women. […] [P]rescriptive literature was directed at (re)constructing and shaping moral subjectivities by encouraging decency and conformity among the public at large" (Mawani, 2006, p. 172). This very brief discussion about efforts to control venereal disease in Canada is not meant to be an in-depth historical analysis[30] of such campaigns,

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[30] For these kinds of historical analyses, see for example: Mawani, R. (2006). Regulating the "respectable" classes: Venereal Disease, Gender, and Public Health initiatives in Canada, 1914-35. In A. Glasbeek (ed.) *Moral Regulation and Governance in Canada: History, Context, and Critical Issues* (pp. 145-168). Toronto: Canadian Scholars Press; Chunn, D.E. (2000). A little sex can be a dangerous thing: Regulating sexuality, venereal disease, and reproduction in British Columbia, 1919-1945. In S.B. Boyd (ed.) *Challenging the Public/Private Divide: Feminism, Law, and Public Policy* (pp. 62-86). Toronto: University of Toronto Press; Hunt, A. (1999a) *Governing Morals: A Social History of Moral Regulation*. Cambridge: Cambridge University Press; Hunt, A. (1999b). The purity wars: Making sense of moral militancy. *Theoretical Criminology*, 3, 409-436; Buckley, S. and McGinnis, D. (1982). Venereal disease and public health reform in Canada. *The Canadian Historical Review*, 63(3), 337-354; Adams, M.L. (1993). In sickness and in health: State formation, moral regulation, and early VD initiatives in Ontario. *Journal of Canadian Studies*, 28(4), 117-130; Valverde, M. (1991). *In the Age of Light, Soap, and Water: Moral Reform in English Canada*. Toronto: McClelland & Stewart; Cassel, J. (1987). *The Secret Plague: Venereal Disease in Canada 1838-1939*. Toronto: University of Toronto Press.

but an example of the ways in which medico-moral-legal modes of regulation function to demarcate 'good healthy citizens' from 'bad, impure, diseased citizens' who threaten the health of the (white) body politic. As McGinnis (1990) argues, anti-venereal disease campaigns involved the identification of a scapegoat population ('loose' women and immigrants), the designation of a scapegoat activity (sex), and a general climate of moralizing – tendencies that continue under the dark cloud of HIV criminalization.

In the early days of the HIV/AIDS epidemic, it was predominantly stigmatized groups (e.g., intravenous drug users, sex workers, Africans, and gay men) that were subject to the gaze of criminal law (Buchanon, 2015), characterizing the politics of AIDS as "a politics of division, stigmatization, and moral blame" (Singer, 1994, p. 1321). For instance, early HIV media coverage claimed that Africa, or what they dubbed the "African green monkey" or the African swine", was the source of HIV (Cohen, 1999, p. 50). In one of the first books to critically think about Blackness and HIV, Cohen (1999) contends that any attempt to create alternative understandings of HIV, ones that did not construct HIV as a problem of only one group (white gay men) or a disease brought over by Africans, had to come from local sources of information within Black communities. Unfortunately, Black communities were becoming increasingly stratified during this time, which hindered their ability to create a unified fight against their disempowerment within the context of HIV. For instance, the response to HIV by many Black leaders and organizations in the early days of the epidemic led to processes of secondary marginalization, in which they replicated dominant discourses that divided marginal group members into 'worthy' and 'unworthy'. In some cases, these discourses were modified to distinguish the more vulnerable segments of African-American communities living with HIV

into ‘innocent victims’ of HIV and those whose ‘bad’ behaviour led to their infection; as Cohen (1999) writes,

> Characteristics such as class, gender, sexual orientation, geographical location, education, and even one’s relationship to welfare all *interact* with one’s racial identity to structure life choices. Without increased recognition of the broadening of identities through which people exist in and understand the world, traditional Black leaders and scholars may end up so out of touch with the differing experiences of multiple segments of Black communities that they fill no real function in their communities and thus are left to talk to themselves. (pp. 346-347)

Given that HIV/AIDS spread rapidly among gay men and men who have sex with men (MSM), it was primarily considered a disease of the gay body – that of “the distant and diminished Other” (Singer, 1994, p. 1323). This exceptionalism constituted HIV/AIDS as, what Treichler (1987/1989) famously termed, an “epidemic of signification” or the varying ways in which HIV/AIDS represented both a transmissible lethal disease and a social phenomenon characterized by a “chaotic assemblage of understandings” (p. 32): an illness created by the state to interfere in people’s lives and sexual practices; a gay plague; a plot to destroy homosexuals; god’s punishment for sin; and even that HIV/AIDS was created by the CIA as an exercise of biowarfare – an account that was largely circulated by the KGB (Treichler, 1987/1988). As Susan Sontag (1978) so eloquently writes,

> Nothing is more punitive than to give a disease a meaning—that meaning being invariably a moralistic one. Any important disease whose causality is murky, and for which treatment is ineffectual, tends to be awash in significance. First, the subjects of deep dread (corruption, decay, pollution, anomie, weakness) are identified with the disease. The disease itself becomes a metaphor. Then, in the name of the disease (that is, using it as a metaphor), that horror is imposed on other things. The disease becomes adjectival. Something is said to be disease-like, meaning that it is disgusting or ugly. (p. 58)

HIV/AIDS is attached to a myriad of metaphors, including that it is an invasion, pollution, contamination – these metaphors imbue a sense of shame and guilt in those living with the illness (Sontag, 1989) but also mark those infected as people to be avoided and punished for their

inability to care for themselves. Such an array of meanings results in confusion about how HIV is transmitted, how best to treat it, who can become infected, how it affects the body, and why the illness came about.[31] Adam (2006) calls these kinds of metaphors "semiotic snares":

> A semiotic snare is a message where a well-understood but unspoken subtext undermines the overt thrust of the message, unintended meaning that contradict overt messages, and safety messages that promote self-exemption, thereby allowing for more unsafe practices. […] When the categories of epidemiological research, which identify HIV risk in terms of types of sex and demographic groups enter into personal strategies of navigating risk in societies, they necessarily operate as a hierarchy of risk and safety, and cannot but become imbricated with widespread cultural binaries of clean and unclean, guilt and innocence, moral and immoral. (Adam, 2006, p. 175)

Discourses, metaphors, and semiotic snares operate as techniques and practices of medical, moral, and legal modes of regulation to constitute HIV/AIDS and those who live with the virus as 'morally depraved' and dangerous to the predominantly white, heterosexual, affluent body politic. As in the early anti-venereal disease campaigns, these modes of regulation are enacted most readily along lines of social location including gender, race, class, and sexual orientation.

In the next section, I discuss the responsibilizing rhetoric emerging from the public health strategy known as Treatment as Prevention (see below) whereby a moral imperative is imposed upon PLWH to diligently take their medications to prevent HIV transmission and by doing so, protect the wider HIV-negative body politic. This medical (by way of public health) and moral mode of regulation bifurcates PLWH into the good HIV-citizen who reaches and remains undetectable and the bad HIV-citizen who fails to adhere to their treatment plans and is thus detectable. Legal modes of regulation are enacted by punishing those who are not able to abide by this imperative.

[31] A prime example of this is the story of Gaëtan Dugas. See footnote 2 in the introduction for a more detail explanation of this origin story.

### 2.1.2. Emerging HIV Identities and Seropolitical Governance

Today, we see the distribution of medical, moral, and legal modes of regulation enacted through the criminalization of HIV nondisclosure, where biomedical discourses about viral load and undetectability and public health narratives about the moral imperative to adhere to treatment intersect with the law to outline what it means to be a 'good' HIV citizen.[32] The diffuse medical, moral, and legal modes of regulation coalesce in the criminalization of HIV nondisclosure by way of what Swiffen and French (2018) term a "*seropolitical* rationale of governance" (p. 554, emphasis in original) in which new medical knowledge and tools[33] are used to trace responsibility and assign blame:

> Similar to biopolitics, seropolitics involves the fusion of medical and legal forms of knowledge and power within logics of governance, but it is specific in also involving material access to and control of blood. Within a seropolitical logic, various apparatuses of criminal accusation surface. The phenomenon of HIV criminalization is one example. It is based on a criminal accusatorial apparatus that includes elements of public health systems of care and medical treatment of individuals living with HIV. In this sense, seropolitics involves hybrid criminal accusatorial apparatuses involving the fusion of medical and legal power over the individual and their blood. (p. 566)

In other words, people's blood is being used to determine, not only their guilt or innocence in the context of the law, but their ability to adhere to the imperative imposed by public health policies

[32] Redden (2002) argued that HIV is an issue for citizenship because the "rhetorical construction of disease is a reflection of the citizen-state relationship: who is included, who is excluded, who is privileged, who is disadvantaged, who is innocent, who is guilty. Thus, the politics of disease is a discourse of inequality, identity, rights, and responsibilities" (p. 370). Squire (2010) concludes that "the naturalising process of medicalization appears […] to allow HIV citizens to live, and to be a part of a wider citizenship – but also constrains them within often imperfect medical technologies… HIV citizenship operates in a very particular context, characterized by the virus's fatality, medical intractability, stigmatization and social embeddedness" (p. 422).

[33] In the *Mabior* (2012) decision discussed in the introduction, the SCC used a report prepared by an expert physician on the different risks of HIV transmission, such as vaginal sex without a condom and when the PLWH has a low viral load, expert testimony from a public health nurse, and various scientific studies attesting to the risk of transmission. These medical and epidemiological knowledges were mobilized by the SCC to determine the current legal standard that PLWH do not have to disclose if they wear a condom and have a low viral load. Tools like phylogenetic tests, where the blood given by PLWH during healthcare appointments is analyzed (without their consent) for genetic similarities between the HIV subtypes of the accused and that of the complainant, are inc (Swiffen & French, 2018).

that suggest taking one's medications as the morally right thing to do to prevent onward transmission of HIV. As such, this seropolitical rationale of governance is occurring at the same time that HIV is becoming normalized in the 'Treatment as Prevention' (TasP) era, with medications transforming HIV into a chronic and manageable illness and leading to narratives about a 'post-AIDS world' (Lloyd, 2018; Squire, 2013, 2010; Walker, 2019, 2020).

The public health strategy TasP was first conceptualized in a paper by Dr. Julio Montaner and his colleagues in *The Lancet* in 2006 to theorize using antiretroviral therapy as a preventative tool at the population level. It later entered broader public discourse via the Swiss National AIDS Commission in 2008, in a report known as the "Swiss Statement," which, for the first time, specified that people living with HIV who regularly take their medications and have a sustained undetectable viral load are not sexually infectious, as long as they do not have another sexually transmitted infection (Vernazza et al., 2008 as discussed in Lloyd, 2018, p. 471). The notion of TasP and the "Swiss Statement" eventually led to the UNAIDS (2018) declaration and the now commonly used turn of phrase, U=U or undetectable equals untransmittable, to signal that PLWH who adhere to antiretroviral therapy and have an undetectable viral load are at a 'negligible' risk of sexually transmitting HIV.[34] These biomedical innovations have made it possible to think about a 'post-AIDS world' or an 'AIDS free generation', what Squire (2013)

[34] Since the discovery that taking ARVs prevents HIV transmission, prominent organizations like the BCCFE have promoted the increased use of TasP (Guta, Murray, et al., 2016). The BCCFE launched the 'Seek and Treat for Optimal Prevention of HIV/AIDS' (STOP HIV/AIDS) program to expand HIV testing and treatment through various partnerships with public health and housing that would support the retention of people in care (Johnston, 2013). This program involves actively searching for people who have fallen out of care or "at-risk" individuals to engage them in testing and treatment, thereby entering them into public health databases for follow-up counselling, treatment, and partner contact tracing (Guta, Murray et al., 2016). In other words, intensifying the surveillance over PLWH and those deemed to be "risky" such as people who use drugs, sex workers, men who have sex with men etc. (Guta, Murray et al., 2016). These kinds of programs and TasP more broadly, have been critiqued for focusing too much on getting everyone on treatment while neglecting to provide the best possible healthcare for people and for hiding the deeply problematic truth that many people are coerced into unnecessary treatment that could cause them to suffer from side effects (Strub, 2010).

terms the “naturalisation” position in that it assumes that “AIDS will disappear, and that HIV will become a regular, natural part of the biosocial order of things, still difficult, but no longer to be seen in catastrophic terms” (p.13). Yet, Canada has seen an increase in new HIV cases by 24.9% from 2021 (PHAC, 2024), thus challenging the success of TasP (Nguyen et al., 2011).

Squire (2010) describes three interlinked processes involved in HIV’s naturalisation: medicalisation, normalisation, and marketisation. She contends that these processes transform the virus “into something universal, permanent, and incorporated into biological, social and political relations—although still with the trace of otherness that any ‘naturalised’ condition carries” (Squire, 2010, p. 404). Regarding the first process, medicalisation, Squire argues that HIV treatment technologies and practices constitute a medicalised field, allowing PLWH to live longer lives, feel healthy, and to understand HIV as just another part of life. However, these medicalised discourses and practices overshadow non-medical aspects of living with HIV and underplay the limits of medical knowledge. She argues that people living with HIV “are always citizens in relation to this viral condition, obliged to live within the pandemic but also enabled by this definition to take action as biological HIV citizens” (Squire, 2010, p. 407). HIV’s normalisation functions as a moral imperative and expectation that constitutes PLWH as self-regulating, healthy citizens; “they are expected, and expect themselves, to be citizens like any others, able and obligated to live healthily, work and love” (p. 408).

Lastly, HIV citizens can become naturalised through their assimilation into modern systems of consumption. By replacing the knowledge-driven focus of medicalisation and the ideology-driven focus of normalisation, marketisation transforms individuals into “manageable packages of buyable, sellable elements” (Squire, 2010, p. 411). As Squire (2010) argues, “living with HIV is … part of broader consumption economies …. [where] citizenship is constructed

through sets of responsibilising discourses and practices, including particular forms of thinking and feeling, as well as action, that can be bought or bought into" (p. 412). Scholars are critical of naturalisation because it disappear the complexities of living with HIV and has resulted in shifts in HIV identities and notions of risk and responsibility (Gagliolo, 2021; Guta, Murray et al., 2016; Guta, Gagnon, et al., 2016; Lloyd, 2018; Manning, 2016, 2020; McSwiggin, 2017; Mykhalovskiy, McCoy et al., 2004; Nguyen, 2008; Persson, 2013; Race, 2001; Squire, 2010, 2013; Young et al., 2019; Walker, 2020; Wong & Usher, 2008). Squires (2010, 2013) also examines how HIV is simultaneously denaturalised, such as in low-resourced contexts where access to treatment is limited, the physical effects of living with HIV and taking medications, and the psychosocial impacts of living with HIV. These particularities she contends, are often left behind in narratives of HIV's naturalisation (Squire 2010, 2013). I take these critiques up in the next two subsections.

The literature on how health and illness are experienced is too vast to provide a detailed review. Instead, I focus my attention on the notion of biographical disruption to articulate how HIV is experienced. After a brief discussion of how the concept has evolved since Michael Bury first introduced it, I review the literature that mobilizes biographical disruption in regard to HIV and which complicates ideas about HIV as a 'normalized' virus.

### *Biographical Disruption and the Particularities of Living with HIV*

Narratives about a 'post-AIDS' world in which HIV has become a normalised part of life, are "fraught with contradiction—it is a language of seeming possibility—biomedical, political and social" – and it is a narrative that remains at odds with the embodied and structural experience of living with HIV and AIDS (Walker, 2020, p. 95). As Manning (2020) contends, TasP has all but disappeared people's choice to test for and engage in HIV treatment in that "HIV testing under

TasP is often done without a person's explicit consent, through routine testing protocol which subsumes HIV testing under regular bloodwork, and with little to no pre-testing counselling" (p. 249). Under TasP, the short- and long-term effects of treatment are downplayed if not completely refuted because "prevention supersedes the quality of life for people living with HIV" (p. 249). Squire (2013) thus prefers to talk about HIV's "particularities" in that living with HIV is complicated and often intersects with other aspects of people's lives. Living with HIV means coming up against constant disruptions that affect one's body, familial relationships, work situations, and one's personal and social identities.

In 1982, Michael Bury first conceptualized the notion of biographical disruption to explain how chronic illness creates a rupture in the structure and understanding of people's daily lives, including their sense of self and relationship to their body, family, and wider social networks. He contends that there are three aspects to the disruptive effects of chronic illness. First, there is a disruption of past ways of being, including bodily performance and help-seeking (Bury, 1982). Second, there is a disruption in the person's explanatory systems such that there is a "fundamental re-thinking of the person's biography and self-concept" (Bury, 1982, p. 169). Lastly, disruptions occur to various social and material resources that people rely on to live out their lives (Bury, 1982). This concept enables us to move beyond thinking about illness in solely medical or biological ways. Instead, it forces us to put illness into context, considering it in relation to broader life experiences and trajectories (Kilty & Orsini, 2021).

Since Bury's initial formulation of this concept, several others have mobilized it in relation to breast cancer (Trusson et al, 2016), end-stage kidney disease (Cluley et al., 2023), chronic obtrusive pulmonary disease (Lippiett et al., 2021), inflammatory bowel disease (Saunders, 2017), ménière's disease (Bell et al., 2016), stroke (Faircloth et al., 2004) and HIV

(Carricaburu & Pierret, 1995; Orsini & Kilty, 2021; Wells et al., 2023; Wouters & de Wet, 2016). Many of these same scholars have also articulated different conceptualizations of biographical disruption in light of their critiques of Bury's initial formulation. There are those who contend that biographical disruption is a process and can re-occur throughout one's life with chronic illness, particularly those illnesses which come and go in episodes or flare-ups (Bell et al., 2016; Cluley et al., 2023; Lippiett et al., 2005; Saunders, 2007). For example, writing about people who are experiencing end-stage kidney disease, Cluley et al. (2023) developed the notion of *biographical dialectics* to position chronic illness as not something that is disruptive once a person is diagnosed but that it is a continually disruptive and changeable experience that people with chronic illness must learn how to negotiate. Using a dialectics approach, they challenge the binary between life before and after illness, instead arguing that contradiction can be productive, which is evidenced by how their participants "could not have [life before ESKD] without [life with ESKD], they exist because of each other" in an ongoing and cyclical process (Cluley et al., 2023, p. 7). Similarly, Saunders (2017) offers the concept of *recurrent biographical disruption* to explain how disruptions can be experienced at different times throughout young people's lives with inflammatory bowel disease.

Others argue that biographical disruption is mediated by context, including a person's age, class, gender, race, illness history, specific illness, timing, expectations, and previous difficult life situations such that illness experiences may become continuous or reinforced (Carricaburu & Pierret, 1995; Faircloth et al., 2004; Sinding & Wiernikowski, 2008; Tan, 2018; Williams, 2000). Faircloth et al.'s (2004) notion of *biographical flow* and Williams' (2000) *biographical continuity* show how illness becomes integrated within existing biographical trajectories. In a study of older people with late-stage kidney disease, Llewellyn et al. (2014)

described how receiving a diagnosis later in life, particularly if already touched by illness, did not lead to biographical disruption but rather a continuity of their biography. Temporality thus becomes an important dimension in how biographical disruption is experienced. Introducing the concept of *biographical oscillation*, Bell et al. (2016) contend that "health and wellbeing exist as a continuum that we oscillate along as our roles, responsibilities, priorities and capabilities shift with different life events and transitions" (p. 184). They argue that at certain moments in life, we may fall further towards illness, which can be temporary, or it may become permanent at which point people must adjust their "way of being, doing, feeling and thinking in the world" (Bell et al., 2016, p. 184). Studying people who were diagnosed with Autism Spectrum Disorder (ASD) later in life, Tan (2018) uses the term *biographical illumination* to describe "a transformed conception of self that is facilitated by but extends beyond medical meaning and context, enriching personal biography and social relationships. The self is not negotiated; rather, through a medical framework, it is cultivated and refined" (p. 161). Being diagnosed with ASD allowed Tan's participants to see themselves with greater clarity as the diagnosis gave them a different explanatory system for their atypicality (Tan, 2018). Tan's (2018) study exemplifies the particularities of how biographical disruption can play out, sometimes not leading to negative consequences for the person.

There is a large body of work that explores biographical disruption in the context of HIV/AIDS (Alexias et al., 2016; Campbell, 2021; Carricaburu & Pierret, 1995; Ciambrone, 2001; Orsini & Kilty, 2021; Wells et al., 2023; Wouters & de Wet, 2016). This literature shows that HIV is anything but normal and, in fact, is often experienced as a disruptive event to people's biographical lives, to varying degrees and depending on other life circumstances,

including experiences with violence and substance use, and one's gender, race, and socio-economic status (Ciambrone, 2001; Wells et al., 2023; Wouters & De Wet, 2016).

Studying the experiences of PLWH, Carricaburu and Pierret (1995) introduce the concept of *biological reinforcement* to describe how people diagnosed with HIV reinterpret their identity and in the process, reinforce "components of identity that, prior to HIV-infection, had already been built around haemophilia or homosexuality" (p. 85). For example, an HIV diagnosis for haemophiliacs is integrated within a lifelong illness experience and may disturb any sense of normalcy they had worked hard to build (Carricaburu & Pierret, 1995). On the other hand, for gay men, this new illness experience may re-affirm their individual and collective, personal and political struggles as gay men. In this sense, the illness experience is shared such that "being HIV-positive is not just a matter of being individually infected: it is also a question of being affected as part of a group that has its own history and has been decimated by AIDS" (Carricaburu & Pierret, 1995, p. 86).

Many people living with chronic illness face disruptions at work as they manage their symptoms, including the side effects of taking new medications and job discrimination (Frank, 1995/2013; Kleinman, 1988/2020; Liu, et al., 2012; Perri et al., 2021). Wells et al. (2023) show how PLWH felt their HIV diagnosis was a disruption to their future plans with regard to work and migration opportunities, making their future less certain.[35] In response to this disruption, PLWH often get involved in the HIV community, either in advocacy, in AIDS Service

[35] PLWH diagnosed earlier in the epidemic faced job loss because of HIV-related stigma as employers were allowed to lay people off because they were HIV positive. This only changed in 1989, when the Canadian Human Rights Tribunal ruled that the Canadian Pacific train company had discriminated against Gilles Fontaine because of his illness (Clément, 2016). Although it is now illegal to fire someone because they are living with HIV, HIV related employment disruptions continue to affect PLWH. Medication side effects or if newly diagnosed, the symptoms of seroconverting, may lead to job loss because people take time off work to manage their symptoms, potentially missing important deadlines, and/or working at a slower pace (Ontario HIV Treatment Network, 2016). Indeed, 45-65% of PLWH are unemployed or on some form of disability (Ontario HIV Treatment Network, 2016) compared to only a 6.6% unemployment rate for the general population in Canada (Statistics Canada, 2025).

Organizations working to support others living with HIV (Gould, 2009), or alongside academics working as peer researchers (Greene et al., 2009). This advocacy work becomes part of the support mechanisms people mobilize to help "lessen the blow of HIV/AIDS", allowing them to incorporate the diagnosis within their illness trajectories (Ciambrone, 2001, p. 514). As Wells et al. (2023) found, when PLWH were able to integrate their diagnosis within their biographies, they felt an improvement in their health and that HIV provided them with opportunities for personal and emotional growth.

Exploring the embodied experience of living with HIV/AIDS, Alekias et al., (2016) found that PLWH had a generalized negative body image as a result of physical changes brought on by HIV and the side effects of medications, subsequently feeling a loss of control over their body. This changed perception made them feel alienated from their bodies, precipitating a transformation in their sense of self (Alekias et al., 2016). Medically, HIV weakens the immune system, making PLWH vulnerable to opportunistic infections. These infections can be life threatening and can disfigure the body in visible ways. For instance, in the early days of the epidemic and prior to the advent of HAART, the most prominent infection was HIV-related wasting and a form of skin cancer, Kaposi's sarcoma, images of which became the identifying markers of AIDS in the 80's (Persson, 2004). Although the advent of HAART, now more commonly referred to as antiretroviral drugs (ARV) or antiretroviral therapy (ART), saved lives and helped reconceptualize HIV as a chronic but manageable illness, the medications came with several side effects (Andany et al., 2011; Carr & Cooper, 2000; Hulgan, 2018; Quatrem et al.,

2017; Umeh & Currier, 2006).[36] As Persson (2004) argues, "drugs [are] *embodied* processes […] [with the] capacity to reconfigure bodies and diseases in multiple, unpredictable ways" (p. 46).

PLWH do not always feel their HIV diagnosis is the most disruptive event when faced with complex life histories (Kilty & Orsini, 2021). For example, women living with HIV face violence from partners when disclosing, experiences of sexual assault, problematic substance use and living in poverty which may be factors in how they acquired HIV, and are sometimes separated from their children either by choice or forced removal of children from the home (Ciambrone, 2001; Wouters & De Wet, 2016). HIV continues to be disruptive in the lives of PLWH because they experience HIV stigma regardless of new biomedical technologies that make HIV undetectable in people's blood, rendering PLWH blameworthy for their illness, unworthy of support, and people in need of regulation and control (Earnshaw & Kalichman, 2013; Logie et al., 2011; Moyer & Harden, 2014; Squire, 2013; Woodgate et al., 2017). It also continues to be disruptive because of the continued criminalization of HIV worldwide (Hastings et al., 2022; HJN, 2022), the associated media coverage of these cases, which mobilizes racist, sexist, and stigmatizing rhetoric to describe the accused (Kilty & Bogosavljevic, 2019; Hastings, Mykhalovskiy et al., 2020; McClelland, 2024; Mykhalovskiy, Hastings, et al., 2016; Mykhalovskiy, Sanders, et al. 2021), and the legal and other forms of violence and surveillance that criminalization brings about for people who are criminalized for HIV nondisclosure (McClelland, 2019; 2024). Kilty and Orsini (2021) show how biographical disruption for PLWH

[36] These include fatigue, muscle wasting, hypertension, heart disease, and nerve damage (peripheral neuropathy) that results in things like numbness, liver damage, pancreatitis and bone disease, abdominal cramping, lipodystrophy syndrome which manifests itself as fat loss (lipoatrophy) and/or central fat accumulation (lipohypertrophy), rashes, gastrointestinal issues such as diarrhea, nausea, and vomiting, insomnia dizziness, depression, memory problems, sexual dysfunction, and diabetes (Carr & Cooper, 2000). Research shows that there are gendered and raced/ethnic differences in the prevalence, manifestation, severity, and pathogenesis of some of these adverse events (Andany et al., 2011; Umeh & Currier, 2006). For instance, Andany et al. (2011) found that Black women are most vulnerable to lipodystrophy and particularly lipohypertrophy when taking certain antiretrovirals.

must be negotiated within the context of the medico-legal borderland brought on by the criminalization of HIV nondisclosure, which has hailed in a new 'regime of truth' about the "duties and obligations necessary to live an ethical and moral life as a HIV-positive subject", contributing to the creation of new categories of HIV citizens (p. 1140). They argue that criminalization has framed PLWH as morally and ethically risky subjects, where "the existence of 'irresponsible' sexual citizens" is only possible with the simultaneous creation of 'ideal' HIV subjects who *always* practice disclosure" (p. 1142). Next, I discuss how biomedical innovations have led to the creation of new HIV identities, bifurcated into those whose viral load are undetectable and those whose are not.

***New HIV Technoscientific Identities***

Earlier in this section (2.1.1) I showed how in advanced liberal democracies, marked by neoliberal political rationalities, there was a shift from more negative and coercive forms of 'self-control' to a more positive concern for 'self-formation' (Hunt, 1999a; Rose, 1999, 2007). Rose (1999), building on Foucault's work on biopolitics, names this shift in our modern epoch as an "ethopolitics," which entails the shaping of conduct via ethics or the "*self-techniques necessary for responsible self-government* and the *relations between one's obligation to oneself and one's obligations to others*" (emphasis in original, p. 188). He contends that ethopolitical concerns are organized around vitalism or the value given to life itself. However, linking discussions about inequality with biopolitics shows that ethopolitics is not just about the value of life, but also the values and meanings given to *particular* lives (Marsland & Prince, 2012) – what Fassin (2009) calls biolegitimacy. Under a seropolitical regime of governance and the naturalisation of HIV, biolegitimacy plays out in that reaching an undetectable status marks one in opposition to those who remain detectable, exacerbating existing inequalities within the

HIV/AIDS community (Guta, Murray, et al., 2016; Guta, Gagnon et al., 2016). With the criminalization of HIV nondisclosure, undetectability becomes evidence of the highest standard of self-governance – something one must continually strive for.

Using a primarily Foucauldian approach, scholars have articulated how biomedical interventions, such as viral load testing and antiretroviral therapy, undetectability, and medical and public health knowledge about HIV, are reshaping HIV subjectivities and risks in different ways (Gagliolo, 2021; Guta, Murray et al., 2016; Lloyd, 2018; McSwiggin, 2017; Nguyen, 2008; Persson, 2013; Race, 2001). Race (2001) argued that even though viral load testing offered a sense of relief for people who are HIV-negative and functions as a risk management tool for PLWH, these technologies have a profound impact on how people understand themselves and their relation to others. He contends that predictive tests generate a process of "medical identification," producing individuals as a unit of risk (Race, 2001, p. 9). This leads to the creation of "new socio-sexual classes – categories within the traditional 'risk' categories, such as the HIV positive, those with detectable virus, and those with drug-resistant virus" (Race, 2001, p. 9).

More recently, Lloyd (2018) argued that undetectability is a technoscientific identity that emerges from the increasing biomedicalization of life. Lloyd (2018) mobilizes the theoretical framework of biomedicalization, which evolved from Conrad's (1992, 2005, 2007) notion of medicalization. Conrad (1992) emphasized the importance of understanding the social processes involved in the construction of medical knowledge, how things come to be known medically, who has the ability to define a problem in medical terms, and the repercussions of knowing something medically. For instance, when we define a problem medically, it becomes susceptible to medical surveillance, a form of social control in which certain conditions or behaviours fall

under what Foucault (1973) termed the "medical gaze" (p. 9). Medicalization is marked by increasing uses of biotechnology, the transformation of patients into consumers, and corporatized medicine and managed care (Conrad, 2005). Clarke et al. (2003) argue that medicalization is intensifying and being transformed, as "largely technoscientific changes in biomedicine are now coalescing into what [they] call *biomedicalization*" (p.162). They contend that under biomedicalization,

> …health itself and proper management of chronic illness are becoming individual moral responsibilities to be fulfilled through improved access to knowledge, self-surveillance, prevention, risk assessment, the treatment of risk, and the consumption of appropriate self-help and biomedical goods and services. Standards of embodiment […] are now transformed by new corporeal possibilities made available through the applications of technoscience. (Clarke et al., 2010, p. 48).

In other words, biomedicalization leads to emerging technoscientific identities wherein science and technology are increasingly applied to "our bodies directly, to our individual and collective histories, and/or to bodily products such as blood, DNA samples or images" (p. 80).

Biomedical interventions used to manage HIV, which are advertised in HIV education and prevention literature as heroes that save the day, have come to mediate the practices that people engage in to "make themselves up as particular subjects" (Lloyd, 2018, p. 472):

> 'Being undetectable' is not only the so-called 'new face of HIV', but is critically, a new mode of technoscientific subjectification. The transformation of the self through the consumption of antiretrovirals in order to achieve a particular biomedical state, 'virally suppressed', is productive not only of emergent identities and social categories, but also new expectations for the performances of biomedical engagement, the very modes of subjectification, that bring into being these identities (Lloyd, 2018, p. 488).

Being undetectable then becomes presented as a prized biomedical ideal that people can and should organize themselves around, both individually and collectively (Guta, Murray et al., 2016; Lloyd, 2018). Being undetectable has, therefore, gone past its original intention of assessing viral suppression, instead developing as a moral project that reveals social fractures

along virological and social lines (Guta, Murray et al., 2016; McSwiggin, 2017). As Colvin et al., (2010) argue, if creating responsible citizens is experienced through technologies of treatment and surveillance, the concern is how pharmaceuticals and political subjectification become covertly connected, leading to a possible "mis-reading of the political effects of 'neutral' state practices like public health" (p. 1180).

Those who are unable to attain an undetectable status are framed as irresponsible and immoral and thus are excluded from full biological citizenship,[37] while those who reach and maintain an undetectable status are constructed as responsible and thus worthy of full citizenship and all the rights and obligations it bestows (Guta, Murray et al., 2016; Pienaar, 2016). The work of biopower is most readily evident in the way that HIV naturalization is generative of new identities distinguished along biomedical, racial, and viral lines (Lloyd, 2018; McSwiggin, 2017; Pienaar, 2016), which has important material implications for PLWH. Speaking specifically about Black people living with HIV in Canada, Odhiambo et al., (2023) described how their participants understood undetectability as an institutionally dominant discourse that privileges white people who can consistently engage in care, adhere to ART, and achieve viral suppression while failing to acknowledge the lived realities of Black people that make such things more difficult to attain. In their study, Black participants talked about structural barriers such as having a precarious immigration status, housing and employment precarity, and the lack of health insurance and drug coverage as contributing to uncertainty in reaching undetectability. Their

[37] Rose (2007) defines biological citizenship as a set of ideas and practices requiring individuals to continually monitor and enhance their health. He contends that it is both individualizing and collectivizing. It is individualizing in the way that "the responsibility for the self now implicates 'corporeal' and 'genetic' responsibility: one has long been responsible for the health and illness of the body, but now 'somatic individuals must also know and manage the implications of one's own genome" (p. 134). It is collectivizing in the way that biosocial groupings or collectives are created "around a biological conception of a shared identity [which] have a long history" in medical activism where people refuse to be seen as mere patients (p. 134). Notably, both the individualizing and collectivizing aspects of biological citizenship are organized within the field of hope (Rose, 2007), an emotion I explore in depth in Chapter 6.

participants described how undetectability produces class and racial differences by categorizing PLWH as good versus bad patients and expressed their fears about criminalization, given the structural inequities that make reaching undetectability difficult for Black PLWH (Odhiambo et al., 2023). In short, with the bifurcation of HIV identities into undetectable and detectable under a seropolitical regime of governance, where legal and medical knowledges converge, PLWH are at the center of medico-moral-legal modes of regulation. They are responsibilized to take care of their health and the health of others through treatment adherence, while structural barriers that hinder undetectability are framed as personal moral failings, justifying criminalization (Guta, Murray et al., 2016).

PLWH are not, of course, without agency; they actively negotiate emerging technoscientific identities, biomedical technologies and discourses, and HIV's normalization in different ways. While AIDS-related deaths have dropped due to the availability of effective treatments, the quality of life that PLWH experience is complex as they find manage the challenges of living with a disease for which there is no cure (Wong & Usher, 2008). For example, PLWH describe having an undetectable viral load as regaining control over the HIV circulating in their blood and removing fears and anxieties around transmitting HIV to sexual partners, but it did not always improve psychosocial well-being (Wells, Philpot et al., 2023). PLWH still feared disclosing to sexual partners, and strictly adhering to treatment protocols served as a constant reminder of past experiences, which led to decreased mental well-being (Wells, Philpot et al., 2023).

For PLWH, health is understood and constructed in relation to medical technologies, alternative health models, social location, and bodily experience (Persson et al., 2003). Health and illness are always challenged as opposed to coherent and are evolving and changeable rather

than sedimented (Persson et al., 2003). PLWH have a “certain creative capacity to negotiate bodily symptoms and medical technology and make meaningful connections (or dis-connections) between these markers of health, a capacity honed by living in a society where all things bodily are continually and diversely thematized” (Persson et al., 2003, p. 411). In other words, PLWH are able to innovatively explore, construct, reject, resist, or combine different understandings of health, illness and biomedical technologies that will “support their wellbeing, that empower their choices and their sense of control over their lives” (Persson et al., 2003, p. 411). Indeed, for older people living with HIV, ‘old’ narratives that are saturated with despair and distress often parallel narratives of productivity and potential made possible by the biomedicalization of HIV (Walker, 2019). This suggests that new technoscientific identities are not always readily taken up with such gusto by PLWH (Persson, 2013). Indeed, PLWH make sense of these normalizing and biomedical discourses within the histories of HIV, resisting or implementing them in relation to their own experiences (Persson, 2013). For example, being responsibilized citizens through adherence to treatment for PLWH in South Africa, meant not just “caring for the self” but also “caring for the social” by way of political activism and community engagement (Colvin et al., 2010, p. 1180).

The next section introduces the field of critical victimology as a framework for understanding the ways in which moral and legal regulation modes of regulation operate to configure notions of ideal and non-ideal victims, guilt and innocence, and victims and perpetrators.

## 2.2. Critical Victimology

Prior to the 20$^{th}$ century, there is a notable absence of information on victims of crime (Fattah, 1989, 2000) because criminological research focused on those causing harm. Victimology

emerged in the post-World War II era in response to the brutalities of the Holocaust and as a corrective to criminology (Spencer & Walklate, 2016, 2018); as a subdiscipline it can be broadly divided into two models (Francis, 2017). The orthodox model derives its ideas from mid-20th-century positivism, conceptualizing victims through the law and mobilizing concepts of risk, lifestyle, and vulnerability to explain victimization (Francis, 2017). The revisionist model rose from the 1970s onwards and is informed by radical, feminist, and other critical ideas that challenge positivist assumptions about victimization through the use of concepts such as power, politics, and representation (Francis, 2017).

Positivist victimological research focuses on defining victimhood through psychological typologies and the concept of "victim precipitation" (and its many iterations), or the idea that victims could in some way initiate their own victimization (Francis, 2017). These victimologists are concerned with identifing the characteristics that render people more vulnerable to victimization. For example, Mendhelson (1958, 1976), who is known as one of the fathers of victimology, worked from a legalistic perspective and developed a typology based on the notion of 'victim culpability'. His typology included the completely innocent victim, the minor guilty victim, victims who were as guilty as the offender, victims who were more guilty than the offender, and an offender who then becomes a victim through acts of aggression, this last point signifying the most responsible and thus guilty victim (Mendelsohn, 1958 as cited in Francis, 2017). von Hentig (1948), also a founding scholar in the field, likewise focused on identifying victim-prone personalities, arguing that victims contribute to the genesis of crime. Identifying

types of victims based on their psychological makeup[38], he argued that the production of victims and offenders is a mutually constitutive process.

Both Mendelhson's and von Hentig's work is critiqued for methodological flaws in that they had incomplete data, and the typologies were speculative rather than based on robust empirical analysis (Francis, 2017). Positivist approaches in victimology are also critiqued for blaming the victim, facilitating a "weapon of ideological oppression" (Mawby & Walklate, 1994, p. 9; Rock, 2018; Spencer, 2015), defining crime as it is "conventionally understood", neglecting to include crimes committed by corporations, and its focus on interpersonal violence (Walklate, 1990, p. 26). Positivist victimology failed to adequately consider the socio-political and cultural powers at play when identifying victims and how we respond to victimizing events (Miers, 1989, 1990). For instance, the political alignment of victims' rights groups has helped to place certain victims at the centre of criminal justice policy-making (Stanbridge & Kenney, 2009), which solidifies definitions of victimhood through a predominantly legal framework. The focus on interpersonal forms of violence has made positivist victimology a close companion to conservative politics, leading to increases in retributive forms of justice offered in the name of victims (Godfrey, 2018; Fattah 1992a, 1989; Mawby & Walklate, 1994; Walklate, 2005, 2016). The alignment between punitive politics and the victims' rights movement has also led to a theoretical deficit such that we rarely question what it means to be a victim or how it is that one

[38] Victim types include the depressed victim who is indifferent to self-preservation and whose physical slowness makes them easier to catch; the acquisitive victim whose "greed can be hooked by all sorts of devices" making it easier to lure them "away from the moral supports of his home and his usual surroundings"; the wanton victim who deliberately makes herself a victim; the lonesome victim who is an easy target because the wrongdoer assumes no one will come looking for them; the heartbroken victim who is easy to exploit in their state of grief and sadness; the tormentor who was once the victim of abuse and who becomes an abuser; the blocked victim who is helpless and cannot fight back; the exempted victim that is disqualified especially in property crimes; and fighting victims who resist their aggressors and in doing so aggravate the situation (von Hentig, 1948, pp. 419-438).

comes to identify as a victim (Rock, 2002, 2018; Quinney, 1972; Walklate, 2007, 2011, 2016). This gap in knowledge is what revisionist victimology tries to fill.

The revisionist model of victimology is primarily concerned with the victimization of people by the state and its associated institutions, corporations, the spaces in which victimization occurs – including those that are conventionally ignored (e.g., the home), the impact of marginalization, globalisation and structural relations on crime and victimization, and the power and politics of representation (Francis, 2017). For instance, Miers (1990) called for a critical victimology that explores how we recognize individuals as victims, who has the power to apply this label, the impact of this labelling process, and the social functions of victimization. For Walklate (1990), critical victimology must also include feminist calls to recognize the material reality of women's and children's (but also other's) structural positions. Specifically, she articulates four processes that must be a feature of a critical victimology:

> First, human beings actively construct and reconstruct their daily lives. Such constructions reflect both the strategies of resistance and acceptance (the constraining and enabling effects of structure) of their social reality. […] Second, it proposes the existence of generative mechanisms (both unobserved and unobservable) that nevertheless have a real impact on individual's lives. Third, these processes have both intended and unintended consequences. Fourth, these consequences feed back into the knowledgeability of actors (their capabilities) to construct further responses to a situation. In this way, it is the duality of structure operating through time and space that becomes the theoretical framework for empirical investigation. (pp. 32-33)

According to Spencer and Walklate (2017), critical victimology challenges conventional, positivist victimology in three ways: "contestation over the ontological and epistemological basis of victimization; state and corporate victimization, especially in relation to green crimes; and victim blaming, particularly as it pertains to female victims" (pp. xiii-xiv). As such, a critical victimological approach is concerned with understanding processes that render some victims visible while making others invisible (McGarry & Walklate, 2015). It recognizes that victims are

people who can be active agents as well as passive, with their suffering mediated by power and choice (McGarry & Walklate, 2015). This framework interrogates the word 'victim' itself and the ways in which it is applied or not by focusing on underlying power relations that seek to (re)produce harmful binaries (McGarry & Walklate, 2015). It starts from the position that the "power of the victim label, in and of itself, [is] a unifying device (and frequently used as a uniform concept) for ideological purposes that has inclusive and exclusive properties" (McGarry & Walklate, 2015, p. 14). This project is situated within the critical victimological framework as it attempts to understand how people relate to the word victim in the context of the criminalization of HIV nondisclosure.

In the next section, I explore the different bodies of knowledge (i.e. legal, psychiatric, and feminist) that coalesce to construct particular understandings of victimhood. I examine the historical origins of the word victim, the politics of victimhood, the notion of psychiatric victimology, and the ongoing debate about victim and survivor language.

### 2.2.1. Normalizing 'The Victim' in Law and Psychiatry: On Legal and Psychiatric Victimhood

In this section, I take up Paul Rock's (2002) concern with how one "becomes a victim" or can be made a victim. He asks, "when and with what consequences does a person understand himself or herself to have *become* some existential entity called a victim?" (p. 19). He defines the victim as an identity that is crafted out of an interactive process between people and institutions. He contends that a victim is,

> …a social artefact dependent, at the outset, on an alleged transgression and transgressor and then, directly or indirectly, on an array of witnesses, police, prosecutors, defence counsel, jurors, the mass media and others who may not always deal with the individual case but who will nevertheless shape the larger interpretative environment in which it is lodged. (p. 14)

Rock was particularly concerned with the array of meanings ascribed to victims; notably, that victim can be both a negative term conveying meanings of weakness, loss, and pain and a positive term that includes the availability of certain benefits including sympathy, attention, being treated as blameless, financial compensation, exemption from prosecution, and mitigation of punishment among others (Rock, 2002). For Rock (2002), becoming a victim means occupying a "privileged moral place [with] a history, a present, and a future" in a world where people compete to earn the victim title (p. 15). As such, the term is not only used to describe someone who has been harmed but is also a political tool, lending moral capital to those who claim it as a resource and a status (Fassin & Rechtman, 2007; Meyers, 2011; Walklate, 2005, 2007).

In what follows, I discuss the ways in which victims come to be known through legal, psychiatric, and feminist narratives. I call the kind of victimhood that emerges from these narratives 'legal victimhood' and 'psychiatric victimhood' or the legally and psychiatrically ascribed and recognized victim. Dispersed within these discussions, I include literature about how people experience victimhood, including how they resist, take up, or alter this subject position.

***Recognizing Victims Through Law: Distinguishing Ideal and Non-Ideal Victims***

Critical victimologists have argued that the victim is a social construction (Quinney, 1972) and a social status that is attributed to a person according to certain formal and informal rules (Strobl, 2004). Strobl (2004) argued that if one is to acquire the status of a victim, one must first identify themselves as a victim and then display their suffering and victimhood in a way that complies with what and who is considered an ideal victim. This includes requiring the victim to dispense with any individualistic ideas about justice and instead choose the law as the mechanism through

which to seek redress (Strobl, 2004). The victim is thus expected to understand their experience through the law, to suppress their own needs to help with the prosecution of the person who harmed them, and therefore to cooperate with the police, courts, and other criminal justice institutions (Strobl, 2004). Cole (2007) similarly argues that a cult of 'true victimhood' permeates American culture, limiting who can make such claims. She identifies a true victim as someone who is noble and therefore refuses to complain publicly or display weakness, takes responsibility for their fate, has personally experienced harm and therefore cannot be a victim by affiliation, and is innocent because they have not contributed to their injury, and are morally upstanding (Cole, 2007).

Nils Christie (1986/2018) famously conceptualized the term "ideal victim", arguing that 'victim' is not an objective category and that regardless of how victims are socially and culturally constituted, the person harmed defines the situation based on their experiences and social location. He described the ideal victim as a "category of individuals who – when hit by crime – most readily are given the complete and legitimate status of being a victim" (Christie, 1986/2018, p. 12). The attributes he assigned to the "ideal victim" include: being weak, sick, old, and very young; the victim was engaging in activities at the time of being harmed that are considered respectable; the person harmed was in a place where she cannot be blamed for her victimization (e.g., she was at home); the offender is large and bad and the victim could not fight him off; and the victim had no personal relationship with the wrongdoer. Victims who conform to these ideals are more easily able to make the "political claim" to the legal status of victim and are more likely to be accepted as victims in the court of public opinion (Christie, 1986/2018; McGarry & Walklate, 2015; Strobl, 2004). This conceptualization implies that non-ideal victims: are strong and have a larger stature through which they can defend themselves; were

participating in unrespectable activities (e.g., substance use; sex work); were in nefarious spaces at the time the harm was committed; and have a relationship with the offender. Recognizing her own ideal victimhood, Brison (2002) writes,

> I realized that I had all the advantages, from a public relations point of view, that a rape survivor could have: I'm a white, well-educated, married, middle-aged, financially secure professional, who was wearing baggy jeans and a sweatshirt when attacked in a safe place in broad day light. I was badly beaten. My assailant was apprehended and had confessed to the crime. It seemed inexcusably selfish to worry about *my* credibility when I compared myself to, say, a young black woman or a heroin addict or a prostitute in my support group. We were all brutally raped. We all thought we were going to die. Their stories were just as credible as mine. But, through no merit of my own, I was in a far better position (than most of the women in the group) to tell my story. (p. 94)

According to Strobl (2004), Brison would be considered an "actual victim" because she not only recognizes herself as a victim, but she is also socially recognized as such –an ideal victim. On the other hand, "designated victims" are those who do not feel like victims but are nonetheless given this status. Non-ideal victims are "rejected victims," or those who feel like victims but are not socially ascribed that status; notably, regardless of their experiences, 'offenders' are rarely accepted as victims (Kilty & Frigon, 2016). Lastly, Strobl (2004) claims the "non-victim" is someone who has been harmed but does not identify as and is not recognized as a victim.

The word *victim* in the English language is derived from the Latin word for sacrificial animal, *victima* (van Dijk, 2009).[39] The word victim did not start to be used to refer to victims of crimes until the 19th century (van Dijk, 2009). Prior to this, 'victims' relationship with the law and the criminal justice system, including their participation in the legal process, has been turbulent. In the eighth century, according to Anglo-Saxon justice, disputes between two parties

[39] The oldest appearance of the word *victima* as a word for a human being is in the book *On the Institutes of the Christian Religion* written in Latin by the lawyer and religious reformer Johannes Calvin in 1536 (van Dijk, 2009). Calvin used the word *victima* as a special name of Jesus Christ in an elaboration of the sacrificial nature of the Crucifixion (van Dijk, 2009). In some religious texts, Jesus Christ is referred to as the 'victim of our sins' or the expiatory victim, meaning "the person who through his victimhood redeemed mankind" (van Dijk, 2009, p. 4).

were dealt with by “the Moot”, which was a kind of court composed of community members (Godfrey, 2017). During this period, complaints were brought to the Moot directly by people who were harmed or their families and settlements included a complex system of monetary compensation by the person who committed the harm (Godfrey, 2017); however, this rarely occurred in practice (Henderson, 1985). From the eighth century onwards, as monarchs gained and solidified their power, crimes were no longer considered offences committed against the individual, but rather against the King and by extension against society (Godfrey, 2017; Henderson, 1985). As such, the person who was harmed ceased to be the main instigator of prosecution and instead became witness to the offences committed against them in cases brought forth by the State (Godfrey, 2017; Henderson, 1985; Waller, 2011). In other words, responses to victimization became “state-centred and bureaucratized” so that those who were harmed were pushed out of the courts and restitution for those harmed “was increasingly policed, restricted and marginalized” (Godfrey, 2017, p. 15).

Nils Christie (1977) argued that conflicts became “other people’s property—primarily the property of lawyers—or it has been in other people’s interests to define conflicts away” (p. 5). In other words, within the contemporary punishment apparatus, the harm-doer and the person experiencing the harm no longer have ownership over the conflict which is instead relegated to judges, lawyers, and other criminal justice agents. Victims function only as witnesses, applicants for compensation, or as complainants until the end of the trial. As van Dijk (2009) argues, the changing nature of the harmed person in criminal justice processes was a “newly imposed moral imperative for crime victims” because they were now expected to “renounce their traditional right of revenge and/or blood money,” forcing them to “abandon their once powerful legal position in relation to” the person who did the harming (p. 6). During the 19th century, harmed

people were not simply 'disappeared' from criminal justice proceedings but were "re-imagined and re-configured, with the socially located victim of crime as a real actor in the day-to-day practice of criminal justice becoming usurped by the 'Victim of Crime' as a symbolic and generic construct in popular/public discourse" (Godfrey, 2018, p. 19).

As such, 'victims'[40] surfaced as an important part of the criminal justice system and criminal justice policy making, particularly during the 1960s, when a number of movements (feminist, civil rights, or anti-war) started to re-shape attitudes towards social and structural relations that produced victimization (Best, 1997; Henderson, 1985; Mastrocinque, 2010; Mawby & Walklate, 1994; Smith & Huff, 1992; Stanbridge & Kenney, 2009). 'Victims' have thus become stakeholders in criminal justice policy and even investors who mobilize their lived experiences to make tougher laws. Indeed, the victims' rights movement[41] has contributed to the rising punitiveness in Western nations, particularly in the United States (Pratt et al., 2005), by asserting a moral stance in which harm-doers are supposed to suffer through their punishment and have less rights than their 'victims' (Baker & Roberts, 2005). The 'victim' thus became a political tool for justifying tough-on-crime legislation throughout the Western world (Godfrey, 2017; Mawby & Walklate, 1994; Henderson, 1985/1992) and has been normalized in law – giving birth to the notion of, what I call, legal victimhood.

Investments in legal victimhood have long been made by what Bernstein (2012) has called "carceral feminists" or the middle-class, white women who have historically supported punitive state interventions to address social issues. For instance, first-wave feminists advocated

[40] I purposefully use the word 'victim' here to differentiate it as a label or status that is imposed upon people who were harmed regardless of how they might themselves identify. I also use the word 'victim' here to denote its productive capacity in the making of criminal justice policy.

[41] I refer here to the victims' rights movement that is aligned with the conservative law and order agenda that relies on carceral responses to lawbreaking (Fattah, 1989, 1992). These groups are distinct from the "unofficial victims' movement" that privileges alternatives to confinement like restorative justice and "whose activities are aimed at achieving common political and social goals" (Spalek, 2006, p. 5).

for social purity, temperance, juvenile delinquency training centers, and reformatories to transform criminalized women into ‘proper’ ladies (Gottschalk, 2006). By the 1960s, second-wave feminists became actively involved in addressing violence against women, aligning their efforts with the emerging victims' rights movement. However, critical scholars problematize dominating (Whalley & Hacket, 2017), carceral (Bernstein, 2012), and governing feminisms (Halley, 2006) for leveraging institutional power—particularly the carceral state—within a white supremacist system to achieve gender equality (Whalley & Hackett, 2017). For example, Nagel (2015) argues that sex work prohibitionists are anti-feminist because they take a paternalistic approach, aligning themselves with conservative anti-sex, abstinence-focused right-wing Christian agendas that seek prohibition. Rising public fears about crime, particularly among middle-class white women—often portrayed as ideal victims—have fueled increased policing, surveillance, and criminalization measures to enhance urban safety and protect “proper law-abiding citizens” (Bumiller, 2008; Fattah, 1992, pp. 4-5).

The convergence of feminism, victims’ rights advocacy, neoliberalism, and the punitive turn (Bernstein, 2012, 2007; Bumiller, 2008; Gottschalk, 2006; Ricordeau, 2019/2023; Whalley & Hackett, 2017) has led to new legal measures, such as civil protection orders and criminal remedies for domestic violence survivors (Bumiller, 2008) and anti-trafficking policies that have intensified policing and the criminalization of street-based sex work (Bernstein, 2007, 2010). Notably, the alignment of feminist and victims’ rights movements enabled the state to co-opt grassroots rape crisis centers, which historically opposed criminalization and prioritized peer support and self-help for sexual assault survivors (Gottschalk, 2006; Ricordeau, 2019/2023).[42]

[42] For instance, rape crisis centers funded by the U.S. Department of Justice’s Law Enforcement Assistance Administration urge victims to report sexual assault to the police and, in some cases, deny services to those who choose not to (Gottschalk, 2006; Taylor, 2019).

The reliance on carceral solutions to address gender-based violence (GBV) frames victimhood "as a negative term indicating regression: healing can only come through engaging with carceral systems" (Whalley & Hackett, 2017, p. 462). This carceral feminist approach, which aligns with conservative criminal justice policies, has ultimately reinforced the perception of women as inherently vulnerable and perpetually victimized (Ricordeau, 2019/2023; Smart, 1992, 1995).

Now that the plight of victims is acknowledged as a symbolic, protected, and political status in law, certain ideas about who a victim is and how a victim should behave have also become naturalized. In other words, legal victimhood has led to the creation of normative standards of victimhood that separate the 'ideal' from the 'morally corrupt'. The law produces certain kinds of victim subjectivities through "normalizing judgements", which Foucault (1977/1995) describes as those subtle ways in which,

> The work-shop, the school, the army were subject to a whole micro-penalty of time (lateness, absences, interruptions of tasks), of activity (inattention, negligence, lack of zeal), of behaviour (impoliteness, disobedience), of speech (idle chatter, insolence), of the body ('incorrect' attitudes, irregular gestures, lack of cleanliness), of sexuality (impurity, indecency). At the same time, by way of punishment, a whole series of subtle procedures was used, from light physical punishment to minor deprivations and petty humiliations. It was a question both of making the slightest departures from correct behaviour subject to punishment, and of giving a punitive function to the apparently indifferent elements of the disciplinary apparatus: so that, if necessary, everything might serve to punish the slightest thing; each subject finds himself caught in a punishable, punishing universality. (p. 178)

The normalization of victimhood within the law means that the only way to legitimize experiences of pain and suffering is through the law even if its processes and outcomes do not correspond with the sufferer's feelings (Doe, 2012; Smart, 1989; Strobl, 2004). For example, to be recognized as a rape victim, an individual must have had experiences that meet legal definitions of sexual assault, regardless of how she might feel or identify her experiences (Gavey, 1999). Law's power lays in its ability to limit possible interpretations of behaviour and

events and to declare the 'one truth', which Smart (1989) contends corresponds closely to masculine ideals that are embedded in law and legal practice that read female sexual assault victims in problematic ways.[43]

The "truth" about victims is enshrined within law's power to define complex interpersonal experiences within clearly demarcated categories of victim and perpetrator, regardless of the victim's lived reality (Smart, 1989). This double bind creates standards about how a victim should behave to be deemed credible by police and the courts (Bakht, 2012; Bogosavljevic & Kilty, 2021; Doe, 2012; Gotell, 2002; Murphy-Oikonen et al., 2022). Lalonde (2020) writes about this double bind in her memoir about her experience with intimate partner violence:

> The few women who decided to report to police lived in a double bind. They had to look bad enough for their trauma to be taken seriously, but not be too much of a mess or else risk being seen as crazy and unstable. It wasn't enough that women were subjected to discrimination, violence, and neglect, I realized. We also had to perform our trauma in a very precise way in order to get any semblance of justice. (Lalonde, 2020, p. 114).

The performance of victimhood that is imposed by the law and criminal justice system leaves no room for alternative ways of being. Law interferes with how people define their victimization, siloing them into legalistic definitions of and redress options for victimhood (Smart, 1989)[44].

The victim/perpetrator dyad is a particularly poignant topic in the literature on armed conflict and political violence, where the lines between victim and perpetrator are often blurred (Derluyn et al., 2015; Golubović, 2019; McGarry & Walklate, 2015; Moffett, 2016). For

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[43] I do not suggest that we should prosecute people based on how one feels; rather, I argue that even when victims do not consider themselves as or feel like victims, the law imposes its own definition of victimhood upon women who have been sexually assaulted. As Ronai (1999) argues, victim language has "served both to enable and to constrain the lived experiences of women and men" (p. 139).

[44] While restorative justice literature presents alternative ways of addressing victimization (Aertsen & Pali, 2017; Acorn, 2004; Lippens, 2017; Pemberton & Aarten, 2017; Rossner, 2019; Wemmers & Canuto, 2002), the implementation of such strategies is not widely accepted by policymakers as legitimate avenues for dealing with harmful acts like sexual violence, despite some victims requesting such processes (Gallant, 2023).

instance, while child soldiers are regarded as victims in children's rights law, questions arise about their ability to take responsibility for their actions as perpetrators in times when nations transition from authoritarian regimes to more democratic forms of government (Derluyn et al., 2015). Others, like Golubović (2019), have explored the politics of victimhood in post-war nations like Bosnia and Herzegovina as operating via a "moral economy of victimhood":

> Because this economy depends on a clear separation between victims and their perpetrators, because it depends on the association of victimhood with innocence, those complex and ambiguous experiences that blur the line become contentious and are often silenced…But it is not only stories of victimization that are silenced in this process, so too are more unsavory ethno-nationalist scripts about the war (p. 1193).

Victim/perpetrator language has thus "served both to enable and to constrain the lived experiences of women and men" precisely because it neglects to include the thoughts and feelings of people who have experienced harm (Ronai, 1999, p. 139). This hyper-polarized dichotomy has, over time, become more limiting than empowering in the way that it sediments individual narratives within "suffocating, rigid, reductionist categories that leave much of the information pertaining to their lived experience on the 'cutting room floor' because it cannot be made to fit in the confines of the existing terms" (Ronai, 1999, p. 141).

Notably, the victim/perpetrator dyad is especially fuzzy in the context of criminalizing HIV nondisclosure. PLWH may be 'victims' of someone's nondisclosure (in cases where they do not know their partner's status) and always-already potential perpetrators of nondisclosure. As Battin et al. (2009) argue in relation to the victim/vector relationship,

> …contagion may occur despite whether the victim knows the vector, and despite whether the victim can even identify the vector or the time of contagion. Transmission can be reciprocal, chained in a sequence of transmissions, or exponentially widespread. Any person can be both victim and vector simultaneously, or victim of one disease but at the same time vector of another…(p. 79).

Given the uncertain nature of contagion and transmission, law's transformation of complex situations into the binary narrative of victim/perpetrator is a byproduct of settler-colonial logic that individualizes social problems where "instead of helping to undo forms of social harm, this *us versus them* understanding of harm further extends and enables its manifestations" (McClelland, 2024, p. 71). Cases of HIV nondisclosure are made up through the bifurcation of people's experiences into categories of victim and perpetrator and "official ways of knowing that promote the legal facts of the case, such as police safety warnings, court files, and media reports" (McClelland, 2024, p. 90). When police press releases contain the accused's face and call potential victims to come forward about HIV nondisclosure, it reveals how law calls into being people who experienced nondisclosure *as* victims who must cooperate with police and testify in court (McClelland, 2024).

Next, I discuss how 'victims' came to be recognized in psychiatry and victim-feminism, leading to ideas about passivity and weak victims that dissuade some people from identifying in this way, instead choosing to identify as survivors.

***Recognizing Victims in Psychiatry: The Victim and Survivor Debate***

Fassin and Rechtman (2007) call the positivist victimology of Mendhelson and von Hentig *psychiatric victimology*, which they use to trace how trauma became a powerful tool to unite victims "by providing the unifying element it had lacked: a common hub joining the destinies of all affected" (p. 114). They contend that "by blurring the boundary between visible and invisible injuries, trauma became the mark of all victims: the injured, the survivors, and the 'involved,' a group that would include rescue workers and therapists, and soon even television viewers" (p. 114). Early psychiatric victimology examined the psychological characteristics of victims, or what made them more or less culpable in their victimization (Fassin & Rechtman, 2007). Today,

psychiatric victimology is more concerned with the effects of violence, expanding notions of trauma such that it is "common property, part of everyone's life, its reach extending far beyond the scope of psychiatric expert opinion" (Fassin & Rechtman, 2007, p. 127).

Descriptions of the effects of victimization are couched within psychiatric/psychological literature that focuses on symptomology and trauma[45] thereby making psychiatric victimology one of the dominant ways of knowing experiences of suffering and harm (Fassin & Rechtmen, 2007). Victimhood is thus recognized within psy narratives that medicalize, pathologize, and stigmatize experiences of harm and trauma (Caplan, 2006; Laugerud, 2021; McGarry & Walklate, 2015). Speaking about how harmed people narrate the harms of rape, Laugerud (2021) argues that "the medicalization of trauma simultaneously transforms rape into an experience in which expert knowledge is claimed, which, in turn, shapes the ways in which victims understand the causes and consequences of victimization" (p. 23). People who have experienced harm find these narratives useful for explaining their experiences, giving them a new way of articulating their messy feelings and behaviours (Brison, 2002; Laugerud, 2021). Brison (2002) describes how she put faith in medications used to treat her PTSD after her rape, only to be let down when she periodically fell back into depression. Yet overall, her diagnosis of PTSD offered her a sense of relief because it,

> …can be empowering to a victim whose efforts to recover have been hindered by her (and society's) belief that her injuries are 'all in her head.' It can be more enabling to learn to work around—or to overcome—the symptoms of PTSD than it is to pretend that they are simply not there. (p. 80)

[45] It is beyond the scope of this project to review this literature, but I do not deny that victims suffer from depression, PTSD, anxiety, and other psychological conditions following a victimizing event. See for example: Barlow, R., Turow, R. E. and Gerhart, J. (2017). Trauma appraisals, emotion regulation difficulties, and self-compassion predict posttraumatic stress symptoms following childhood abuse. *Child Abuse & Neglect*, *65*, 37-47; Turanovic, J.J. and Pratt, T. C. (2015). Longitudinal effects of violent victimization during adolescence on adverse outcomes in adulthood: A focus on prosocial attachments. *The Journal of Pediatrics*, *166*(4), 1062-1069; Walsh, K., DiLillo, D. and Messman-Moore, T. (2012). Lifetime sexual victimization and poor risk perception: Does emotion dysregulation account for the links?. *Journal of Interpersonal Violence*, *27*(15), 3054-307.

This statement is reminiscent of biographical illumination (discussed in section 2.1.3), the way the self is cultivated and refined through a medical framework (Tan, 2018). There is even a burgeoning field in positive psychology that explores the notion of post-traumatic growth and resilience and suggests that victims cannot only recover from trauma but can overcome it, transforming their sense of self, relationships, and outlook on life (Green et al., 2021; Tedeschi & Calhoun, 2004).

The historical origins of victimhood defined within psy discourse can be traced to the victims' rights movement, which emerged because people who were victimized, particularly women, noticed that harmed people were experiencing trauma but being ignored by the criminal justice system. As such, feminists and other victims' rights advocates organized collectively to advocate for better treatment of victims by the criminal justice system, more services for victims of crime, and for harsher punishment of offenders (Mawby & Walklate, 1994; Spalek, 2006; Waller, 2011).

Yet, as Lamb (1999) argued, the focus on trauma's symptomology (such as PTSD), portrays women who have experienced male-perpetrated abuse, including rape and sexual harassment, as damaged goods, thus re-creating and reinforcing notions of female passivity and the idea that women must be rescued. This popular image of victims garners public sympathy

and counters victim-blaming narratives[46] (Doe, 2012; Goodmark, 2011; Lamb, 1999; Leisenring, 2006). However, trauma has problematically become legal evidence used to adjudicate rape cases (Laugerud, 2021), revealing the collusion of the institutions of medicine and law in assessing women's claims of sexual assault (Doe, 2012; Fassin & Rechtman, 2007; Mcgarry, & Walklate, 2015; Laugerud, 2021) and the limited subject positions that victims can take up (Ovenden, 2012). Relying on legal and therapeutic intervention can lead to the 'double bind' that victims find themselves in with regard to the need to perform trauma in appropriate ways to be deemed credible (Bogosavljevic & Kilty, 2021; Lalonde, 2020). Sweet (2019) identifies this double bind as the "paradox of legibility":

> To be recognizable to institutions, women learn to narrate their experiences through the language of emotions, selfhood, and internal transformation. They make themselves into survivors by performing personal growth and recovery, typically via 'proper' sexuality and motherhood. By individualizing women's experiences into psychological accounts, these same stories erase the structural inequalities shaping women's victimization, and the structure-building work they have executed to survive abuse. (p. 413)

As such, there are structural forces that seek to *make* victims into survivors and, thus, productive members of society (Cole, 2007; Koyama, 2011; Larson, 2018). Stringer (2014) conceptualizes this tension between survivorship and victimhood as a "neoliberal victim theory" in the way it pits conceptions of victimhood as subjective and psychological against victimhood as social and

[46] Today, the dismissal of violence against women is seen in how often cases of sexual assault are deemed 'unfounded'. The Globe and Mail's investigation into unfounded sexual assault cases discovered that 5,000 sexual assault cases are closed and designated as unfounded by Canadian law enforcement every year. This means that 1 in 5 cases of sexual assault allegations in Canada are dismissed as unfounded and baseless. The national unfounded rate for sexual assault cases is about 19.39% which is twice as high than for physical assault (10.84%). Inflated unfounded rates create the impression that police receive fewer complaints of sexual assault than they actually do. In turn, that indicates that more complaints lead to an arrest (Doolittle, 2017). According to the Globe's data, 42% of sex-assault complaints lead to a charge, while Statistics Canada, which has data from all jurisdictions, reports 44%. However, when unfounded cases are factored in as complaints, the charge rate drops to 34%. Complaints of sexual assault in some parts of Canada are far less likely to be believed than in other parts. For example, Toronto, Winnipeg, Surrey and Windsor have single-digit unfounded rates, while police in 115 communities dismissed at least 1/3 of sex-assault complaints as unfounded. In Toronto, the 5-year rate of unfounded sexual assault cases is 7%.

political, reverses victimology so as to pit deserving victims against undeserving or "power victims" who play the role of victim by blaming others for their suffering, and conceptualizes feminists as being "negatively fixated on suffering" and resentment (Stringer, 2014, pp. 11-12).[47]

The term survivor arguably connotes a more positive tone in that it signifies a sense of resilience or existence after harm that should be celebrated (Alcoff & Gray, 1993; Dunn, 2010; Gavey, 1999; Larson, 2018; Stringer, 2014). Yet, as some have critiqued, surviving implies a kind of "compulsory survivorship" that "marks those who experience trauma as abnormal and asks [them] to overcome their experiences with pain—both of which serve to eradicate mental illness from a normative social order" (Larson, 2018, p. 688). As such, there have been increased calls for reconceptualizing and reappropriating the word victim (Koyoma, 2011; Mardorossian, 2002; Stringer, 2014). For example, Gay (2017) writes,

> I have learned the importance of survival and claiming the label 'survivor,' but I don't mind the label of 'victim.' I also don't think there's any shame in saying that when I was raped, I became a victim, and to this day, while I am also many other things, I am still a victim. It took me a long time, but I prefer 'victim' to 'survivor' now. I don't want to diminish the gravity of what happened. I don't want to pretend I'm on some triumphant, uplifting journey. I don't want to pretend that everything is okay. I'm living with what happened, moving forward without forgetting, moving forward without pretending I am unscarred. (pp. 20-21)

The terms victim and survivor thus imply particular orientations towards the self. For example, Koyama (2011) suggests that victimhood is viewed as something that must be overcome and that failing to do so may result in victim-blaming. Instead, she calls on feminists and the anti-violence movement to embrace,

[47] This sentiment is echoed in criticisms of resiliency as masking the structural barriers that lead to harm: "Resilience is that 'silver lining,' the positive residue left from trauma and tragedy. We are exhorted to be or become resilient, to summon the inner strength to deal with what life has flung our way. Develop the capacity to deal with adversity and, presto, you can bounce back stronger than ever. Of course, it seems almost silly to oppose resilience. After all, what is the alternative? Getting stuck? ... The resilience industry is rooted in an individual model of change, one that leaves untouched the structures and systems that are responsible for the trauma in the first place" (Orsini, 2020, n.p.)

> …unproductive whining and complaining as legitimate means of survival in a world that cannot be made just by simply changing our individual mentalities. We must acknowledge that weakness, vulnerability, and passivity are every bit as creative and resilient as strength and activeness. And I think we can start that by reclaiming 'victim' and 'victimhood' and resisting the heteronormative 'victim to survivor' discourse of the trauma recovery industry that imposes compulsory hopefulness and optimism in the service of neoliberal capitalist production. (n.p)

Similarly, Anonymous (2016) writes,

> I cringe when someone calls me a 'survivor,' or as is more common, calls all rape/abuse victims 'survivors.' The use of 'survivor' has been carefully promoted under the assumption that all rape/abuse victims will eventually come to their senses and "reclaim" their trauma. These stories absolutely inspire and comfort rape victims, but they also tell those who aren't thriving that all rape/abuse victims have the ability to become renowned wrestlers or performers. Then they're asked by themselves and others, What's wrong with you? Why aren't you doing something productive with all that trauma? What does this mean for victims who don't go on to create beautiful art or otherwise turn their trauma into something that other people find value in? What about the victims who are still in bed and can't seem to move on? The 'powerful and empowered survivor' narrative is the mirror image of what being a rape victim was like back when no one discussed rape or abuse in polite company. (n.p)

Anonymous, Koyama, and Gay's narratives challenge us to reimagine what it means to be a victim, to *read* the narrative of victimhood differently, and to disassociate victimhood from the notion that it is something that *must* be overcome in a particular way. This is reflected in the colloquial saying "it's okay to not be okay"; despite the push to be productive, we do not have to continuously work to align the self with social or cultural narratives about the need for transformation after painful experiences.

People who experience harm may not feel like they fit into either category of victim or survivor (Boyle & Rogers, 2020; Leisenring, 2006; Ovenden, 2012). Some use the language of 'victim' to help explain their experiences of violence as out of their control and to garner sympathy and support, while others refuse to use this language because they want to distance themselves from being blamed for what happened to them and they do not associate with the

weakness and powerlessness that victimhood denotes (Leisenring, 2006). Boyle and Rogers (2020) found that women of colour were no less likely to identify as victims regardless of the association of victimhood with whiteness, but identifying as survivors led to reports of greater happiness and self-esteem among women of colour compared to white women. Unsurprisingly, men identify less as victims and more as survivors given the latter's association with strength and agency (Boyle & Rogers, 2020). People experiencing harm often go back and forth in using the language of victim, employing it in strategic ways to justify rights or supports from the criminal justice system (Leisenring, 2006). Trying to understand experiences of harm through victim-feminist, legal, and psychiatric discourses and categories neglects the lived reality of suffering and stifles alternative understandings of harmful experiences and avenues for justice (Doe, 2012).

I, therefore, heed Rock's (2002) call to be more attentive to what it means to suffer and experience a harmful or traumatic event rather than trying to apply a label *to* and *for* people who have experienced an event that might be harmful, painful, or traumatic. Victimhood is thus not only a legally or psychologically ascribed status, but is also a process of recognizing oneself, or not, within the language of victimhood (Brison, 2002; McGarry & Walklate, 2015; Strobl, 2010). This politics of recognition and victimhood is what I explore in this dissertation as it relates to how people understand their experience of HIV nondisclosure, diagnosis, and living with HIV.

## 2.3. Final Thoughts[48]

In this chapter I explored the ways in which health is productive, in the age of “advanced liberalism” (Rose, 1993, 1999) and of new identities and relations (Brown, 2015). This is an age marked by diffuse medical, moral, and legal modes of regulation (Corrigan, 1981; Hier, 2023; Hunt, 1999a, 1999b; Timmermans & Gabe, 2002) that govern at a distance, transforming people into self-governing “entrepreneurial selves” (Rose, 1999, p. 142) responsible for their own health, well-being, and risk management (Armstrong, 2014; Crawford 1980, 1984; Petersen, 2015; Petrakaki et al., 2018). In section 2.1.3, I explored the notion of “biographical disruption” (Bury, 1982) and all of its iterations to show the ways in which illness acts as a disruptive event, particularly to one’s sense of self. I then discussed the implications of the public health policy TasP and the narrative of HIV normalization. I showed how undetectability is emerging as a new identity configuration among PLWH that is based in biomedical discourse and that functions as a marker of good and respectable HIV citizenship. This analysis allows me to frame the criminalization of HIV nondisclosure within this broader project of governing through health and to explore the relationship between law, medicine, and morality in constituting new subjectivities and new forms of sociality.

I then shift to give a brief history of the discipline of victimology to situate myself and this project within critical victimology which seeks to examine who has the power to ascribe the label victim (Miers, 1990; Strobl, 2004), what it means to be a victim (Quinney, 1972; Rock, 2002; Walklate, 2007), and “the politics of recognition in relation to victimhood” (Spencer & Walklate, 2016, p. xi). I discuss the ways in which victims have become an important part of the

[48] I use the term ‘final thoughts’ rather than ‘conclusion’ here and throughout the dissertation because, following Frank (2010), I do not subscribe to the idea that there is such a thing as a narrative whole or that as a researcher I ‘have’ the whole story. This chapter offers one interpretation of the stories told to me by participants out of many possibilities.

criminal justice apparatus, what I refer to as 'legal victimhood'. I do this to distinguish the ways in which one can be called into being as a victim by the law while also rejecting that label. I also discussed what I called 'psychiatric victimhood' and the role of victim-feminists in organizing around gender-based violence to describe how victim's experiences are often couched within psychiatric terms such that victimhood becomes associated with defeat and passivity and something that one must overcome. I showed how survivorship becomes the expectation for all those who have experienced harm.

The chapter reviewed how pain, trauma, injury, and disease can lead to changes in how one feels about and constitutes the self. Writing about her experiences of sexual violence, Brison (2002) states that, "piecing together a dismembered self seems to require a process of remembering in which speech and affect converge" (p. 56). With respect to chronic illness, the person mobilizes former social experiences, cultural meanings, and knowledge to "engage in a mental dialogue about the meanings of present physical and social existence, specifically, the emergent indications of identity elicited by illness" (Charmaz, 1983, p. 170). As such, experiences of pain, injury or trauma can lead to disruptions in the person's "structures of explanation and meaning […] relationships and material and practical affairs" and thus to a complete re-evaluation of the person's biography and self-concept (Bury, 1982, p. 175). For example, people with chronic illness often re-arrange friendship and community ties because of physical limitations and feelings of embarrassment brought on by a diagnosis (Bury, 1982). Illness, like victimization, represents an assault on one's sense of self that forces the person to reconstruct their identity (Frank, 1995/2013; Williams, 1984). Part of this re-orientation involves interpreting the meaning of one's victimization or diagnosis. For people living with HIV,

> there is a collective dimension to HIV-infection that shapes the individual's experience. Interpretations of AIDS are rife. Everyone is familiar with public

> discourses about AIDS. The latter is usually presented as a 'disease others catch' – the others being persons with 'risky behaviours'. Coping with everyday, HIV-positive life means adopting a stance in relation to these discourses. (Carricaburu & Pierret, 1995, p. 71)

Public discourses position PLWH as dangerous and in need of control (Kilty & Bogosavljevic, 2019; Bogosavljevic & Kilty, 2023), which in turn shapes how they might interpret their own diagnosis and sense of self. Victimization, like illness, disrupts the biography of the victimized person (Brison, 2002; Bury, 1982; Mann, 2023; Pemberton, Mulder, & Aarten, 2018), leading to the "narrative reconstruction" (Williams, 1984) of identity as one attempts to create order in their life. Experiences of harm and illness are thus inextricably linked in that they represent an assault on one's sense of self, forcing one to reconstruct their biographical self.

Together, this review of the literature demonstrates the ways in which we are continuously pulled into the neoliberal centrifuge, particularly in moments when we are most vulnerable. Its forces of regulation work to divide the healthy from the unhealthy, the undetectable from the detectable, the good from the bad, the innocent from the guilty, the victim from the perpetrator, the ideal victim from the non-ideal victim, and the victim from the survivor; to form new identities and subjectivities along medical, moral, and legal lines; to responsibilize individuals into self-governing autonomous entities separated from community; and to make ever more individuals expendable and unprotected (Brown, 2015) and subject to increasing forms of punishment and surveillance (Wacquant, 2004/2009). This chapter has shown how harm and illness both involve broader and shifting institutional, cultural, social, political, legal, and psy narratives that provide important interpretative frameworks.

In chapter 3, I outline my theoretical approach and conceptualize the notion of the *affective narrative self* to show how people are inextricably linked through the narratives we tell and the narratives that make up the cultural field. I understand the preceding discussion as socio-

cultural and political narratives about what it means to be healthy, living with HIV, a victim, how one *should* live with HIV or *be* a victim, and who *should* be given the status of victim. I aim to make sense, throughout this dissertation, how these broader narratives are imbued with affect as they circulate through and within time, making some narratives resonate and reverberate, and therefore mobilized in people's understandings of self, their experiences, and relations to others. To do this, I review the literature on affect theory and narrative to explain the co-constitutive nature of emotions and narratives, what I am calling *affective narratives*, that then are mobilized in the configuration of the stories we tell.

# Chapter 3.

# Theoretical Framework: Configuring the Affective Narrative Self

In this chapter, I outline a theory of what I call the *affective narrative self*. While there are many theories as to how the self is formed, ranging from psychological explanations to sociological ones, in this dissertation, I consider the formation of the self as it is developed through the stories and narratives we tell ourselves and others (Frank, 2010, 1995/2013; Holstein & Gubrium, 2000; Plummer, 1995; Ricoeur, 1984/1985). We employ affective practices (Wetherell, 2012) that structure how we tell stories, what narratives we choose to mobilize, who we tell our stories to, and in what contexts. Importantly, the affective narrative self is formed relationally. Following Ricoeur (1983/1990, 1985/1990, 1991a, 1991b, 1991c) and Frank (2010, 1995/2013, 2002), we mobilize certain narratives from other's stories that leave impressions upon us; in turn we use and mold these to help explain our experiences and our sense of self. The affective practices (Wetherell, 2012) we develop become habituated, although not sedimented, over time through our social interactions with various individuals, groups, and institutions. Moreover, our access to affective practices (Wetherell, 2012) and narratives is dependent on our lived experiences as they are mediated by the intersection of race, gender, sexual orientation, age, ability, health, and other social locations. These practices help to structure our identities by making us identify *with* or *away from* certain aspects of the self. Narratives that make us feel happy, safe, and proud lead us to *identify with* certain facets of another's or our own identities. Narratives that disgust, repulse, or scare us lead us to *identify away* from those characteristics. Of course, our ability to distance ourself from the 'bad stuff' is dependent upon our social positioning, not everyone will have the capacity to detach from the characteristics that feel 'bad'. Alternatively, a certain narrative might

anger someone to such a degree that it jolts them into action and identification with others who feel the same.

Developing the concept of the affective narrative self allows me to consider how affects, feelings, and emotions structure the ways in which people who have experienced HIV nondisclosure narrate their experiences in the context of HIV criminalization. I use this concept to explicate how participants consider their experiences in relation to the label 'victim', given that this is how the law identifies those who have experienced HIV nondisclosure, regardless of whether HIV was transmitted or not. Using the conceptualization of the affective narrative self, I attempt to 'shake up', or, to use Ricoeur's words, "refigure" our collective understandings of what/who constitutes a victim through an exploration of how participants configure their own life experiences. By exploring the affective narrative practices of PLWH within the context of HIV criminalization, I endeavour to understand how affects, feelings, and emotions become attached to an HIV diagnosis and the context within which one became HIV positive, and how they are mobilized in and structure the stories PLWH tell to communicate their affective narrative selves.

In the first section of this chapter (3.1), I map the field of emotions studies, showing the contours and boundaries offered by different camps of scholarship. I use Wetherell's (2012) notion of "affective practices" to reconcile the different epistemological and ontological perspectives on emotions by foregrounding definitions that offer a useful way to 'get at' affect in the analysis. In section 3.2, I outline a theory of the affective narrative self; following Ricoeur (1983/1990, 1984/1985), I define narrative as a practice that involves a "hermeneutic circle" of prefiguration, configuration, and refiguration. Following Frank (2010), I also make the case that narratives are not only structured in particular ways, but that they have an active function – they

*do* something by way of entertaining, deceiving, dividing, stimulating, connecting, instructing and so on.[49] I use this conception of narrative to develop the notion of the affective narrative self in section 3.2.2, where, through storytelling and emotions, we configure our sense of self.

By beginning to theorize the relationship between affect, narrative, and the self, I am emphasizing the importance of understanding how different emotional narratives, such as those written and told about HIV and PLWH, prefigure and configure one's sense of self. I am particularly influenced by Ahmed's (2004) theorization about how "histories are bound up with emotions precisely insofar as it is a question of *what sticks*, of what connections are lived as the most intense or intimate […]" (p. 54). Conceptualizing the affective narrative self can help to unpack how certain narratives become saturated with affect and thus to stick around, which affects stick to which narratives, what these affective narratives do as they circulate, how they are mobilized to configure one's narrative self, and how they are used to read others in ways they might not read themselves.

## 3.1. A Note on Distinguishing Between Affect, Feeling, and Emotion

Emotions have been studied by many scholars from the ancient Greeks to modern-day philosophers, neuroscientists, psychologists, legal scholars, and social scientists. According to Lupton (1998), the study of emotions falls into two major camps: emotions as inherited and the social construction of emotions. Others might refer to these as the cognitive and mechanistic viewpoints (Kahan & Nussbaum, 1996), the organismic and interactive perspectives (Hochschild, 1979), the positivist and social constructivist approaches (Kemper, 1981), and the micro (positivist, social constructivist, and symbolic interactionist perspectives) and macro level

[49] I discuss Frank's (2002) ideas about the need for narrative analysts to be humble in chapter 4 where I review the methodology I undertook for this project.

(historical, structural and ideological underpinnings of emotions) of emotions research (Thoits, 1989).[50] Amongst these approaches there are a plethora of arguments relating to how one ought to define and conceptualize emotions.

The social constructivist position considers the relationship between emotions and society. Here Lupton (1998) suggests that there are two distinct theses: the weak thesis which blurs the line between theories that define emotions as inherent and those that see them as socially constructed (see for example: Kemper, 1987)[51], and the strong thesis which contends that emotions are relational, dynamic, and changeable depending on the particular historical, social, and political contexts in which they are generated, reproduced, and expressed (Burkitt, 1997). Structuralists such as Hochschild (1979, 1983) argue that our emotions have increasingly become commercialized into what Illouz (2018) terms "emodities", writing that "emotions have become smoothly imbricated in rational modes of conduct promoted by [an] ever-deepening grip of economistic forms of thinking in various realms of life" (p. 5).

Structuralists have been critiqued for their rigid interpretation of the feeling subject, noting that they have been represented as passive and therefore manipulated or controlled by organizational feeling rules (Lupton 1998). Sociology of law as well as law and emotions scholars emphasize that law's appearance as objective, rational, and emotionless is a fallacy given the unavoidable presence of emotions in law (Aronovich, 2007; Nussbaum, 2001, 2016, 2004; Posner, 2000). Indeed, scholars have explored the role of specific emotions such as remorse in shaping determinations of guilt or innocence (Bandes 2016; Kilty, 2010; Kilty &

[50] It is important to note that while I separate these different approaches to the study of emotions, much of the scholarly work bleeds between camps, making the study of emotions a messy project.
[51] Kemper (1987) specifically argues that there are four key physiologically grounded primary emotions: fear, anger, depression, and satisfaction. He argues that these emotions are universal to all humans, that they are integral to evolutionary processes, and that they occur at a very early stage in human development. The secondary emotions he identifies, such as guilt, shame, pride, gratitude, love, nostalgia and so on, are gained through processes of socialization that are felt in response to one of the primary emotions.

Frigon, 2016; Weismann, 2014/2016); disgust and shame in structuring laws and policies (Karstedt, 2002; Kilty & Frigon, 2016; Nussbaum, 2004); forgiveness and anger in our understandings of justice (Minow, 2015; Nussbaum, 2016); and closure as the basis of arguments advocating for capital punishment (Bandes, 2009).

Cultural and affect theorists outline the relationship between affects, mass culture, and the creation of public cultures such as lesbian and trauma cultures (Cvetkovich, 1992; 2003a, 2003b); the function of emotions, including their relationship to language and bodies (Ahmed, 2004); a "non-dualistic thought and pedagogy" in relation to affects and drive, feelings and texture, and performativity and performance (Sedgwick, 2003); the relationship between movement, sensation, and the body (Massumi, 2002); and how disgust operates as something that is implicated in our relationships, selves, politics, and love (Miller, 1997). Scholars have also critiqued cultural theorists about the ways in which they celebrate affect as a uniquely situated concept that can lead to social transformation while ignoring the ways in which affect plays a prominent role in reproducing problematic social structures such as racism, sexism, homophobia, misogyny, and HIV/AIDS stigma. For example, Hemmings (2005) argues that in cultural studies, affect "often emerges as a rhetorical device whose ultimate goal is to persuade 'paranoid theorists' into a more productive frame of mind" (p. 300).

As these bodies of work show, coming to a concrete definition of emotions is a difficult task, especially given that even within each area of affect/emotion theory scholars converge and diverge in the ways that they understand emotions. As such, it is beyond the scope of this dissertation to provide a detailed review of the literature in each camp (for an in-depth account of the various approaches to the study of emotions see Kemper, 1981; Lupton 1998; Thoits, 1989; Turner, 2009). Instead, I focus my attention on the cultural and sociological approaches, creating

a theoretical framework informed by the work of Margaret Wetherell, Ian Burkitt, Sara Ahmed, Ann Cvetkovich, and Deborah Lupton who bring to light the ways in which emotions are cultural and political entities that work in particular ways to produce and structure our world. This approach avoids the limitations borne from understanding emotions as signals located in particular parts of the brain or body that so much of the psychological, cognitive science, biological, and neuroscientific scholarship on emotions emphasizes (see for example: Adolphs & Anderson, 2018; Ekman et al., 1972; Fisher et al., 2013; Gray, 1988; Jones 2016; Larsen & McGraw, 2011; Tracy & Matsumoto, 2008) Such studies have been critiqued for being too linear and rationalistic and for defining emotions in a mechanical form akin to outputs generated by people as if they are computers (Lupton 1998). A theoretical framework situated in the sociological and cultural study of emotions allows me to consider how affects, feelings, and emotions shape personal and social identity narratives[52] as they are mediated by gender, race, class, sexual orientation, and serostatus. I contend that there *are* important differences between these concepts and that these corporeal, sensory, and cognitive experiences *do* something different to our bodyminds[53], shaping our relations with objects and others, our sense of self, and our experiences.

Affect is perhaps the most confusing and thus the most difficult to describe because it is something that occurs in the body without us necessarily being aware of it. According to Gould

[52] Goffman (1956; 1963) articulates that personal identity is the unique characteristics that make up each person as distinct. This is the way that individuals perceive themselves. Social identity is how individuals define themselves in relation to group affiliations and other's characterizations of themselves. For Goffman (1963), identity is shaped by people's interactions with each other and with institutions and it is actively (re)constructed in different settings as people engage in impression management. He developed the notion of frontstage and backstage to describe how people perform their social identities in public in ways that ascribe to social norms and expectations while backstage, they can be their authentic selves (Goffman, 1956). I mobilize Goffman in the section on narrative identity as well.
[53] In an effort to acknowledge how the mind and body constitute each other, I use the term "bodymind", articulated by Price (2015), to critique the distinction between the body and mind and to recognize how the two affect one another and work together as one. She defines the concept as "a socio-politically constituted and material entity that emerges through both structural (power-and violence-laden) contexts and also individual (specific) experience" (p. 271).

(2009), affects are “nonconscious and unnamed, but nevertheless registered, experiences of bodily energy and intensity that arise in response to stimuli impinging on the body” (p. 19). That affects are nonconscious, means that language may be insufficient to describe how we experience them as they occur in our bodies without our conscious mind necessarily registering their intensities (Gould, 2009; Massumi, 2002). Since affects are nonconscious, they are also malleable and may be used, directed, and mobilized in various ways (Gould, 2009; Seigworth & Gregg, 2010). This becomes particularly problematic if we also think of affects as “potential” (Massumi, 1995, 2002) or the ways in which “affect colours nonlinguistic sensory experience by giving it a quantity of intensity, and thus force, which prepares the organism to respond to that which is impinging on it, *but in no predetermined direction*” (Gould, 2009, p. 26 emphasis in original). An organism’s physical response or decision to act in a certain way depends on the level of intensity of affect (Shouse, 2005). For example, affects that are low in intensity might never be brought forth into the conscious realm or felt in the body as an emotion; therefore, we might not physically react. On the other hand, affects that are high in intensity are registered in our consciousness as a feeling because they force us to act with urgency to a particular stimulus. As such, affects seem to work as “free radicals” that “can be, and are, attached to things, people, ideas, sensations, relations, activities, ambitions, institutions, and any number of other things, including other affects” (Sedgwick, 2003, p. 19). These attachments permanently change and intensify the meanings of objects and signs so that “objects become sticky, or saturated with affect, as sites of personal and social tension” (Ahmed, 2004, p. 11; Sedgwick, 2003) – what Anderson (2014) terms an “affective charge” (p. 16).

If affects are “free radicals” that stick to objects and subjects, then they *do* something in the sense that they create boundaries and borders around and between that which is normative

and non-normative, moral and immoral, good and bad (Sedgwick, 2003; Ahmed, 2004). Affects constitute, shape, and (re)produce normative standards upon which we come to evaluate the morality and 'goodness' of people's actions. Since affects become attached to people, ideas, signs, objects, and/or groups, we come to value (or not) things based on the affects we attach to them – these objects become saturated with affect such that they form the surface of the subject and object (i.e., as hateful or hated respectively) (Ahmed, 2004). In that sense, people, ideas, signs, and/or groups get transformed "into objects of feeling" by the very affects that get fixed to them (Ahmed, 2004, p. 11). Moreover, these attachments grow over time and therefore gain affective value – either negative or positive depending on the feeling(s) that get(s) attached (Ahmed, 2004).

For example, HIV and AIDS are objects, that over time, have accumulated much affective value or charge – the anger felt towards the American and Canadian governments for their refusal to respond to the HIV/AIDS epidemic in the 1980s helped mobilize friends and family of those who were sick into action through organizations like ACT UP in New York. In Canada, AIDS ACTION NOW! based in Toronto, and other local organizations such as the Gay Men's Health Group in Halifax, Nova Scotia engaged in grassroots organizing to combat the fear and disgust that was culturally expressed toward PLWH and facilitated the 'Othering' of the gay community, as well as the Canadian government's poor response to the illness in its early days. Canadian health officials at the time were known to hold conservative views on gender and sexual orientation. For example, Jake Epp, the Federal Health Minister until 1989, refused to say the word AIDS out loud and purposefully assigned individuals who would resist pressure to change established procedures for responding to the disease to important bureaucratic roles (Rayside & Lindquist, 1992).

Affects do not have to be extraordinary to (re)make subjects, objects, places, and events. Stewart (2007) explains affect as something that is familiar, everyday, and mundane:

> Ordinary affects are the varied, surging capacities to affect and to be affected […]. They happen in impulses, sensations, expectations, daydreams, encounters, and habits of relating, in strategies and their failures, in forms of persuasion, contagion, and compulsion, in modes of attention, attachment, and agency, and in publics and social worlds of all kinds that catch people up in something that feels like *some*thing […]They can be experienced as a pleasure and a shock, as an empty pause or a dragging undertow, as a sensibility that snaps into place or a profound disorientation. They can be funny, perturbing, or traumatic. (pp. 1-2)

Affects are sometimes, but not always, registered in our bodyminds; they exist as forces, intensities, potential (Massumi, 2012), capacities (Anderson, 2014), and they have the ability to move, stick, and give meanings to the objects that become saturated with affect (Ahmed, 2004; Sedgwick, 2003). For Anderson (2014) in particular, "there is no such thing as affect 'itself'" and there is no singular affect that can stand in for a theory of affect or "affective politics" (p. 13). He thus proposes the notion of "affective atmospheres" to articulate how "atmospheres are spatially discharged affective qualities that are autonomous from the bodies that they emerge from, enable and perish with" (Anderson, 2009, p. 80). Atmospheres, he argues, occur in everyday speech as a mood, feeling, ambience, or tone and can include things like epochs, societies, rooms, landscapes, couples, artworks and much more (Anderson, 2010, 2014). Anderson gives affect a spatial quality, showing how certain atmospheres can envelop and press with a certain force, making us feel one way or another.

While affects are nonconscious, non-fixed, inarticulate, and sensory, feelings constitute the felt and conscious cognitive and bodily registering that we are experiencing an emotion.[54]

[54] Affects are particularly difficult to study precisely because they occur at a nonconscious level in our bodymind. As such, researchers tend to interpret the feelings and emotions that people experience. Though I draw distinctions between affect, emotion, and feeling, I can only *really* 'get at' the feelings and emotions my participants describe during the interviews and debriefs.

Registering feelings results from the sensations that affects, if powerful enough, stir up in the body (Gould, 2009). As such, they represent "the ambiguity between feelings as embodied sensations and feelings as psychic or cognitive experiences" (Cvetkovich, 2012, p. 4). Feelings help us to differentiate between diverse affects and thus work closely with emotions as sense-making tools. In 'trying to figure out' what it is that we are feeling, we draw upon memories, knowledges, habits, experiences, impressions, and histories of contact to name our feelings (Ahmed, 2004; Cvetkovich, 2012; Gould, 2009). Through the naming of emotions, the affects we experience readily become fixed into named emotions as we try to explain what we are feeling (Gould, 2009). This process of naming results in the emotions that we have become familiar with and that we have the language to describe. These include anger, sadness, happiness, and disgust to name but a few. Moreover, what we come to call an emotion (e.g., anger, fear, shame, sadness etc.) is simply an approximation of an affective experience (Gould, 2009). As such, emotions are the "sociolinguistic fixing of the quality of an experience which is from that point onward defined as personal. Emotion is qualified intensity, the conventional, consensual point of insertion of intensity into semantically and semiotically formed progressions, into narrativizeable action-orientated circuits, into function and meaning" (Massumi, 2002, p. 28).

It is precisely in the naming or fixing of affects to emotions that we attach meanings to events, objects, and people. As Lupton (1998) contends,

> …what we call 'emotions' and how we experience them always gain their meaning as part of a wider sociocultural frame. The very mutability, ephemerality and intangible nature of 'the emotions', as well as their inextricable interlinking with and emergence from constantly changing social, cultural and historical contexts, means that they are not amenable to precise categorization. (p. 5)

For example, it is generally accepted that an increased heart rate, rising body temperature, heavy breathing, and raised eyebrows can reflect the felt emotion of anger – this is perfectly

exemplified in the old *Looney Toons* cartoons when Marvin the Martian gets so angry at Bugs Bunny that his face turns red as he shouts "you have made me very angry", paces left and right, and is seen huffing and puffing as if out of breath. On the other hand, these descriptions could also mean that someone is having a heart attack. That the affective response to anger closely resembles feelings of having a heart attack means that anger can act as a force that tells us to create distance from the object that has made us angry; yet it can also be a collectivizing and motivational force (Srinivasan, 2018; Kilty & Orsini, 2024). The words used to describe affects and the objects of our feelings "circulate and generate effects" in the sense that they orientate us in particular ways towards or away from objects (Ahmed, 2004, p. 14). When we fear someone or something, we move away from them or it, creating a distance that separates 'us' from 'them'. This separating results in the identification of "affect aliens" who challenge the status quo and do not "desire in the right way" (Ahmed, 2010, p. 240).

Some PLWH have accumulated negative affective value through their representation as hypersexual deviants who engage in risky and unrestricted sex for nonreproductive purposes (Kilty & Bogosavljevic, 2019). As such, their sexuality is constructed as dangerous and threatening to the health of the nation and to the purity of (predominantly white) women who, culturally, represent innocence and thus all that is 'good'. These constructions of PLHWA invoke sensational feelings which serve to make "events emotionally vivid by representing in tangible and specific terms social and historical structures that would otherwise remain abstract" (Cvetkovich, 1992, p. 23). To make one feel is to render those events real or natural and therefore uncontestable. The naturalness of affective responses performs a disciplinary function[55]

[55] Cvetkovich (1992) uses a Foucauldian approach to suggest that affect is historically and discursively constructed, a "mechanism for the containment and discipline of the self" as "mass culture enables the regulation of subjectivity through the management of affect" (p. 31).

"by means of the individual subject's feelings [and] is quite literally embodied in the self" (Cvetkovich, 1992, p. 25). In short, feelings, emotions, and affects impact one's sense of self as much as they impact our orientation towards others. For example, the felt associations I make with a particular event or action or the ways in which this event or action impresses upon me influences the ways in which I tell stories about my experiences and narrativize my identity.

Although there are distinct differences between these concepts, trying to distinguish between them has proven quite difficult given that affects and emotions often occur at the same time (Gould, 2009) and affects are not always neatly organized and can, at times, be chaotic, messy, and unclear (Wetherell, 2012). I use the term affect throughout this dissertation, although I may also use the three terms interchangeably precisely because affect "as sensory intensity… can stir an inchoate sense that we are experiencing something, a vague stirring, if forceful enough, can induce efforts—more or less conscious—to figure out what we are feeling and how to express it" (Gould, 2009, p. 21). I prefer Wetherell's (2012, p. 12) notion of affective practices in which she describes affects as,

> Always 'turned on' and 'simmering', moving along, since social action is continually embodied. But, affect also comes in and out of focus. The ongoing flow of affective activity can take shape as a particular kind of affective performance, episode or occasion, as in, for instance, a child's tantrum, a self-aggrandising narrative, or a bounded experience of joy. Affective practices unfurl, become organised, and effloresce with particular rhythms. Understanding the chronological patterning of these figurations, along with their sequencing and 'parsing', is crucial. Something like self-pity, for instance, can flare up, rise to a crescendo and diminish in pace with the changing medley of 'interpretative repertoires' being articulated.

In this way, analyzing affects involves searching for the patterns and routinized ways of feeling, expressing, speaking about, and storying emotions. Researchers must not only look for how these practices are situated and connected but also how they might be "thrown together" in the moment (Wetherell, 2012, p. 13).

### 3.1.1. Reconciling these Perspectives: Towards Affective Practices

For Wetherell (2012), emotions research has several key challenges. First, she argues that the work on emotions that is rooted in psychology and neuroscience is too restrictive. For instance, 'basic emotions' such as sadness, anger, fear, surprise, disgust, and happiness do not effectively describe the "range and variety of affective performances, affective scenes and affective events" (Wetherell, 2012, p. 3). Second, the line of thinking on affect that is rooted in Deleuzian concepts of force, intensity, and potential, are unhelpful in terms of describing how affect functions for social scientists doing empirical work (Wetherell, 2012) not to mention the lack of focus on how affect functions as a central feature of social reproduction such as the pleasure we take in punishment or consumerism or feelings of belonging in fundamentalism or fascism (Carvalho & Chamberlen 2018; Hemmings 2005). As such, Wetherell's (2012; 2013a, 2013b; 2015) notion of affective practices is an all-encompassing critique of the dizzying work of cultural theorists such as Brian Massumi who she argues makes affect too abstract and difficult for social scientists to examine in everyday practices; Eve Sedgwick who she contends has returned the study of affect back to its "hermetically sealed, culturally absolutist, psychobiological black box of 'psychological primitives' (fixed stimuli/response pairs) " (Wetherell, 2015, p. 145); Ben Anderson who conceptualizes affect as a disembodied force that makes the human subject a way station through which "affects as autonomous lines of force pass on their way to somewhere else" (Wetherell 2013a, p. 228); and even Sara Ahmed who she maintains disappears the subject as an active agent in the "practical human relational work" that is central to an affective experience (Wetherell. 2015, p. 159).

Despite Wetherell's critiques, I do not agree that these theories lack usefulness to empirical research. I contend that as social researchers studying affect and the social and political

manifestations of affect, it is our job to think *with* these conceptual ideas as we embark on our empirical work. This entails figuring out *how* to *feel* affect as a force, intensity, and atmosphere through our fieldwork and to interpret these feelings (our own and our participants') and how to *see* the impressions, stickiness, and affective economies in our data. Wetherell also fails to consider the researcher's emotions which play an important role in bringing abstract understandings of affect to the surface (Bergman Blix, 2015; Bergman Blix & Wettergren, 2015; Chadwick, 2021; Gould, 2009; Hemmings, 2012; Mario & Bogosavljević, forthcoming).[56] Gould (2009) speaks to the researcher's "emotional self-knowledge" as something that guides analysis in the way that it "allows one to observe and read in a manner that can pick up the unspoken, the repressed, the less-than-fully conscious, the inarticulate" (p. 30).

While Ivana (2020) agrees with Wetherall's critique of Ahmed's work, she contends that the concept of affective practices runs the same risk of disappearing the subject. Ivana (2020) thus proposes that Ahmed's concept of 'impressions' can complement Wetherell's affective practice because it acknowledges the subject. The formation of impressions, as described by Ahmed (2004), involves acts of perception, cognition, and emotion. Therefore, "forming an impression about someone or something, being impressed by a situation or an event is at the same time being moved, shaken, emotionally touched, while also having a thought or a belief" (Ivana, 2020, pp. 16-17). Ivana (2020) is particularly concerned with Bourdieu's concept of habitus, arguing that,

> …impressions are found at the intersection between the world and a social actor whose body is not only a vehicle for routine and gymnastics, but whose embodied affect and cognition play a crucial role in the construction and sedimentation of meaning. At a sociological level, the accumulation of impressions as the basis for future meaning-making in relation with the world represents the pathway towards

[56] More on this in chapter 4, where I discuss the methodological process I undertook to conduct this research.

> bringing affective practice more into cultural analysis, without renouncing structural influences or depersonalizing subjects. (p. 24)

Through the impressions we form, we engage in an interpretative process that positions us in relation to an object. Our emotions are a key mechanism in how we relate to others, ourselves, and the world and how we make meaning of different situations, events, objects, and histories.[57]

Wetherell's (2012) conceptualization of affective practices makes affect palpable "in actual bodies and social actors, negotiating, making decisions, evaluating, communicating, inferring and relating" (p. 159). Affective practices thus describe the complex interplay of various components and modalities such as bodily sensations and functions (e.g., facial muscles, heart rate, sweat glands etc.), feelings and thoughts, social interactions and relationships, narratives and interpretive repertoires, social relations, and personal histories (Wetherell, 2012). In fact, this is what Ahmed's notion of impressions entails, as it "allows [her] to avoid making analytical distinctions between bodily sensation, emotion and thought as if they could be 'experienced' as distinct realms of human 'experience'" (p.6). Affective practices are patterned together in practical ways, forming and re-forming layers in ways that can interrupt, contradict, and build upon each other. Some affective practices might only involve a few contributing patterns with some fading away quickly while others "might be very densely knotted in with connected social practices" such that it reinforces affect, making it resistant and durable (Wetherell, 2012, p. 14). Wetherell (2012) uses the example of a panic attack to illustrate this point: "in a panic attack […] the push of the body and the power of a figuration of a situation as threatening are extreme and unusually resistant to any other ordering forces" (p. 13-14).

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[57] Perhaps Wetherell's critiques of cultural theorists like Ahmed lay more in the empirical data they choose to analyze (e.g., literary works, grand narratives, and policies) rather than the intricate emotion worlds of humans interacting, acting, and thinking in particular ways. For instance, Wetherell (2012) argues that "…emotion is above all a relational pattern and as such, I would say, is automatically distributed and located across the psychosocial field. Affect is never wholly owned, always intersecting and interacting" (p.24).

Wetherell (2012) uses the notion of practices to theorize affect as a flow or fluid and thus as ever-changing. While people actively engage in affective practices and are thus "agentic", they are also constituted by past practices and *as* they practice. Importantly, Wetherell (2012) rejects the Cartesian dualism between mind and body, instead conceptualizing affect as both cognitive and embodied, such that "the mental and social life of human agents is a whole which is greater than the sum of its atomised physical parts" (Crossley, 2001, p. 22).

Affective practices become routinized processes through repetition. Reckwitz (2002) defines practice as a patterned type of behaviour that consists of several interconnected elements including bodily and mental activities, objects and their use, and background knowledge that comes in the form of understanding, common sense, emotion, and motivation. A practice—a way of feeling, a way of emoting, a way of overcoming, a way of taking care of oneself, etc.—represents a pattern of multiple unique actions and experiences (past and present) that encourage one to reproduce the practice (Reckwitz, 2002). We can think of disclosing one's HIV status as a practice in the way that people have a routinized way of telling people they are living with HIV, leaving out bits and pieces of their diagnosis history they do not want others to know (Bruce et al., 2020; Hardon & Posel, 2012; Krüsi et al., 2018; Mackworth-Young et al., 2020). An individual functions as a "carrier" of a practice (imbued with routinized ways of knowing, understanding, and desiring) and also carries out social practices that do not have to be coordinated with each other (Reckwitz, 2002). Importantly, ways of knowing, understanding, and desiring are components and qualities of a practice in which the individual participates; they are not personal characteristics of the individual (Reckwitz, 2002). These practices are discernable not only to the individual, but also to others living in the same culture. A practice is

"thus a routinized way in which bodies are moved, objects are handled, subjects are treated, things are described and the world is understood" (Reckwitz, 2002, p. 249-250).

Finally, affect is praxeological, while "practices incorporate affectivity, delineating the role of affect in practices" (Wiesse, 2019, p. 134). Reckwitz (2016) argues that every social practice has an affective dimension such that "(1) affects are not subjective, but social; (2) affects are not properties, but activities; (3) affects are states of physical arousal, of pleasure or displeasure, directed at some definite person, object, or idea" (pp. 118-119). Wetherell's conception clearly sits in the camp of affect-practice scholarship in that she outlines a theory of affect as a practical accomplishment (Wiesse, 2019). In Wetherell's (2012) words, "affective practice is a figuration where body possibilities and routines become recruited or entangled together with meaning-making and with other social and material figurations. It is an organic complex in which all the parts relationally constitute each other" (p. 19).

Emotions are therefore not static entities that have preconfigured responses to particular stimuli; instead, affective practices allow one to consider the open and flexible patterns of shifting "bodyscapes", actions, and "subjective states" (Wetherell, 2015, p. 147). These patterns are constantly being configured and reconfigured, semi-routinized such that particular "affective repertoires emerge in bodies, in minds, in individual lives, in relationships, in communities, across generations, and in social formations" (Wetherell, 2015, p. 147). The concept of affective practices thus allows me to consider the ways in which emotions are 'out there' doing political and cultural work by sticking and solidifying to individuals, groups of people, events, places, and objects (Ahmed, 2004; Cvetkovich, 2002; Sedgwick, 2003). We also do something *with* these emotions in the sense that we use them to evaluate and construct ourselves, situations, people, and objects in particular ways (Wetherell 2012; Hochschild 1979, 1983, 2016). In this way,

affective practices are inter-subjective in that they can be held across a few or many people (Wetherell, 2012, p. 14). In other words, affective practices account for both the human work involved in managing affect and emotion but also the "super ordinate construction of affect and the process of subject and identity formation through the constituting power of what is being assembled" (Wetherell 2013a, p. 231).

## 3.2. Conceptualizing the Affective Narrative Self

Emotions are both 'out there' creating surfaces and boundaries through their relation to culture and politics (Ahmed, 2004; Cvetkovich, 1992) and routinized ways of being and relating (Wetherell 2012). Putting the selected authors into conversation allows me to explore the ways in which the patterning of affects, feelings, and emotions function in the way that people configure their affective narrative selves. In other words, it is the combination of feeling and meaning that comes together in people's narrative accounts of their HIV stories that PLWH locate their sense of self. Indeed, emotions are fundamental to our understandings of self (Lupton, 1998). As such, in this section, I think about the affective narrative self as it allows me to consider the felt and discursive elements of affects and how these are implicated in the ways in which people come to form particular conceptions of their identities.

Sociological identity theories, like those of emotions, are varied and complex. Identity has been defined as relational, fluid, embodied, (Lawler, 2014), performative (Butler,1990) and/or performance (Goffman, 1956), self-reflexive action (Giddens, 1991), intersectional (Crenshaw, 1989; 1991; Collins and Bilge, 2016), and/or requiring a sense of recognition by oneself and others (Alcoff, 2006). Some would argue that there is no clear, unified definition of identity (Lawler, 2014). As Wetherell (2010) contends, identity studies are methodologically and theoretically complex, laden with unsettled disputes over the meaning, significance, and the

source(s) of 'identity' that require ongoing reflexivity. Others, such as Brubaker and Cooper (2000), assert that we should avoid using identity as a theoretical concept altogether given its complex history and overuse. This section, far from offering a detailed review of this long and varied history,[58] seeks to outline a view of identity as an affective narrative configuration. Specifically, I outline a theory of identity as constructed through the affective practices and narratives that make up our daily lives. As the affective practices are storied in particular ways and over time, they calcify, forming into affective narratives that we take up from the stock of knowledge we mobilize to constitute our affective narrative selves. Affective narratives thus represent the histories, memories, events, and impressions (to use Ahmed's words) that make up our lives and that we use to configure who we are and how we want to act and be in this world. This section therefore seeks to explain how the self is constructed through narrative, drawing on the work of Paul Ricoeur, Arthur Frank, Stephanie Lawler, and Couze Venn to develop a theory of affective narratives and their role in the formation of the affective narrative self[59] to facilitate my analysis of participant stories about their experiences of living with HIV and HIV nondisclosure in the context of criminalization.

[58] For a more detailed history see: Wetherell, M. and Mohanty, C.T. (2010). *The Sage Handbook of Identities*. SAGE.
[59] I have been using the terms 'identity' and 'self' interchangeably thus far, but I favor the use of the word 'self' to place emphasis on "the more personal, ambivalent, reflective and reflexive sense that people have of who they are" while also recognizing its "public manifestations" or how identity is often invoked to refer to categories of race, gender, nation, class, sexuality (Lawler, 2014, p. 6) and, for the purposes of this study, victimhood, perpetrator, undetectable, detectable, HIV-positive, and HIV-negative. The configuration of an affective narrative self may involve these public iterations of identity categories and/or the personal and reflexive practices of making sense of who one is. Affective narratives therefore can provide the stock of knowledge with which to identify others or place oneself within an identity category and/or they can be mobilized in the reflexive work of understanding who one is. I also heed Lawler's (2014) caution that "while […] such [identity] categories are important both individually and collectively, they cannot in any way account for the complexity of identity as it is lived. For one thing, identities cross categories (no one belongs to only one category), and different forms of categorical identity must be managed. For another, publicly available categories of identity may not easily map on to how people live, experience and understand themselves within those categories. And, again, people's subjective feelings may not map on to the ways in which other people position and identify them." (p. 6).

### 3.2.1. On Narrative

Generally, narratives in scholarly work come up as an object of study, as a method, and/or as autobiography (Ewick and Silbey, 1995). I understand narrative as all three. First, with narrative as object I examine the way that narratives are implicated in the constitution of identity and people's understandings of living with HIV and experiencing HIV nondisclosure. Second, with narrative as method I employ a thematic narrative analysis to examine the interviews and lifelines produced by participants as well as a method for writing up the findings (more on this in chapter 3). Third, with narrative as autobiography and in the tradition of feminist scholars, I include personal narratives throughout this dissertation to position myself in the research and to explore the meaning of victimhood and health more broadly. In this way, I heed Ewick and Silbey's (1995) argument that sociology (and its disciplinary sister, criminology) *is* narrative in that the very act of writing a dissertation (or any form of scholarly work) is a form of narration. With this discussion on narrative, I want to emphasize how narratives that create binary distinctions between victims and "offenders", undetectable and detectable, healthy and unhealthy, fold into each other and thus may contain the seeds of their own destruction as our identities are formed in relation and interaction with each other and the institutions and structures that surround us.

For Frank (2010), a story is something that people tell about their lives, while a narrative(s) is a cultural resource that people use when formulating those stories – although maintaining a clear distinction between the two in our everyday usage of the terms is difficult. Harrington (2008) provides a most useful distinction between stories and narratives arguing that,

> Stories are living, local, and specific. They are the things we read in books and newspapers, hear on the bus, tell over dinner, and use to guide behaviour and experience. They refer to immediate, concrete events, people, scientific findings, and more. Narratives, however, are templates: they provide us with tropes and

> plotlines that help us understand the larger import of specific stories we hear, read, or see in action. They also help us construct specific stories of our own—including ones about our own experience—that others can recognize and affirm. We learn these narrative templates from our culture, not in the way we might formally learn the rules of grammar in school, but in the way we might unconsciously learn the rules of grammar at home—by being exposed to multiple individual examples of living stories that rely on them (pp. 24-25).

Stories are thus smaller and palpable as we use them in our day-to-day interactions while narratives provide an overarching frame and contain a discernable plot and sequence of events. I draw on these definitions to differentiate between the stories that participants tell me about their lives and the broader narratives they mobilize in that telling. As such, the narratives I produce in this dissertation are composed of multiple stories put together to form a framework, or what Harrington (2008) above refers to as "tropes" and "plotlines."[60]

For philosopher Paul Ricoeur (1983/1990), the work of linguists such as William Labov who focus on narrative structures and what he calls the "semiotics of the text" can only get at the "internal laws of a work of literature, without any regard for the two sides of the text" (p. 53). Semiotics involves deconstructing the structure of a text rather than showing how narratives work and the role of the reader/listener in composing and giving meaning to a particular text. For Ricoeur (1983/1990) narratives glean their meaning from how they are received by the reader/listener. As such, I draw heavily from Ricoeur's conceptualization of narrative to formulate the notion of the affective narrative self. How are emotions involved in the configuration of narratives? What kinds of memories, histories, and impressions do we draw upon as we create these narratives? What kind of affective practices are deployed and suppressed when we configure our life experiences into a narrative? How are emotions implicated in the

[60] I use this distinction specifically as a methodological tool in which I mobilize stories as a smaller unit of analysis to articulate moments in participants lives (e.g., diagnosis story, nondisclosure/disclosure story, treatment story, stories about criminalization etc.). While I use narratives as a lens through which to make sense of participant's stories and to place their stories within a narrative of my own creation.

refiguration of a plot or the kinds of interpretations we make when we hear others' stories? Who has the "configurational power" (Weir, 2020) to tell certain narratives about themselves?

Ricoeur (1983/1990) works with the philosophical problem of time (what is it and how do we, as humans, relate to it), arguing that we understand time through narrative. He contends that "time becomes human to the extent that it is articulated through a narrative mode, and narrative attains its full meaning when it becomes a condition of temporal existence" (Ricoeur, 1983/1990, p. 52). He makes this argument by outlining his theory of the *mimetic* feature of plot – a term which realists would suggest means to imitate, that narratives represent life, and/or that through narrative "one has captured something true" (Mattingly, 1998, p. 25). Ricoeur prefers to work with the mimetic activity of narrative in a more substantive way by making the case that narrative transforms, distorts, and/or makes life by way of the kinds of interpretations or 'readings' we undertake of particular stories. This aligns with the work of Frank (2010) who argues that "stories tell the truth, but stories tell the truth by twisting it" suggesting that stories are weaved together to show a particular window into reality (p. 88). Indeed, he argues, stories are not the best for telling *the* definitive or singular truth because they are told from memory which is subject to lapses and reconstruction (Frank, 1995). Ricoeur (1991b) stresses that "life is lived and […] stories are told" but that stories help to make sense of our lives (p. 32). To explain how this happens, he denotes three types of mimesis that work together to mediate narrative and time. Mimetic narrative comprises prefiguration, configuration, and refiguration. Ricoeur (1983/1990) is concerned with the "process by which the textual configuration mediates between the prefiguration of the practical field and its refiguration through the reception of the work" (p. 53).

By prefiguration Ricoeur (1983/1990) means the lived experiences that make up the narratives we tell. As Ezzy (1998) clarifies, “the historical lived experiences of ‘being in the world’ prefigure and lead to the symbolic quasi-fictive narrative interpretation” (p. 244). Prefiguration thus comprises a “pre-understanding of the world of action, its meaningful structures, its symbolic resources, and its temporal character” (Ricoeur, 1983/1990, p. 54). First, actions involve not just physical movement but goals “which commit the one on whom the action depends”; actions towards goals involve motives “which explains why someone does or did something, in a way that we clearly distinguish from the way one physical event leads to another”; and motives are held by agents “who do and can do things which are taken as *their* work, or *their* deed” and whose actions have consequences (Ricoeur, 1983/1990, p. 55). Mastering each of these elements in a narrative action gives one the “competence we can call practical understanding” (p. 55). This practical understanding becomes important in its relation to narrative competence.

Narrative competence involves an element of the “symbolic resources of the practical field” (p. 57). Ricoeur (1983/1990) argues that our actions can be narrated precisely because they are always already articulated by signs, rules, and norms, meaning they are “symbolically mediated” (p. 57). In other words, symbolism or “symbolic mediation” creates the cultural norms that give meaning and therefore interpretability or “readability” to action (p. 58). Put differently, moments that characterize lived experience have a prenarrative quality and, therefore, have no *intrinsic* meaning (Ezzy, 1998; Ricoeur, 1983/1990). These moments become *something* when they are composed into narrative and interpreted (Ezzy, 1998). As Ezzy (1998) explains,

> Interpretations are enabled and constrained by the text, but they are also anchored in the imaginative world of the reader. It is therefore a mistake to assume that lived experience is in some way separate from its narration—as if one were reality and

> the other fiction. Action is always symbolically mediated, with symbols acting as a quasi-text that allows conduct to be interpreted. (p. 244)

This readability and interpretability can be understood as an evaluation or judgement based on a "scale of moral preferences" that gives actions "relative value" such that one action is constructed as more valuable than another. These degrees of value, initially related to action, can also be extended to the "agents" of that action, such that they themselves are held to be good or bad, better or worse (p. 58). For example, many of the early narratives about HIV were imbued with moral value (gay plague, god's punishment of our sins, etc.). Indeed, recall that Treichler (1987) famously called HIV an "epidemic of signification" to describe the varying ways in which HIV/AIDS represents both a transmissible lethal disease and a social phenomenon that is characterized by a "chaotic assemblage of understandings" (p. 32). Narration thus inevitably involves a moral component such that "there is no action that does not give rise to approbation or reprobation, to however small a degree, as a function of a hierarchy of values for which goodness and wickedness are the poles" (Ricoeur, 1983/1990, p. 59).

Narrative competence also involves a temporal dimension "onto which narrative time grafts its configurations" (p. 59). Ricoeur (1983/1990) is particularly captivated by Augustine's conception of time as a threefold presence: "a present of future things, a present of past things, and a present of present things" (p. 60). This leads Ricoeur to define our relation to time as action that happens within time or a structure of "within-time-ness" or a "being in time [that] is already something quite different from measuring intervals between limiting instants; it is first of all *to reckon with* time and so to calculate" (Ricoeur, 1980, p. 173). We do this through language that denotes time (e.g., then, after, later, earlier, since, till, while, until, whenever, now, that) and expressions such as "'having time to,' 'taking time to,' [or] 'wasting time,'" (Ricoeur, 1980, p. 173). Storytelling places narratives 'in' time and brings into the present past experiences and

memories (Ricoeur, 1980, p. 173). For example, media representations of Black men who are criminalized for HIV nondisclosure consistently bring into the present historically racist ideas about Black men's virility and the 'monsterization' of Black men's sexuality (Persson & Newman, 2008; Kilty, 2021; Kilty & Bogosavljevic, 2019; Mykhalovskiy, Sanders et al., 2021; Mykhalovskiy, Hastings et al. 2016; Hastings, Mykhalovskiy et al., 2020). In other words, narratives "provide a means of conceptualizing people in the context of history: if the past is always interpreted through the present, then, equally this (interpreted) past informs the present" (Lawler, 2014, p. 32).

By configuration, Ricoeur (1983/1990, 1991b) means the ways in which events are composed into a narrative "whole." It is important to note that narratives are not always presented as a unified "whole" nor do researchers ever have the "whole story" because "claiming wholeness would finalize the story" (Frank, 1995, p. 103). Even though Ricoeur makes mention of a 'narrative whole,' narrative in Ricoeur's sense of the word is not something that is unified, fixed, and closed off but an active meaning-making tool or "agent of construction" that weaves and unweaves differences among people (Klepper, 2013, p. 1). This is exemplified in Ezzy's (2000) study of the narratives of people living with HIV, where he describes the notion of polyphonic narratives as,

> …characterized by overlaid, interwoven, and often contradictory stories and values. They are 'many voiced' in the sense that they explicitly contain a variety of different and often contradictory goals, values, temporal assumptions and attitudes. While all narratives contain contradictory elements, polyphonic narrators embrace many of the contradictions and tensions in their accounts rather than suppressing them. Stories about HIV as a source of sadness through lost friends and careers, or of rejection during a sexual encounter, were mixed with celebrations of the insight and self-understanding HIV had provided. (p. 613)

This understanding of narrative is in line with the way that Frank (2010) describes the act of emplotment, which he borrows from Ricoeur: "to emplot is to propose a plot that transforms

what are still incoherent things-that-are-happening into experience that has meaning" (p. 136). Emplotment is thus the fundamental organizing component of a narrative that mediates between prefiguration and refiguration (Ricoeur, 1983/1990, 1991b).

Importantly, some emplotments have an institutional foundation and connection; groups and institutions can impose particular stories on people through the act of emplotment (Frank, 2010). But people also resist these emplotments, which necessitates the need for people to have the "broadest range of narrative resources to work with" (Frank, 2010, p. 138). Yet, as Weir (2020) makes clear, the configuration of a plot also involves an element of "configurational power" or the "ability to legitimately organize a set of events and experiences into a narrative whole" (p. ii). Individuals cannot, with equal weight, narrate their experiences in the way they might want or with the kind of credibility needed for their story to be believed (Bakht, 2012; Porter & ten Brinke, 2009; Powell et al., 2017; Smith, 2012; Weir, 2020). This is particularly important when thinking about the ability of PLWH and other complainants who may or may not be accepted as credible to narrate their experiences outside of medical discourses that might construct them as weak or vulnerable and legal discourses that construct them as dangerous and in need of surveillance and control (Bakht, 2012; Caron, 2014; Fritsch et al., 2022; Frazee, 2023; McClelland, 2024; Porter & ten Brinke, 2009; Weir, 2020).

Given that emplotment turns disparate events and experiences into a narrative form (Lawler, 2014), narratives organize and give meaning to life (Frank, 2010, 2013; Mattingly, 2010, 1998; Plummer, 1995). Ricoeur (1983/1990) conceptualizes this element as refiguration, which restores the story to the world of action such that it "marks the intersection of the world of the text and the world of the hearer or reader" and "unfolds its specific temporality" (pp. 70-71). Readers and listeners interpret and produce narratives by interacting with the piece of text or the

person telling the story (Frank, 2010; Lawler, 2014; Ricoeur, 1991b). Narratives are also interpretations themselves (Lawler, 2014). When we narrate, we do so from our memories, which are interpretations of past experiences and stories (prefiguration), but we also interpret by way of selecting which events will make up a particular story (Frank, 2010; Lawler, 2014). Frank (2010) speaks of emplotment as an assumption that "life has an interpretive plasticity: what happens can be understood in diverse ways, and anticipations of what will happen become self-fulfilling prophecies, affecting what does happen" (p. 193). Similarly, for Ricoeur (1983/1990), the interpretative function *constructs* and *gives meaning* to a narrative: "the act of reading that accompanies the narrative's configuration … actualizes its capacity to be followed. To follow a story is to actualize it by reading it" (p. 76). Narratives are thus event and experience centred and do not only refer to past experiences; they also produce experiences for the audience (Mattingly, 1998). In other words, emplotment involves placing human interaction and action within a plot which has a beginning, middle, and end (Mattingly, 1998). Narratives are active in that they, for example, investigate human character, evoke meaning and emotion, and entice the listener or reader into a world (Mattingly 1998; Frank, 2010).

The mimetic activity (prefiguration, configuration, and refiguration) of narrative is summed up by Ezzy (1998) as follows,

> The narrative imagination prefigures lived experience by providing a symbolic structure and temporal schema of action. These events are then configured into a story with a central theme or plot that "mediates between the individual events or incidents and the story taken as a whole" [Ricoeur 1984, p. 65]. This story, or text, then encounters lived experience again in the world of the listener or reader who refigures the story as it influences his or her choices about how to act in the world. (p. 244)

The mimetic activity of narrative shows how narratives make life by way of 'doing' something, in the sense that stories are living 'things' that circulate. Like Ahmed's (2004) notion of the

stickiness of affect, narratives 'travel' through and within time, calcifying in our memories. For example, the stories of HIV from the early days of the epidemic in the 1980s as a deadly disease and gay plague lasted into the present such that HIV and PLWH are considered hyper-sexual and dangerous – especially if the story involves people of colour (Kilty, 2021; Kilty & Bogosavljević, 2019; Mykhalovskiy, Sanders et al., 2021; Mykhalovskiy, Hastings et al., 2016, 2020). Some narratives may stick to people or events, while others are more transient or temporary. Narratives and stories have a certain power to do political, cultural, and social work, but they also create and construct political, cultural, and social worlds. In other words, narratives not only structure our experiences, but they also make points *about* those experiences. As Ewick and Silbey (1995) found in their study of legal narratives, narratives are not just constructed within particular social contexts (e.g., the courtroom, the police station, the home, the school etc.), but *are* social practices constituted within those institutions. In other words, narratives contain and carry dominant cultural meanings and relations of power and are implicated in the production of those meanings and power relations (Ewick & Silbey, 1995; Frank, 2010; Lawler, 2014). Narratives are thus living entities that "breathe as they animate, assemble, entertain, and enlighten, and also deceive and divide people" (Frank, 2010, p. 16).

Frank (2010) identifies several different narrative capacities, each of which I take up in turn as they are important for thinking about what a narrative is and what narratives do as they are mobilized in different settings by different people, for different purposes, including the construction of one's identity. Frank (2010) writes that stories have the capacity to explain people's *troubles,* but they can also make trouble. Stories display and test people's *characters* as they do the work of responding to trouble. Stories therefore create stock character types that audiences draw upon when constituting their own character. By linking a character's actions to

consequences, stories have an *inherent morality* that informs our sense of what is good and bad, and how to behave. Stories may emphasize one perspective, persuading audiences that certain *points of view* are the most believable. Stories can be narrated in ways that leave *interpretation open-ended* in terms of what happened or how best to respond to an event. In this way, stories have a *truth telling* capacity while also balancing the production or presentation of multiple truths; stories thus "*become true*" in their telling (Frank 2010, p. 41).

Stories are *suspenseful* in that they remind people that life is characterized by ups and downs, aways keeping us 'on our toes'. Stories are thus *out of control* in that they have a "capacity to act in ways their tellers did not anticipate" (p. 35). Their out-of-control nature also makes them "tricksters" in that "stories readily take sides; they just refuse to stay on the same side… stories conduct both tellers and listeners to take different sides" (Frank, 2010, p. 36). Importantly, stories *resonate* in that they "echo other stories, with those echoes adding force to the present story" (Frank 2010, p. 37). Stories are told to be repeated, recruited, molded, and mobilized in future stories. Stories can "summon up whole cultures" and are "textures of resonances" (Frank 2010, p. 37). Since stories are stored in our memories, they are also great *shape-shifters* in that the plot and characters can be configured and reconfigured to fit multiple circumstances so that different audience members may readily identify themselves.

Frank (2010) emphasizes that stories are not only performed by those narrating, but that they themselves *perform*: "stories *do* things; they *act*" (p. 40). Storytellers act out the story in particular ways depending on their goal: reporting, convincing, instructing, indoctrinating, recruiting, amusing, generating sympathy or antipathy, or simply passing the time. Importantly, stories "do not cease to perform when they are not being told, after any specific performance ends. They remain *resonant* when they are not consciously remembered. The…location of that

resonance is in humans' memory traces; stories are held deep in memory" (Frank, 2010, p. 40). As such, stories live in a *symbiotic* relationship with people, objects, and places. Stories do not take shape without people; "we are born into stories that we depend on for our identities and that depend on us to perpetuate them" (Frank 2010, p. 38). This signal's Ricoeur's notion of prefiguration, that Venn (2020) argues is made up of two domains of memorization: the "psychical imaginary" or the "relay between the psychic and the cultural/social" and a "cultural unconscious" (p. 57). The former is one in which "feelings, desires, cathexes, and dispositions…fill with content the 'interiority' of the subject, thereby [constituting] the psychic domain as semiotic systems" while the latter is a "stock of narrative understandings of the world and of subjects" (p. 57). The interplay between these two domains articulates a complex process of corporeal and signifying practices that inform and is informed by configuration and refiguration (Venn, 2020). Finally, stories have the capacity to induce our *imaginations* such that "they make the unseen not only visible but compelling" as they surface our emotions (Frank, 2010, p. 41).

In short, narratives organize, structure, and even produce life through the act of prefiguring, configuring, and refiguring (Somers, 1994; Sommers & Gibson, 1994; Lawler, 2014; Ricoeur (1991a, 1991b, 1991c, 1983/1990). Narratives are constructed such that the stories we tell and the various events or 'episodes' we decide to include in our narrative are dependent on the particular social, political, and cultural milieu we are in (Holstein & Gubrium, 2000). As such, a person's narrative repertoire is contingent on their social location (Frank, 2010). Narratives can be shared amongst groups of people, but they can also be dividing forces that make visible the boundaries of our various social and cultural locations (Ewick & Silbey, 1995; Lawler 2014, 2005). Stories thus create the social: they "connect people into collectivities, and

they coordinate actions among people who share the expectation that life will unfold according to certain plots" (Frank 2010, p. 15). In this way, narratives *do* certain things and have capacities as they work for and on people. Most importantly, "people not only think *about* stories…[they] think *with* stories…stories give people their first system for thinking" about the world they live in and who they are (Frank, 2010, p. 47).

By mobilizing Ricoeur and Frank's work on narrative, I am able to explore how stories are actively constructed through and within time, place, and people and how they provide meaning to our lives. This active function of narrative can be thought of as a practice in the way we tell our stories and configure them in patterns that can be traced and routinized. Gubrium and Holstein (1998) characterize narrative practice as "simultaneously the activities of storytelling, the resources used to tell stories, and the auspices under which stories are told" (p. 164). By thinking about narrative in this way, I can explore how selves are made through narrative. I now turn to the notion of narrative identity to explain how narratives help us construct our sense of self.

### 3.2.2. From Narrative Identity to the Affective Narrative Self

In volume 3 of *Time and Narrative* (1984/1985) and in *Oneself as Another* (1992) (among other texts) Paul Ricoeur conceptualizes what he terms narrative identity. He argues that knowledge of the self is an interpretation,[61] that narrative is a "privileged mediation" for this interpretation, and that this mediation "draws on history as much as it does in fiction" (Ricoeur, 1991a, p. 188). Ricoeur (1991a, 1984/1985, 1992) investigates how historical (what was) and fictional (what could be) narratives reconcile the relationship between what he terms identity as sameness

[61] The idea of the self as interpretation is similar to Foucault's (1988) description of the self as a "reflexive pronoun" and Gidden's (1991) notion of the self as a "reflexive project."

(*idem*) and identity as selfhood (*ipse*). The former situates identity as something that "remains identical to itself over time" and the latter as something that "considers itself to remain the same being in spite of changes over time, for example, in a person's biographical history" (Venn, 2020, p. 45). Said differently, selfhood is characterized by one's reflexive ability while identity is a narrative configuration that results from this reflection (Ezzy, 1998). Here, Ricoeur is concerned with definitions of identity that emphasize uniqueness, similarity, and continuity.

According to Ezzy's (1998) interpretation of Ricoeur, "narrative identity constructs a sense of self-sameness, continuity and character in the plot of the story a person tells about him or herself." (p. 245). Ricoeur (1992) examines what he terms "*permanence in time*" or the problematic of personal identity in which the 'self' (ipse) intersects (or fails to intersect) with the 'same' (idem) regarding (p. 116). As Klepper (2013) explains,

> Personal identity is the mediation between two extremes: a person may have the strongest sense of self, of being a presence, of momentarily experiencing her/his actions as a fully conscious agent, but simultaneously disown her/his past selves and future accountability; or, a person may have an overwhelming sense of continuity and similarity, but hardly feel like an agent: an acting character who 'owns' her/his connectedness to the moment (p. 5).

In other words, Ricoeur is concerned with how we may still *be* the same person even though who we *believe* ourselves to be or how others may recognize us changes over time.

His answer to this problem is that in narrative configuration, our messy lived experiences are organized into a coherent[62] storyline, which gives a particular meaning about who we are (Ricoeur, 1992). For example, Williams (1984) demonstrates how the biographical disruption brought on by illness necessitates "narrative reconstruction" whereby people experiencing chronic illness "attempt to reconstitute and repair ruptures between body, self, and world by linking-up and interpreting different aspects of biography in order to realign present and past self

[62] See below for a more nuanced discussion about narrative coherence.

with society" (p. 197). In other words, narrative offers a way for people to reconstruct a sense of order from the messiness that chronic illness has brought about (Williams, 1984). Ezzy (1998) explains that narrative identity responds to critiques of the postmodern self as "pure illusion or philosophical smokescreen" by arguing that "narrative identity is coherent but fluid and changeable, historically grounded but "fictively" reinterpreted, constructed by an individual but constructed in interaction and dialogue with other people" (p. 246). Identity, therefore, is not something that is permanent, continuous, and fixed but rather a "mode of relating to being that can be characterized as selfhood" (Venn, 2020, p. 45).

Stories told about one's life are refigured by all the stories someone may mobilize in that telling (Ezzy, 1998; Holstein & Gubrium, 2000; Lawler, 2014; Ricoeur, 1983/1990, 1984/1985; Somers & Gibson, 1994); "this refiguration makes this life itself a cloth woven of stories told" (Ricoeur, 1984/1985, p. 246). Narrative identity involves both the narration and reading of a life story, the interpretation of which suggests a new insight into the self (Crowley, 2003). Somers and Gibson (1994) describe these as ontological narratives, or that which we mobilize when defining who we are, which then become a precondition for knowing what to do in certain situations. These actions, in turn, produce new narratives and new actions such that "people act, or do not act, in part according to how they understand their place in any number of given narratives – however, fragmented, contradictory, or partial" (Somers & Gibson, 1994, p. 61). Ontological narratives thus root identities in relations of time and space but are never fixed. They are embedded in and make up social life and help us make sense of, account for, and even predict the practices of social and historical actors (Somers & Gibson 1994, p. 61). Polkinghorne (1988) explains the process of making sense of our identity stating that,

> We achieve our personal identities and self-concept through the use of the narrative configuration, and make our existence into a whole by understanding it as an

> expression of a single unfolding and developing story. We are in the middle of our stories and cannot be sure how they will end; we are constantly having to revise the plot as new events are added to our lives. Self, then, is not a static thing or a substance, but a configuring of personal events into a historical unity which includes not only what one has been but also anticipation of what one will be. (p. 150)

Identity is thus (re)constituted and configured through narrative – our own and others such that life is lived in a "spiral movement of constant interpretation and reinterpretation (Lawler, 2014, p. 32).

Narrative identity is formed *within* this lifeworld[63] and in interaction/relations with others. Ricoeur's conception of narrative identity is therefore inherently social. However, there need not be a 'real' person with whom we interact to help form our narrative identities because we do this through our internalized or imagined intersubjective encounters; "the self dialogues with phantom imagined others who inhabit our thoughts and whose perspective we use as we narrate our past, present, and anticipated experiences" (Ezzy, 1998, p. 246). For example, Ezzy (1998) shows how Goffman articulates "institutionally sanctioned narratives" or how institutions construct and maintain narratives about patients indicating "the role of power and politics in the narrative construction of identity" (p. 249). Ricoeur's (1984/1985) concept of narrative identity allows me to challenge the notion of the neoliberal atomized individual by thinking of people as woven together in a "web of social relations" (Lawler, 2014, p. 32), a "knot in a network of intersubjective action and understanding" (Venn, 2006, p. 33), "webs of interlocution" (Taylor, 1989, p. 36), and a "choreography of co-action" (Venn 2006, p. 29). Indeed, "the story of my life is a segment of the story of your life" such that the stories of our lives become entangled (Ricoeur, 1996, p. 6). In this way, narratives of victims and 'offenders', undetectable and

[63] By lifeworld I mean the world in which we live out our lives as social beings, the intersubjectivity of our sense of self, or as Harrington (2006) describes, "the world of everyday communicative interaction" (p.342).

detectable, healthy and unhealthy, are woven together such that one cannot read one's story without reading the other.

Ricoeur's conception of narrative identity, however, lacks some nuance. For instance, not all experiences are coherent or are told in a linear manner and, in fact, sometimes do not necessitate a narrative (Strawson, 2004). Nonetheless, stories may provide structure and, therefore, a level of certitude in how one understands one's experiences (Klepper, 2013). As Meuter (2013) contends, "a narrative identity understood in this way is, however, not a static or seamless identity but a dynamic one that is undergoing permanent change and development and implies contradiction" (p. 37). This plasticity of identity is an important component when considering how people talk about their experiences. Indeed, when we narrate ourselves, we may never come to a final configuration: "one never arrives at a knowledge of 'who' oneself or the other *is*, one is always in a process of 'where,' 'when,' and 'how' one has arrived at this particular transitional moment" (Klepper, 2013, p. 28).

Identities are formed in particular social contexts that dictate the kinds of stories we are able to tell, suggesting that place is just as important as time in how we construct our narrative identities (Eakin, 2008; Holstein & Gubrium, 2000; Klepper, 2013). For instance, Eakin (2008) writes about a "narrative identity system" in which "the interpersonal exchange of self-narration is a rule-governed regime and […] the rules are enforced" by normative guidelines (p. 24). Protocols exist that determine how we should talk about ourselves, and these are often outlined in and through the institutions with which an individual regularly comes into contact: churches, courtrooms, meetings of Alcoholics Anonymous, school, etc. (Eakin, 2008). These protocols are what Meuter (2013) calls "model stories" that we mobilize to orientate our own lives and actions.

In this way, we may also be ascribed a particular narrative identity by others; others may *read* us in ways that we do not *read* ourselves.[64]

Here, I am thinking about Goffman's (1963) notion of social identity as the ways in which a person is characterized and categorized by others based on stereotypes, social roles, group memberships, and social expectations, and their personal identity which are the attributes and categorizations a person holds regardless of how others may perceive them. When there is a discrepancy between how a person understands themselves and the societal expectations placed upon that individual, people may experience stigma, or "an attribute that is deeply discrediting" and the stigmatized person is reduced from a "whole and usual person to a tainted, discounted one" with a "spoiled identity" (Goffman, 1963, p. 3-5). Some stigmatized people possess visible markers of difference and may therefore assume that their differentness is known; the discredited are thus often concerned with impression management (Goffman, 1963). Others, however, possess only invisible markers of difference and engage in information management to pass as normal (Goffman, 1963). According to Goffman's (1963) conceptualization of stigma, there are three types: "abominations of the body" which represent physical changes to one's body as a result of something like an illness; "blemishes of individual character" which he describes as aspects of people's personalities, such as a "weak will, domineering or unnatural passions, treacherous and rigid beliefs, and dishonesty" that are inferred from their experiences of such things as imprisonment, mental illness, addiction, unemployment, and homosexuality; and third,

[64] Sara Ahmed (2004) makes a similar claim about emotions: "The emotion does its work by 'reading' the object: for example, others might get read as the 'reason' for the loss of the object of love, a reading which easily converts feelings of grief into feelings of hate" (p. 13).

"tribal stigma of race, nation, and religion" that can be transferred through family (p. 4).[65] The characterizations that people are ascribed and the stigma they may experience are particular narratives that act as powerful tools of regulation, and may also become internalized, informing how one tells the story about their life.

That narrative identities are confined to specific rules also speaks to the social and power dynamics that are involved in a narrative configuration such that some people do not have access to certain narratives and thus the ability to freely construct their own narrative identities (Ewick & Silbey, 1995; Frank 2010; Lawler, 2014; Weir, 2020). For instance, the ways in which some enslaved Black people assimilated patriarchal definitions of male-female sex roles imposed upon them by white slave owners, or the "silence of the oppressed", when Black women "did not see 'womanhood' as an important aspect of [their] identity" and thus denied an important part of themselves in the hopes that if they worked to free themselves from racial oppression, then they would be liberated, disregarding the need to also fight for freedom from gendered oppression (hooks, 1981, p. 1). In its most oppressive form, when people lose or were never afforded access to certain narratives with which to counter readings of themselves by others or in the construction of their own identity, they may experience devastating consequences. For example, when PLWH are criminalized for HIV nondisclosure:

[65] That many of the stigmas Goffman outlines are health-related, makes stigma a useful concept in health research (Scambler, 2009; Susman, 1994; Weiss, Ramakrishna, & Somma, 2006) as well as other fields. Since his initial conceptualization of the term, scholars have examined how stigma is *lived* and *experienced* among racialized folks (Tabibi, 2012; Huckelbury, 2012), former and current prisoners (Munn, 2012), sex workers (Bruckert, 2012), men who have sex with men (Walby, 2012); people with chronic illness (Scambler, 2004, 2009; Gray, 2002), people who live with a mental illness (Kilty, 2012); and HIV/AIDS (Earnshaw & Kalichman, 2013; Lacombe-Duncan et al., 2020; Liamputtong, 2013; Lo Hog tian et al., 2021; Logie et al., 2011). Others have taken to thinking about the different kinds of stigma such as felt and enacted stigma (Scambler, 2004; Jacoby, 1994); structural and symbolic stigma (Hannem, 2012; Hannem & Bruckert, 2012); self-stigma (Steward et al., 2008); anticipated stigma or stigma consciousness (Pinel, 2004). Indeed, the research on stigmatized identities is rich and I do not have the space to review these studies here nor is this study focused on stigma. However, any study that involves PLWH must consider the effects of stigma.

> they quickly lose the right to share their own account of what happened. Their story is sensationalized and told for them by police, courts, and media. The accused is denied access to autonomy and privacy and is often framed as a violent perpetrator who has intentionally aimed to 'spread' HIV to others and thus needs intervention and incapacitation via forms of state-sanctioned violence. Through the dichotomous victim versus perpetrator logic of the criminal legal system, the process of criminalization transforms people into objects of risk and threat. The blunt violence of the criminal law flattens complexity and nuance, which limits our collective understanding of how these cases came about in the first place. (McClelland, 2024, p.3)

Narratives of guilt, innocence, and redemption become the 'model stories' by which PLWH accused of HIV nondisclosure and complainants come to be understood, which justifies state-sanctioned violence or support (Bogosavljević & Kilty, 2021; Kilty 2021; Kilty & Bogosavljević, 2019; McClelland, 2024).

Narrating identity is also an affective and embodied practice where "desire and loss and pleasures are played out in this choreography" – an element sorely missed in Ricoeur's work on narrative, time, and narrative identity (Venn, 2006, p. 29). If we form our identities through stories, emotions are the building blocks and foundation of those stories.[66] To discern those emotions, we must look to the affective practices of our daily lives. Narratives produce affective readings about specific individuals and groups of people, moments in history, objects, and spaces (among others) (Ahmed, 2004). Through these readings, narratives also become saturated with affect, giving them an affective quality that (re)produces those very readings, making these readings stick. These readings then become a prominent way of knowing oneself and others. Affect thus forms the fundamental elements of these stories and, in turn, our emotional selves (Lupton, 1998) – what I call the *affective narrative self*.

[66] It is also important to note that criminalized people, for example, do not get to feel their complex feelings because they are framed as perpetrators who do not have the 'right' to feel because they caused harm.

I use the term *affective narrative self* to describe the "sense" in "sense-making" or how we articulate a "sense of ourselves" through narratives. I am not thinking about "sense" in terms of our five senses (touch, smell, sight, hearing, taste), although this can certainly be part of any analysis of an affective narrative self. Instead, I am more interested in definitions of "sense" that focus on feeling, understanding, recognition, and registering. As a noun, the Oxford English Dictionary defines "sense" as "that which is felt or perceived by the body or mind," a "feeling or emotional sensation *of* a specific kind", an "impression … *of* something abstract or intangible, as a … pervading tone or mood", and "… a recognition of an aspect of one's own character…" ("sense: noun", 2016). As a verb, "sense" can be "to interpret or ascribe a meaning to" a narrative or experience, "to feel…", "to understand, know, grasp", and "to perceive by intuition or instinct; to be or become aware of…" ("sense: verb", 2016). In section 3.1, I discussed how feelings act as sense-making tools, particularly when translated into emotions. As Gould (2009) argues, when we name an emotion,

> …a transformation occurs, a reduction of an unstructured and unpresentable affective state with all of its potential into an emotion or emotions whose qualities are conventionally known and fixed. And that attempt gives specific form to an inchoate but pressing bodily sensation, shaping it, delimiting it, fixing it into the emotion or emotions that have been named or expressed. An emotion, in other words, brings a vague bodily intensity or sensation into the realm of cultural meanings and normativity, systems of signification that structure our very feelings. (Gould, 2009, p. 21)

By thinking about the affective narrative self, I am interested in how affective experiences that make up life and come about through different moments of contact, are made sense of through narrative and how our feelings shape the very readings of those narratives. In other words, I contend that narratives help us to organize what we are feeling and to ascribe meanings to those

feelings, yet our feelings can also shape and give meaning to narratives as they are read in particular ways and taken up in, potentially, different ways.[67]

The affective narrative self depicts the interplay between our identities as they are configured through stories and emotions. As Lupton (1998) argues,

> Our concepts of our emotions are often integral to our wider conception of ourselves, used to give meaning and provide explanation for our lives, for why we respond to life events, other people, material artefacts and places in certain ways, why we might tend to follow patterns of behaviour throughout our lives. (p. 6)

For example, Venn (2006) speaks of this relation between stories, identity, and emotions in terms of 'the gaze' where we 'see' ourselves through the gaze of the other. In reading Fanon's *Black Skin, White Masks*, Venn (2006) makes the case that through the gaze of the white man the Black person "lacks in being" but only if the Black man sees himself with the eyes of the white person (p. 31). The white man's gaze refuses to recognize Fanon as a human being, thus solidifying him as the Other – the Black/savage (Venn, 2020). This "transformation of the Black body into an object of its own gaze" attributes the Black body as being hateful and hated such that they "assume the *character of the negative*" (Ahmed, 2004, p. 57). In this way, hate establishes the identity of the person through the gaze of the racist colonizer – a gaze that articulates an *affective narrative* that imposes a collective identity onto a group of people.

Above, I discussed how narratives help us to organize and make sense of what we are feeling, but narratives themselves can be affectively charged such that affects organize and make

[67] Ahmed (2004) does a lot of this work when examining the connection between emotions and narratives that read certain people, groups, events etc. in different ways. The affective narrative self that I developed here is a play on much of her work, but it combines it with Frank and Ricoeur's ideas about narrative to understand how people negotiate the various narratives that make up their lives. This includes how they may resist or take up these narratives in the way they tell stories about themselves. They may also choose specific pieces of other's and 'grand' narratives that they want to use to configure a particular sense of themselves. Configuring an affective narrative self is an inherently creative project and is therefore messy and incomplete.

sense of narratives.[68] I use the concept *affective narratives* to denote how narratives become saturated with affect such that they can make an impression. They might stick around for a while, picking up different affective qualities and intensities as they move about, getting told and used in varying ways. As they circulate, we may also change how stories are narrated, replacing components of the story, and making new interpretations. Indeed, it is the affective or emotional attachments to some stories and not others that make some narratives stick, and reproduce over time, while others may fade.

Affective narratives are mobilized in people's interactions, thoughts, habits, and in the configuration of their sense of self. For example, racist colonial affective narratives that construct Indigenous, Black and other people of colour as brutish, uncivilized, and unworthy of respect or dignity, appeal to the recognition of a wrong or injustice done to a particular group such that these affective narratives become central to the oppressive and violent actions and practices of those dominant groups (Venn, 2020). As Bonilla-Silva (2019) writes, racialized emotions tend to be independent of the historical process and relations that construct them, "yet actors' racial subjectivities and their accompanying emotions are the product of historically-specific dynamics and do not generate innocent identities" (p. 5).

Since we not only come to understand our affective experiences through narratives and some narratives become affectively charged as they circulate, the affective narrative self is

[68] It is important to note that while all narratives do not become affectively charged, the narratives that circulate around HIV and PLWH are attached to different emotions that give meanings to the virus and the people living with it. Here I am thinking about Ahmed's (2004) argument that "what *connects us* to this place or that place, to this other or that other is also what we find most touching; it is that which makes us feel. The differentiation between attachments allows us to align ourselves with some others and against other others in the very process of turning and being turned or moving towards and away from those we feel have caused our pleasure and pain" (p. 28). This requires thinking about what connects us to certain narratives and what makes some narratives persist over time. Like Ahmed (2004), I contend that this connection stems from that which makes us feel feelings that are attached to narratives such that they shape our narrative configuration and refiguration. Of course, it may not always be the same feeling as the narrative shifts over time and in some instances, it may stop making us feel.

composed of both self-narratives and collective narratives, the latter being a resource in the configuration of the former (Yuval-Davis, 2006). For example, HIV is a collective narrative, made up of multiple stories, from different time periods, each imbued with their own meaning(s), that permeate people's (both those who are HIV negative and positive) understandings of themselves and others (Treichler, 1999). There are stories about the origins of HIV, stories about HIV as scientific progress, stories about who is 'at risk' and 'risky', community stories of political organizing, resistance, and resilience, stories of death and survivorship, and stories about criminalization and stigma to name but a few.[69] All of these stories form into affective narratives that impress upon people such that they become part of how PLWH configure their sense of self and their relations to others and the institutions (e.g., law, public health, medicine and ASOs and other HIV/AIDS service organizations) that manage their care and treatment. They are also important in how people who are HIV-negative read or interpret HIV/AIDS, PLWH, and the actions PLWH take or do not take, such as decisions to disclose or not to disclose.

While McClelland (2024) sought to "disarticulate" PLWH criminalized for HIV nondisclosure from dominant narratives (what I would call affective narratives) that construct them as guilty, risky, and threatening, my aim is to understand how PLWH may resist or assimilate parts or whole aspects of these narratives as they configure their affective narrative selves. I am also interested in how these affective narratives shape beliefs about HIV nondisclosure. I aim to trace how these affective narratives are central to self-understanding and therefore how they are also about belonging, for the stories told "often relate, directly or indirectly, to self and/or others' perceptions of what being a member in such a grouping or

[69] See footnotes 2-7 in the introduction for a detailed list of these stories and the cultural and academic productions in which they are memorialized.

collectivity (ethnic, racial, national, cultural, religious) might mean" (Yuval-Davis, 2006, p. 202). Stories of belonging can be thought of as a kind of affective narrative as they

> [Capture] more accurately the desire for some sort of attachment, be it to other people, places, or modes of being, and the ways in which individuals and groups are caught within wanting to belong, wanting to become, a process that is fueled by yearning rather than the positing of identity as a stable state (Probyn, 1996, p. 19).

This desire for belonging, for place, is a central feature of identity formation (Probyn, 1996). I am interested in exploring how PLWH talk about and give meaning to their life experiences through affective narratives and the social, historical, political, and cultural underpinnings of 'being-in-the-world' and 'being-with-others'. Importantly, conceptualizing identity as formed through affective narratives allows me to consider the relational and embodied aspects of our self-understanding.

## 3.3. Final Thoughts

This chapter conceptualizes the affective narrative self as a way that we make sense of who we are through emotions and narrative. I understand identity as formed in relation to others such that one's identity is made up of past stories (one's own and others) that one has configured and refigured in particular ways, mobilizing different affective narratives along the way. This theoretical framework allows me to consider the ways in which participants affectively narrate their sense of self in the context of living with HIV. It allows me to understand how people negotiate new HIV identities borne from biographical disruption and configured through the nexus of medical, moral, and legal modes of regulation and seropolitics in the era of HIV criminalization and normalisation. I am particularly interested in how these affective narrative selves may lead to constructions of difference, and subsequently inequalities, along virological

and moral lines including how they reinforce binaries of guilty/innocent, victim/perpetrator, victim/survivor, undetectable/detectable, and good/bad.

The theoretical framework I outlined in this chapter provides an innovative conceptual tool with which to bring the HIV epidemic eras into conversation as people narrate their stories in the present. I can therefore "think of all the periods of AIDS [as] […] linked, ongoing, and co-present" (Juhasz & Kerr, 2022, p. 6) for it is the narratives of HIV/AIDS and living with the virus that connect the past to the present. It thus allows me to trace the narratives that surfaced from the earlier era of HIV/AIDS crisis and how they shape people's accounts of their experiences in this epoch characterized by a normalization of HIV/AIDS. For instance, I am curious about how previous narratives of victimhood, safe sex, and mutual responsibility for sexual health within the HIV/AIDS community are taken up or rejected by PLWH as they narrate their affective narrative selves today. I am also interested in bringing together past stories of crisis into dialogue with present stories of living with HIV, such that in the current context of HIV normalization we see how crisis functions as a "symbol that indicates an easily missed, almost forgotten presence: there and not there, effecting what comes before and after it, but doing so gently, quietly, while maintaining a magnetic pull" (Juhasz & Kerr, 2022, p. 222).

I return now to the question I posed earlier in this chapter in section 3.2.1 as they represent some of the questions that guide me. How are emotions involved in the configuration of narratives? What kinds of memories, histories, and impressions do we draw upon as we create these narratives? What kind of affective practices are deployed and suppressed when we configure our life experiences into a narrative? How are emotions implicated in the refiguration of a plot or the kinds of interpretations we make when we hear others' stories? Who has the "configurational power" (Weir, 2020) to tell certain narratives about themselves? For the

purpose of this dissertation, I focus specifically on the first, second, and third questions to investigate the histories, memories, and impressions that PLWH mobilize as they configure their narrative selves and the affective practices that participants focus on in the telling of their story. In the next chapter, I detail the methodological process I undertook to answer these questions.

# Chapter 4.

# Methodology: A Passionate Criminology

*Our title also flags our sociological interest in the passions and corporeality of sociality, alluding to the importance of recognizing desire within sociology. The desire to know is itself one of the most powerful passions, motivated by desires to know one's own self. The structure of these desires changes the forms of knowledge produced and privileged.*

- Ann Game & Andrew Metcalfe (1996, p. 5)

*I want to insist that it is this question of affect – misery, rage, passion, pleasure – that gives feminism its life.*

- Clare Hemmings (2012, p. 150)

I take the title of this chapter from Game and Metcalfe's (1996) articulation of a "passionate sociology" which they argue is a "sociology concerned with the sharp and specific experiences of life; not seeking to dissolve these experiences in the pursuit of idealized abstraction, it wants to *feel* them, to be on the edge" (p. 5). A passionate criminology recognizes that emotions animate life, our research projects, and the discipline itself. Nnaemeka (2004) argues that theorizing has become a universalizing enterprise; instead, she proposes that "the possibilities, desirability, and pertinence of a space clearing that allows a multiplicity of different but related frameworks from different locations to touch, intersect, and feed off of each other in a way that accommodates different realities and histories" (pp. 362-363). A passionate criminology, therefore, encourages a creative imagination of alternative methods, methodologies, theorizing, and frameworks for studying criminological topics. It involves engagement with emotions, not as an epiphenomenon but as central to investigating the political and cultural work that emotions do in structuring criminal justice policies, spaces, and legal decisions, among other criminological

interventions.[70] It is about engaging in knowledge production as fully embodied and sensual beings who are attuned to emotions and feelings rather than casting them aside as biases. A passionate criminology, therefore, is about *feeling* wholeheartedly, embracing fully how emotions are implicated in the topics we choose to study, the methods we choose to conduct our research, and the epistemological and ontological positions we take up and reject.[71] Emotions are important signals to us as researchers because they alert us to things that might be problematic in our projects (Mario & Bogosavljević, forthcoming). In other words, a researcher's emotions can be a North Star, guiding us toward more ethical and relational ways of conducting research.

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[70] See, for example, Dilts, A. (2021). Carceral enjoyments and killjoying the social life of social death. In K.S. Montford & T. Chloë (eds.) *Building Abolition* (pp. 196-223), London: Routledge; Jacobsen, M. & Walklate, S. (2019). *Emotions and Crime: Towards a Criminology of Emotions*, Abingdon: Routledge. The body of work on carceral geography that links theoretical discussions of affect with space: Doughty et al. (2016). Practices of emotional and affective geographies of sound. *Emotion, Space and Society*, 30, 39-41; Turner, J. et al. (2022). 'It's in the air here': Atmosphere(s) of incarceration. *Incarceration*, 3(3), 1-19; Lachapelle, S. & Kilty, J.M. (2023). "Use your common sense to navigate, and you're gonna get along okay": Exploring the sensorial politics of attunement, survival, and resistance in Canadian federal prisons. *Emotion, Space and Society*, 48. Recent work on emotions and federal prisons in Canada: Fayter, R., & Kilty, J. M. (2023). Walking an Emotional Tightrope: Examining the Carceral Emotion Culture(s) of Federal Prisons for Women in Canada. *The Prison Journal*, 104(1), 24–45; Lachapelle, S. & Kilty, J.M. (2023). « Vous étiez soulagé, mais en même temps terrifié » : explorer les géographies émotionnelles des"admissions et des libérations dans les prisons fédérales canadiennes. *Criminologie*, 56(2), 15–41; Bogosavljevic, K. and Kilty, J. M., & (2024). Playing "Mental Judo": Mapping Staff Compassion in Canadian Federal Prisons. *Punishment & Society*, 26(5), 880-897. Scholarship on the criminalization of HIV nondisclosure and emotions: Bogosavljevic, K., & Kilty, J. M. (2023). Prosecuting and Propagating Emotional Harm: The Criminalisation of HIV Nondisclosure in Canada. *Canadian Journal of Law & Society*, 38(1), 109–128; Bogosavljevic, K., & Kilty, J. M. (2020). "Now, the question here is who to believe": Criminalizing HIV Nondisclosure, Emotions, and Determinations of Credibility in R. v. Smith. *Emotions and Society*, 1–17; Kilty, J.M. and Orsini, M. (2019). Counteracting Shame, Recognizing Desire: Managing the Emotional Reverberations of Criminalizing HIV Nondisclosure in Canada. *The Sociological Review*, 67(6), 1265–1281. Lastly, the field of law and emotions: Bandes, S. and Blumenthal, J. (2012). Emotion and the Law. *Annual Review of Law and Social Science*, 8(1), 161-181; Bandes, S. (2000). *The Passions of Law*. New York: New York University Press; Karstedt, S. (2002). Emotions and Criminal Justice. *Theoretical Criminology*, 6(3), 299-317; Maroney, T. (2006). Law and emotion: A proposed taxonomy of an emerging field. *Law and Human Behaviour*, 30(2), 19-142. This is not an exhaustive list of work that includes emotions as a substantive part of analysis of different criminological topics, but these bodies of work are perfect examples of what I mean when I say that a passionate criminology must include emotions as a research topic.

[71] A perfect example of a passionate criminology that is beginning to take shape in the discipline is the edited collection *Demarginalizing Voices: Commitment, Emotion, and Action in Qualitative Research* (2014) by Jennifer M. Kilty, Maritza Felices-Luna, and Sheryl C. Fabian. In this book, scholars from across Canada document the messiness of conducting qualitative research with marginalized groups on difficult research topics such as medically assisted death and interviews with individuals convicted of sexual offences, for example. They discuss their emotional journeys throughout their respective projects and are honest about the challenges they faced.

Like the epigraph to this section notes about sociology, a passionate criminology involves a desire to know that is motivated by a desire to know oneself. These are desires borne from our positionality which inevitably shape how we conduct the research, the kinds of questions we ask, the methods and theories we use, and the analysis.[72] It would be a lie to say that deciding to do a PhD on the topic of victimization was not a personal decision. I began this journey questioning what it means to be a victim because I am a victim (by legal standards), although I would not necessarily use that term when talking about my experiences. In fact, I never knew how to talk about my experiences until working on this dissertation. As such, this chapter not only provides an examination of the methods I undertook to complete this research, but also a self-exploration of my desires as they relate to my experiences and this project. A desire to know how to speak about and move past what I went through; a desire to understand how others who have experienced a victimizing event narrate their own lives; a passion for rejecting dualisms between objectivity/subjectivity, rational/irrational, body/mind in research (and in life more broadly); and a desire to fight against systems and structures of power that refuse to listen and instead narrate our stories for us.[73]

This chapter reflects upon my positionality, research practices, the ethically important moments (Guillemin & Gillam, 2004) that came up during the research process, and describes the more technical aspects employed to conduct this work. I structure this chapter in two parts. I start by providing an account of a feminist affective methodology where I discuss some of the

[72] I am not arguing here that research is *always* or *must* be about learning about the self. When we conduct qualitative research, we inevitably learn about ourselves through the research process as we reflect on our own positioning and how it might impact the project from the theories we use to the findings we produce. Perhaps this desire to know oneself is more about a desire to be a more ethical researcher.

[73] The irony here is that doing a PhD in which I interviewed people is doing the very thing I want to fight against: creating a narrative about others. I emphasize throughout this methodology and the analysis chapters that what I have written herein is but one narrative configuration of people's stories informed by my own theoretical framework and positioning.

project's epistemological concerns and outline my intersectional feminist and constructivist positionality and emotional journey. In the second section, I dive into the methodological specifics of the research process I undertook to conduct this project.

## 4.1. Feminist Affective Methodologies and Epistemologies: Knowing With and Through Emotion

I approach research, knowledge production, and my role as researcher,[74] with a feminist affective curiosity spurred on by what Clare Hemmings (2012) describes as "affective dissonance" or a "judgement arising from the distinction between experience and the world" (p. 157). This dissonance might turn into a sense of injustice that jolts one into action to rectify that feeling or situation, what she terms an "affective shift", or it might encourage one to suppress that feeling (p. 157). She argues that "in order to know differently we have to feel differently", and so, an affective shift and the dissonance preceding it, may produce a "politicised impetus" to think critically about the world and thus to imagine alternative worlds (p. 150). Sara Ahmed (2017) asks us to reflect on when feminism became a word that spoke to us. For Hemmings (2012) it was her rage at the social and cultural inequalities between, for example, genders, sexualities, and races, and the knowledge systems that normalize these.

My own feminist affective curiosity was sparked by my experiences of child and adult sexual assault (more on that below) and witnessing the emotional abuse suffered by my grandma at the hands of her husband, my grandfather. As such, "becoming a feminist involves coming up against the world" and feminist theory is born from this becoming as we "navigate a way through the world" (Ahmed, 2017, pp. 19-20). Our feelings and experiences generate a feminist curiosity

[74] This is reminiscent of Obioma Nnaemeka's (2004) words, "our journey with and into knowledge is an ever-evolving, boundless love affair that sweeps us along with our neighbors, our ancestors, and those we have neither met nor 'read' ('ndi banyi si/our people said' not 'ndi banyi delu/our people wrote') (p. 366).

to ask different questions, to challenge the ideas and structures around us, to have a sense of "affective solidarity" (Hemmings, 2012) with each other, and to mobilize our anger and frustration to engage in what bell hooks (2015) calls "talking back" – a speech act "that is no mere gesture of empty words, that is the expression of our movement from object to subject—the liberated voice" (p. 9). In other words, "talking back" involves "daring to disagree", to have an opinion, to stand up to authority, and speak truth to power (hooks, 2015, p. 5) – what Ahmed (2017, 2023) terms a feminist killjoy. A feminist epistemology thus "introduces new problems including the politics of knowledge and the impact of the social status as well as the sexed body of the knower upon the production of knowledge" (Alcoff & Potter, 1993, p. 2). To this, I would add, as several feminist queer, Black, Indigenous, other women of colour, and disabilities scholars have argued (Collins, 2000; hooks, 2015; Ahmed 2017; Hemmings 2012; Simpson 2017; Frazee, 2023), not only the sexed body but the racialized, queer, and disabled bodies of the knowers.

To consider how power relations structure the experiences of PLWH and those who were unknowingly exposed to the virus due to nondisclosure, I work from a constructivist paradigm and adopt a feminist stance that understands knowledge to be socially and subjectively constructed, multiple, and grounded in lived experience. Wedding constructivism with feminism requires privileging knowledge gleaned from lived experience and beginning from the premise that people are not simply acted *upon* by discourses that seek to define them but rather are agentic in that they negotiate and challenge dominant constructions. As Nnaemeka (2004) puts it,

> Feminist discourse raises crucial questions about knowledge not only as being but as becoming, not only as a construct but as a construction, not only as a product but as a process. In other words, knowledge as a process is a crucial part of knowledge as a product. By injecting issues of subjectivity and location into epistemological debates, feminist scholarship seeks, as it were, to put a human face on what is called a body of knowledge and in the process unmasks this presumably faceless body.

> By focusing on methodology (and sometimes intent), feminist scholarship brings up for scrutiny the human agency implicated in knowledge formation and information management. (p. 363)

Working within a constructivist and feminist paradigm I not only problematize the dualities (Becarra & Castorina, 2018) between emotion/rationality, victim/offender, victim/vector, and body/mind, health/illness, undetectable/detectable but, as Nnaemeka (2004) writes, I put a human face to a body of knowledge. Keeping with the constructivist and feminist ontology, I understand reality to be both socially created and grounded in the experiences of PLWH and those who were unknowingly exposed to the virus due to nondisclosure, and that these social constructions within the research context are recreated through interactions between researcher and participant (Guba & Lincoln, 1994; Frank, 2010; Brown & Strega, 2005). As such, I use methods of data collection (interviews and lifelines) that allowed me to question those dualities and to put their experiences and emotions at the forefront of analysis.

I confront positivist science's claim that there is an objective 'Truth' or one true reality (Moosa-Mitha, 2005). Instead, a feminist positioning grounded in a constructivist epistemology advocates that there are many *truths* "contextualized within subjective and specific lived experiences" (Moosa-Mitha, 2005, p. 54). Throughout the analysis I center participant's stories that describe how they interpret and make meaning of victimhood and nondisclosure, health and illness, and treatment. I place these narratives in conversation with broader cultural, social, and political narratives about HIV. Given that for constructivists "language is performative and creates social categories" (Gaudet & Robert, 2018, p. 18), I employ a thematic narrative analysis (see below for detail on how the analysis was undertaken) in this project to explore how people story and thus make sense of their experiences (Frank, 2010; Pemberton, Mulder, et al. 2018; Pemberton, Aarten et al., 2018; Riessman, 1990, 2008). As such, I am not interested in whether

people are telling some objective “truth” but rather trust people to be experts in their own experiences and lives, and therefore situate their stories as true for them in that moment and as having emerged in a particular context.

### 4.1.1. The Emotional Researcher

As the epigraphs to this chapter indicate, research is a highly subjective endeavour (Maso, 2003). As researchers we bring with us our own emotions, intuitions, experiences, meanings, values, commitments, presuppositions, prejudices, and personal agendas to the table – including in ways that emerge spontaneously as unconscious reactions in the field (Bruckert, 2014; Fabian, 2014; Hannem, 2014; Munn, 2014) – what some refer to as conceptual baggage (Kirby & McKenna, 1989). Importantly, our emotions and feelings are not conceptual baggage, which implies something weighty and negative, but rather that they are sense-making and navigation tools that are essential to the research process (Barbalet, 2011). As researchers we cannot turn off our feelings to achieve a robotic objectivism (Bergman Blix, 2015; Barbalet, 2011). As Bergman Blix (2015) argues, “keeping emotional distance, trying to be ‘objective,’ runs the risk of either missing the emotional complexity of the situation, or attributing our emotions to the participants we are studying” (p. 131). Instead, we engage in what Bergman Blix (2015) terms “emotional participation” in the research process which helps us sense emotional shifts in the field and be more attuned to participant emotions (p. 127).

By being open about my emotional participation, I accept the constructivist and feminist epistemological and narrative scholar’s position that knowledge is created through interactions between investigator and participant (Frank, 2010; Guba & Lincoln, 1994; Riessman, 2008) and therefore that what we know and come to know is co-created with and through our stories, emotions, feelings, values, and experiences. I was honest about my emotional participation

throughout the fieldwork, by taking notes of my own thoughts, emotions, prejudices, moments of disagreement or agreement with participants (particularly those that were shocking or surprising), frustrations, joy, accomplishments, and moments of awkwardness and ease that I had with participants. Through journaling I aimed to improve the trustworthiness of results by conditioning my approach to analysis and documenting the ways in which my own experiences, emotions, and values shaped interpretation. I also had ongoing discussions with my supervisor about my emotional responses to some of the more difficult interviews and my analytic struggles, including the emotional turmoil of applying my conceptual lens to the data. In this section and throughout the rest of this chapter, I discuss my positionality, emotional participation, and offer an account of my own affective narrative self.

***On Positionality***

As a feminist researcher, I cannot deny the normative ways that my own intersecting identity markers shape this research. For example, as a young, neurodivergent, cis-gendered heterosexual woman, HIV-negative, a white Serbian immigrant, and student. I am also a "victim" of child sexual abuse and adult sexual assault even though I do not identify as a victim or even a survivor, and I am someone who has received a STI diagnosis in the past. These experiences prompted the research itself, including the theoretical, epistemological, and ontological positionings I take up, the methods I used to conduct the research, and the research questions that guided this project. I questioned why I never felt like a victim. Did I repress the memories of that child sexual abuse or was I too young to understand what was happening that I never fully formed my self-understanding as a victim? If so, how do we come to form our identities as victims? Do we call ourselves victims because that is what the law says we are? What does it even mean to be a victim? Is it being the weak passive woman so often associated with that word

or is it just a fleeting feeling until we feel we have survived that experience? How are these feelings racialized, sexed, gendered, classed, ableist etc.?

I am simultaneously someone who has not been diagnosed with HIV, strives to be an ally with people living with HIV and AIDS through my involvement in the CCRHC, a victim of sexual assault, and someone who has been diagnosed with a STI. This positionality put me in a very interesting position as I conducted interviews. On the one hand, I understood the experiences of the women I interviewed who are living with HIV and who had experienced sexual violence. I also empathized with the women who felt betrayed by and angry towards their sexual partners for not disclosing their serostatus prior to engaging in sex. In fact, an older white woman who I have named Natasha and who lived in an African country for several years talked with me for more than two hours about how she came to live with HIV and then several more hours after the interview about how she was considering pressing charges against her ex-partner in Africa. I sensed her rage (even though she was soft-spoken) about how her partner infected her, bled her dry financially, and cheated her in various ways. I had mixed feelings, at times feeling she was justified in wanting to report her ex-partner to the local authorities but was also frustrated that she would consider reporting him to the police when ostensibly, she chose to be in a relationship with someone knowing she would have to support them.[75]

[75] I never spoke with Natasha about the feelings I had after the interview. To be honest, I did not wrap my head around these feelings until much later when I had time to sit and reflect on our interview. I write about this here even with the potential of Natasha one day reading these words because I think it is important as researchers to be open and honest about our own judgements and feelings when we are conducting interviews and when we are doing analysis.

On the other hand, I never reported the sexual assaults I experienced and so found it difficult to sympathize with aspects of Natasha's story.[76] My parents made the decision not to report the childhood sexual abuse I experienced when I was very young. I still remember my father telling me that we would not be going to the police because it would make me re-live everything and cause further harm. We were also new immigrants at the time, trying to settle into life in a new country and my family had an aversion to becoming involved in the criminal justice system out of fear that there could be negative implications with respect to our immigration status. In a way, I am thankful to them for making that decision for me. I went on with my life thinking that what happened was not 'that bad' and so (I think) it had little effect on my life

[76] According to the most recent General Social Survey (GSS) on victim's satisfaction with the justice system and on reporting victimization to police, sexual assault continues to be the most underreported of any crime measured by the GSS, with 6% of incidents in 2019 having come to the attention of police (Cotter, 2021). The survey found that victims of self-reported sexual assault were more likely to report a lack of confidence in the police (17%) compared to those who were not sexually assaulted (9%) (Cotter, 2021; Conroy, 2024). Victims of sexual assault were more likely than those who experienced physical assault and robbery to state that they did not report to police because they thought the incident was not important enough (65% versus 40%), they considered the incident to be a private or personal matter (58% versus 37%), and they did not want the hassle of dealing with the police (57% versus 40%) (Cotter, 2021; Conroy, 2024). Other common reasons given by victims of sexual assault answering the GSS for not reporting to police were that they thought the perpetrator intended no harm (46%), they feared or did not want the hassle of the court process (42%), they felt shame or embarrassment (42%), they did not think it could be reported (40%), they felt they would not be believed (30%), they thought reporting would bring shame or dishonour to their family (26%), and they thought the police would be biased (23%) (Cotter, 2021; Conroy, 2024). These findings are supported in the literature as well. Victims of sexual assault have mixed feelings about involving the police. Some victims want to report because they believe that reporting to the police will help protect other women and hold the person accountable (Johnson, 2017). Women are more likely to report sexual assault to authorities if they are informed about the procedures and policies for reporting, feel confident that institutions will handle their reports appropriately (Spencer et al., 2020) and if the attack was so violent that it required the attention of medical professionals and/or involved weapons (Carbone-Lopez et al., 2016). However, Carbone-Lopez et al. (2016) found that victims in their sample did not report sexual assaults involving penetration as often as attempted attacks and other types of sexual assault like sexual contact. They suggest that the latter type of sexual assault resulted in more shame, which could explain why this type was reported less (Carbone-Lopez et al., 2016). Victims who do not want to report to police cite reasons such as fear linked to perceptions that police will not believe them as officers often hold rape myth beliefs that women are responsible for their sexual victimization or that they lie (Johnson, 2017; Murphy-Oikonen, McQueen, et al., 2022; Murphy-Oikonen, Chambers, et al., 2022) and the social repercussions of coming forward with their experiences (Lathan et al., 2023) especially for women of colour who reported community and cultural norms and expectations as one of the reasons for not disclosing their sexual assault (Ullman et al., 2020) and sex workers who feared losing their jobs (O'Doherty, 2011); feeling ashamed, embarrassed, or somehow responsible for their attack which is particularly true of male victims of sexual assault (Weiss, 2010) and women involved in sex work and who use drugs or alcohol (Carbone-Lopez et al., 2016; O'Doherty, 2011); and knowing the person who harmed them (Johnson, 2017; Spencer et al., 2020). Reporting to police is therefore mediated by the victim's personal circumstances, past experiences of violence and involvement with police, support and pressure from family and friends, and social location, including their gender, race, class, age, sexual orientation, etc. (Carbone-Lopez, 2016; Cotter, 2021; Johnson, 2017).

(although my therapist would probably disagree). When it happened a second time, I again did not report it because I did not recognize the event as a sexual assault until much later, when I was in university learning the legal definition of sexual assault. I hold the perspective that reporting these experiences to the authorities *may* not help and *could* lead to more harm for the "victim" – a view I vehemently hold for instances of HIV nondisclosure.[77] I believe that criminalizing HIV nondisclosure does not make us safer, that it perpetuates harm against PLWH, that it does not increase disclosure practices, and that it reduces the willingness of people to get tested thereby increasing the risk of transmission and the spread of HIV. Having read about how women, and in particular women living with HIV, are treated by the criminal justice system, I put Natasha in touch with organizations like HALCO who would be able to provide her counsel and information. I never heard from her again after that conversation. Was this the right choice? Maybe.

Interestingly, my experience of sexual assault and rejection of a victim label did not come through in how I framed the project. Instead, I leaned heavily into the normative framing of people who experienced HIV nondisclosure as victims. In every piece of documentation, from the recruitment material to the interview guide, I was assuming that people living with HIV feel

[77] I do not mean to say that the authorities never help victims of sexual assault, but wish to acknowledge the literature that points to the secondary victimization experienced by victims when they do come forward with experiences of sexual assault (see for example: Campbell & Raja, 1999; Doe, 2012; Du Bois, 2012; Ehlrich, 2012; Murphy-Oikonen, McQueen, et al., 2022; Murphy-Oikonen, Chambers, et al., 2022) and the illusion that the criminal justice system and victim impact statements brings closure to victims (Bandes, 2021, 2009, 1996; Ruparelia, 2012). I am also thinking about visions of justice that victims hold that do not always align with a punishment narrative. For example, McGlynn and Westmarland (2019) found that victims identified a kind of kaleidoscope justice to refer to justice that is "a continually shifting pattern, constantly refracted through new circumstances and understandings. The variety of patterning resonates with victim-survivors' sense that justice is not linear, but has multiple beginnings and possible endings. Justice is complex, nuanced and a difficult to (pre)determine feeling. Justice is a lived, ongoing and ever-evolving experience and process, rather than an ending or result" (p. 186). Key elements of justice for victims include: wanting consequences, such as punishment and accountability; recognition of their traumas; to be believed; to have a voice by being actively involved in criminal justice processes; to be treated with dignity and respect; to increase prevention of and education about sexual assault; and connectedness which entails a being valued as a whole person in society, not just a victim, survivor or piece of evidence (McGlynn & Westmarland, 2019).

like victims – even though I tried to avoid doing so given that my project was questioning the very notion of victimhood. One of the ASO executive directors I contacted was very quick to call me out[78] on my use of the word victim stating that,

> It can't be assumed that all people living with HIV would view their experience of contracting as being victimized, and if they did at the time, their relationship with the word 'victim' may have changed over time. It CAN be part of the picture, obviously, but it's about individual perspective, experience, and definition. (Executive Director of AIDS Service Organization)

She was particularly concerned that the word "victim" might dissuade some people from participating, writing that it also went against the Denver Principles in which PLWH explicitly refuse to be called victims. I politely responded to every question she had in a detailed email and offered to meet with her over Zoom. She did not want to meet and was satisfied with the answers I gave, agreeing to share my recruitment material and offering to help facilitate knowledge mobilization. Based on her feedback, I changed how I framed the project in the documents I sent to AIDS Service Organizations, removing the word victim/victimhood and instead writing,

> The purpose of the study is to examine how people living with HIV/AIDS and HIV negative people feel about experiencing HIV nondisclosure in order to better understand the criminalization of HIV nondisclosure in Canada. Specifically, the researcher is interested in feelings about being diagnosed and living with HIV, feelings related to experiences of a partner not disclosing their HIV status prior to sex, and feelings about nondisclosure and disclosure generally.

This subsequently changed how I was approaching the interviews, in that I explained to participants that I would be asking questions related to how they felt when their partner did not disclose their serostatus to them prior to sex. Nonetheless, since some participants did not organically talk about victimhood while others did, I had to explicitly ask participants if they felt like a victim, a survivor, none of those subject positions, or something else at any point in their

[78] I very much felt called out by the executive director and remember calling my supervisor in a panic to strategize how to respond.

HIV story, given that this was one of the goals of the project. Some participants identified as victims, but not necessarily because of their HIV seropositivity or nondisclosure, but rather because of other harmful experiences such as sexual assault, assault, stigma, the law on HIV nondisclosure, and systems like public health and immigration. To completely exclude discussions of victimhood would have been inappropriate given that the law on HIV nondisclosure makes some people victims and PLWH into perpetrators.

That I experienced sexual assault facilitated rapport with some participants while hindering my ability to empathize with others. This positionality had repercussions throughout the research process, which I describe below. I now discuss the steps I took to carry out this project.

## 4.2. Research Methods in Pandemic Times

I begin this section with a brief discussion of the project I planned before the COVID-19 pandemic and my initial REB application. The ethically important moments (Guillemin & Gillam, 2004) I experienced while conducting this research are scattered throughout section 4.2.[79] Section 4.2.2 outlines the steps I took to collect data including recruitment, interviews, and the lifeline activity. Section 4.2.3 turns to the data analysis phase where I discuss working with emotions, transcription, and thematic narrative analysis. In section 4.2.4 I discuss some of the strengths and limitations of this project, including working with emotions, and in section 4.2.5 I outline steps taken to ensure methodological rigour in this qualitative research project.

[79] I do this following Rivers-Moore (2016) who wrote her methodological appendix in the same way. She intertwines the straightforward description of the steps she undertook to conduct her fieldwork with the ethically challenging moments, to be honest and open about the "human detail that academics occasionally let slip through the veneer of professionalism" (p. 180).

### 4.2.1. The Project that Did Not Happen and Applying to the Research Ethics Board

When I began planning for this project in Winter 2020, before the world shut down because of the COVID-19 pandemic, it looked somewhat different. I aimed to conduct in-person interviews in Ottawa and Vancouver and focus groups with PLWH in Ottawa who would draw their individual lifelines in a group setting. Then the pandemic happened, and those plans shifted. I prepared my REB application – the procedural ethics component of the project (Guillemin and Gillam, 2004) – at the beginning of the pandemic when we were still usure what the public health restrictions would be or how long they would last. I wrote the application with two possible scenarios, one in which I was able to conduct in-person interviews and one in which I would conduct them virtually via Zoom or over the phone. Given the REB's concerns with the focus groups (see below) and the continued lockdowns we experienced, I removed the focus group component and instead asked participants to do the drawing on their own and to debrief the drawing with me in a second virtual meeting.

Truth be told, I had high hopes for the original plan. The participants and I were to gather and spend time being creative while eating some pizza – as a starry eyed, novice researcher I had envisioned a social atmosphere where I could observe emotions as they happened. Then reality hit and precluded me from gathering with participants in person. The REB pointed out that there was in fact no way for me to ensure the safety of participants in these settings given that people might potentially disclose something that could have legal repercussions. This was especially worrying if conducted over Zoom where people could record on external devices. So, really, the pandemic and the REB helped make sure I did not put participants in a potentially harmful position – an oversight brought on by my excitement and naivete.

### 4.2.2. Data Collection

In this section I outline the difficulties of entering the field, the steps I took to recruit participants, details about which organizations I contacted and the cities from which I recruited, and a description of the sample and sampling procedure. I then discuss the two types of data collected: interviews and lifeline drawings.

***Entering the Field, Recruitment, and Sampling: Getting to Know the Participants***

Given the nature of the pandemic, recruiting participants was a very slow process because building rapport with gatekeepers over email proved difficult.[80] This was exacerbated because many of the organizations I contacted were busy shifting their programs, work schedules, and services from in-person to online. This undoubtedly increased the number of emails they received, relegating my recruitment emails to the bottom of the to do list where they were often lost in the pile. Nonetheless, the pandemic, which necessitated a shift from in person to virtual interviewing, made it possible to expand my recruitment areas such that I contacted AIDS service organizations, housing services, clinics, and other HIV-related non-profit organizations[81] in Vancouver, Toronto, Ottawa, Barrie, Oshawa, Kingston, Brampton, Peterborough, London,

[80] At this point in the project, I had just started working on the CCRHC so I did not have the relationships in place to help facilitate recruitment. Building relationships takes time and doing so over Zoom proved to be even more difficult.
[81] These include: Ottawa - *AIDS Committee of Ottawa*, *Bruce House*, *Ottawa Inner City Health*, the *Gay Men's Sexual Health Clinic*, *MAX Ottawa*, *Wabano Centre for Aboriginal Health*, *Sandy Hill Community Health Centre;* Vancouver - *Pacific AIDS Network*, *AIDS Vancouver*, *Afro-Canadian Positive Network of BC Society*, *Dr. Peter AIDS Foundation*; Toronto – *HALCO*, *PASAN*, *AIDS Committee of Toronto*, *Asian Community AIDS Services*, *The Black Coalition for AIDS Prevention*; Ontario – *The Gilbert Centre*, *AIDS Committee of Durham Region*, *PARN*, *AIDS Committee of North Bay & Area*.

Kitchener, North Bay, Thunder Bay, Hamilton, Guelph, Sudbury, and Windsor. To participate, participants had to have experienced HIV nondisclosure in a sexual encounter.[82]

In addition to recruitment, I used a snowball sampling method (van den Hoonaard & van den Scott, 2022), I recruited N=48 participants, but I am only using interviews from 44 participants because four were with people who were diagnosed with HIV as a result of a blood transfusion or injection drug use.[83] All but one participant identified as living with HIV; this person, although not diagnosed with HIV, was not told of his partner's serostatus prior to sex and is included in this study given that one of the goals of the project is to explore the affective narratives related to victimization among people who experienced HIV nondisclosure from sexual partner(s). By including organizations that specifically catered to racialized and/or 2SLGBTQ+ populations, I was able to secure a diverse sample that included men, women, trans, two-spirit, people who identified as heterosexual, gay, bisexual, and representation from different racial groups including white, Black, Indigenous, Middle Eastern, South Asian and Southeast Asian, Latino, and Indo-Caribbean.[84] Broken down by socioeconomic status, 44% of participants stated that they were middle class, 26% identified as low middle class, 23% were low income, and 7% were working class. Lastly, the age of participants ranged from 24 to 73 with highest number of participants (N=15) in the 50-59 range. All but one woman identified as

[82] See Appendix K and L for the recruitment posters and social media post. I asked participants if they had experienced nondisclosure in a sexual encounter in the pre-interview screening. They had all said yes, and I agreed to interview them. However, through their stories, it was revealed that some people's partners were not aware of their status, yet participants still described this as a nondisclosure experience even though legally, this set of circumstances would not qualify as HIV nondisclosure. I decided to include these participant's stories because I take their interpretation of the event as their truth and because it shows the messiness involved in interpreting the law as people navigate their lives and understand their experiences.
[83] I opted to do these interviews regardless of whether they fit the inclusion criteria because they answered the call and we had set up a meeting to talk. These interviews are going to be a useful comparison for a journal article about different feelings of victimhood based on the particular transmission scenario.
[84] Since some categories only have one participant, I chose not to include a breakdown of these demographics for the sake of anonymity.

heterosexual and all but one of the men identified as gay. Of the white participants, 50% identified as heterosexual, 45.8% identified as gay and 4.2% as bi-sexual meanwhile 55% of the racialized participants identified as heterosexual, 40% identified as gay, and 5% as bisexual. The participants included mothers, daughters, fathers, sons, nurses, artists, people who were diagnosed in Canada, in the US, and in Africa, people who have been long time HIV/AIDS activists and peer workers, people who have lived with HIV for years and people who were more recently diagnosed, and people who have disclosed their status publicly and people who keep their status secret.

### ***Interviews in Pandemic Times***

Interviews provide a forum through which people can share their thoughts, emotions, memories, and ideas in their own words rather than in the words of the researcher (De Vault & Gross, 2014; Reinhartz, 1992). Online interviews offer some convenience for both participant and researcher. Researchers can conduct interviews across the world as long as participants have access to the internet and a device that can support Zoom's features. Online interviews also allow both participants and researchers the ability to squeeze in interviews without the need to travel or incur child care costs. This convenience meant that participants would sometimes get distracted by other members of the household, in particular their children. Not being able to conduct the interview in a neutral place, participants would sometimes be cautious about the information they told me, especially given the sensitive nature of the interview topic. For example, when interviewing a few different women, I could sense that they were talking more quietly and that they would often pause to check if they heard their children waking up or walking into the room. This meant that there were limitations in the confidentiality that I could offer participants and

had to trust that they would choose a space/place which offered them the privacy they required to feel comfortable speaking openly.

Researchers also cite Zoom's video and recording components as advantages to conducting interviews in an online setting (Gray et al., 2020). Being able to see participants gives the online interview more of an in-person feel than a telephone interview, however, this does not apply to participants who did not feel comfortable turning on their camera. As someone researching emotions, Zoom's video feature was very useful so that I could see people's facial and bodily reactions, like an in-person interview. However, the feeling of the space in which an in-person interview is conducted, as well as the feeling of sitting across from someone, has a different feel from[85] the online environment. Upon further reflection, I started to feel quite uneasy about online interviews especially when participants would talk about how they felt dirty and less than because doctors and clinic staff would step away from them when they learned of their HIV status and put on personal protective equipment to talk to them. For example, I wrote in my field notes that,

> I couldn't help but feel that by doing these interviews online, I was just another person creating another physical barrier between myself and the participant. I know that this is the norm now because of the pandemic and that we must put up barriers to protect each other because COVID-19 is more contagious than HIV. I just feel an overwhelming sense of grief and frustration that I won't do these interviews in person – to have that human element.

Conducting interviews online creates an interesting feeling of closeness and distance with the participants. You are at once in this person's home (if they had their video on) and a stranger. The video aspect of Zoom made it personal and almost easier to build that sense of rapport with participants, but it also felt like an invasion into their and my own personal space. This resulted

[85] I use this word purposefully to indicate how the affective atmosphere of online interviews is drastically different from that of in-person interviews. Online, the mood and feeling are more distant and cold, while in-person interviews invite warmth and more embodied ways of relating (but I recognize that this is not always the case).

in an uneasy feeling where I felt that my own home was turned into 'the field.' Thankfully, I was living at my parent's house at the time and was able to conduct the interviews in the basement so that I could separate 'the field' from my personal bedroom space. This was important because the interviews were emotionally draining and I had to create a space where I could leave that behind and reset for the next interview and for my own mental health.

### *Interview Process*

I made sure to obtain oral consent for the interviews and the lifelines so that no participants' names are connected to the project.[86] Given that participants shared information with me that is sensitive and potentially incriminating, maintaining confidentiality and anonymity is especially important (Ogden, 2014). Indeed, without the ability to promise confidentiality and anonymity, the relationship between the researcher, participants, the community under study, and the broader citizenry may be threatened. The interviews were conducted from December 2020 to June 2021, at a time that was most convenient for the participants, and each interview lasted anywhere between 30 minutes to two and a half hours; each participant was given $40 cash through e-transfer or a wire transfer through Western Union to compensate for their time.

The interviews were semi-structured (Gaudet & Robert, 2018) in nature. The more structured component of the interviews involved collecting demographic information by way of close-ended questions pertaining to gender, race, socio-economic status, sexuality, and age[87] and "did you feel like a victim." The semi-structured questions were posed using the narrative interview technique which involves questions that are more open ended (Riessman, 2008). For

[86] See appendix E through H for the oral consent forms given to participants.
[87] Given that I understand identity as a constructed phenomenon, these questions were formed as such: "how do you identify in terms of gender, ethnicity, nationality, and sexuality." By posing this question in this way, I offered participants the opportunity to define their own gender, ethnicity, nationality, and sexuality rather than giving them preformed options to choose from.

example, I started every interview with the question "tell me your HIV story" to invite participants to provide extended accounts of their experiences. Asking this question sometimes meant that I would not have to ask any of the questions on my interview guide because they addressed them in their storying. This approach contributed to the variations in interview length. I structured the interview guide in a chronological order that included questions related to participants' lives before being diagnosed with HIV, their diagnosis, living with HIV, disclosure, and how they feel about the criminalization of HIV nondisclosure.[88] Often, by starting the interview with the open-ended question "tell me your HIV story", participants would naturally recount their histories with each of these components, although, not always in that order. This meant that I simply had to probe further to elicit the information that participants may not have mentioned (Riessman, 2008). Other times, participants' answers to this question were short, which meant that I had to rely more on the interview guide. These interviews were particularly challenging because I often felt a deep sense of frustration and angst at their short answers, giving me nothing to probe further. Or maybe I was not skilled enough as an interviewer to know what to probe.

For example, my interview with Samantha, a trans sex worker, was particularly challenging for several reasons. Samantha would often provide short and to-the-point answers; this threw me off and was made worse by the fact that I felt the most distant from her because of our very different positionalities. I felt like I could not relate to her even though I tried, which often led to awkward moments—maybe it was my effort to relate that made the situation more awkward. In fact, the entire interview felt awkward (transcribing it was even worse) as I probed about why she felt suicidal, lonely (which felt so icky), and how being diagnosed with HIV

[88] See appendix A and B for the interview guides.

changed her life. With regards to the last point, she would respond by stating "everything had to change" and when I would ask what she meant by "everything" she seemed to get frustrated with me, answering very bluntly,

> Everything. Like I had sex with people for money, to eat and pay for my life every single day. And all of a sudden, I'm HIV positive. So, like, everything had to change [said with a furrowed brow and frustrated tone as though I should know what changed].

I felt incredibly awkward when probing, but I also realized that this was part of the interview, and I wanted her to explain her feelings in her own words.

Toward the middle of the interview, I could sense that Samantha wanted to finish because she was starting to move about her room and going off camera to vomit (at least this is what it sounded like). When I asked her if she wanted to take a break so she could get settled, she said she wanted to keep going because she would not be settled until she received the money from the interview. I felt so uneasy and, in that moment, agreed to keep going with the interview because she stated that she wanted to finish. In hindsight, I should have stopped the interview or offered to pay her right then and there so she would not have to wait till the end of the interview. In the context of the COVID-19 pandemic, conducting online interviews, and sending e-transfers, I thought that it made sense, given the flow of the interview and all the technical details I was juggling, to send the money once we were finished. Doing it this way, I ensured I had the time to carefully input participant's information into my banking or Western Union applications. Had we conducted the interview in person, I would have given Samantha the envelope of cash at the start.

This is a decision that I feel deeply shameful and guilty about. Did I make her feel coerced into finishing the interview? This was certainly not my intention, and I would never withhold or deny paying a participant. Yet, my actions, regardless of my intentions, may have

made it feel like coercion. Alternatively, Samantha may not have felt coerced at all and just wanted to get the job done because she had committed to doing the interview. This is one of those ethically important moments in which I had to make a split-second decision. Reflecting upon this choice, it may have been the wrong one to make. Certainly, moving forward, I will endeavor to pay participants at the start of the interview. While this decision haunts me, I will learn from it and strive to be a more ethical human and researcher. No researcher is perfect, including me.

Probing is an interesting practice on its own. How much does one probe? How do we know when to stop? For example, probing Samantha about her experiences of feeling lonely and like no one loves her felt so unpleasant, especially because she started to cry. I do not generally have a problem with people crying in front of me (other than it makes me want to cry along with them, like the way that yawns are contagious) and know how to react well in these situations. In the research context, particularly when exploring emotions, how do we know when to just move on, to let the moment happen and sit in silence as the person feels their feelings, or to keep asking questions when the person has stopped crying? These are the moments that the REB cannot help with, and that we, as researchers, must rely on our gut feelings to navigate. As I was conducting the interviews, I opted to either move on automatically or ask them if they want to move on.

Since narratives are important “meaning-making structures” (Riessman, 1993) and since my epistemological position posits that research is co-constructed (Guba & Lincoln, 1994), I also worried that my own beliefs about who is a victim and who is not would influence the way that I talked with participants, and thus that I might encourage participants to feel a certain way about their experiences – especially as I probed participants for further information, often asking them

if they ever felt like a victim. To try to mitigate this, I kept a research journal where I wrote down my thoughts, emotions, and biases after every interview. I tried to remain critical of how I behaved during interviews, which often led to sleepless nights where I would question if I was being too much of a therapist, too friendly or not friendly enough, whether I was interjecting too much or not enough, and whether I was showing too much or too little emotion.

Interviewing (especially during a pandemic) brought with it a set of emotionally distressing moments that I struggled with throughout data collection. This became particularly difficult as at times I conducted up to three interviews in one day. For example, I wrote in my field notes about the first interview of the day that particularly struck me and how I managed my emotions for the second interview,

> The first interview (Alex) hit me really hard. I don't know if it's because he is young and my brother's age or because he was just recently diagnosed, or it was this sense that I got that he is this really good, sweet guy. I just felt a rush of emotions (sadness) come after finishing the interview. I sat at my desk and just cried. It felt like an elephant was sitting on my chest (probably a panic attack). Do I feel this way because it's my overwhelming need to help people and I'm now realizing that I can't do that nor is it my job? The second interview was better although I felt more like a machine. Maybe that was because I was tired from the first interview or maybe it's because I was trying to detach myself from the process.

Overtime, the weight of hearing and taking on other people's stories built up until I experienced what Yuen (2011) calls emotional paralysis. I felt despair, hopelessness, and anger. The most frustrating thing about having these feelings, is that I could not do anything about them. I could not solve my participants' problems. In this despair and after about the 20th interview, I started to realize that I was feeling emotionally distant from my participants. When I was conducting interviews, I felt a sense of urgency to get the interview done. I was not engaging as much as I was when I first started. I could not take on these stories anymore because of how emotionally overwhelmed I was feeling in relation to what I had heard.

### *Lifelines*[89]

After each interview, I also invited participants to take part in a creative activity where they were asked to draw timelines of their HIV story. I explained the instructions briefly, and if they agreed, we set up a time to meet again to debrief the drawing. The debrief offered an opportunity for the participant to tell me what they wanted to depict rather than me interpreting their drawing. In the end, I obtained 25 lifeline drawings from participants. Most of these participants were female (N=14), white (N=13), heterosexual (N=14), middle class (N=15), and between the ages of 40-59 (N=14).

Lifelines are a "visual depiction of an individual's life events in chronological order" and include interpretations of the events drawn (Gramling & Carr, 2004, p. 208).[90] That said, lifelines have been critiqued for the way they restrict accounts to simple time linearity and sequences of events, making them difficult to use with people who do not experience time in a linear fashion (Adriansen, 2012; Bagnoli, 2009; Jackson, 2013; Monico et al., 2020). Yet, these same researchers show that lifelines or timelines, as they are more often called in the literature, can be useful for visually representing different ways that time is experienced (Adriansen, 2012; Chen, 2018; Jackson, 2013; Kolar et al., 2015; Monico et al., 2020). Indeed, Jackson (2013) recommends that "researchers should encourage participants to construct their own meaning of time and placement of life-events" (p. 427). This flexibility allows for variation in how people choose to depict their life events. For example, Kolar et al. (2015) describe how some drew "list-like timelines" while others drew their life events chronologically with lots of text, while others

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[89] There is also a vast body of literature on body mapping in HIV research that similarly aims to tell stories through drawing, painting, or the use of other methods of artistic expression to create body maps that visually represent aspects of people's lives, their bodies, and the world they live in (Gastaldo et al., 2012). The use of artistic methods to help PLWH make sense of their diagnosis and experiences is not new and this component of the research adds an important contribution to this body of work.

[90] I do not use the lifelines in this dissertation to explore experiences of time specifically. Nonetheless, I recognize that this is a fruitful area of study for future research, and I discuss it in more detail in the conclusion section.

had “continuous-line” timelines in which they used a line, spikes, dips, angles, waves, and curves to represent the positive and negative dimensions of their experiences. Chen (2018) describes something similar in that her participants drew timelines that were linear, a mixture of cartoon drawings and texts, and colourful and pictographic. Lifelines can provide participants the opportunity to order and give different meanings to their life events (Adriansen, 2012; Monico et al., 2020) if they so choose, but it can also allow for creative ways of depicting how they experience time.

Lifelines, therefore, do not have to be drawn in chronological order or in a linear manner (Chen, 2018; Kolar et al., 2015), and when I explained the instructions (see Appendix I and J), I left it open for participants to decide how they wanted to draw them. In the instruction sheet, participants were asked to draw significant life events onto a “traveling line” and to visually document or express their feelings in relation to their experiences (Martin, 1997, p. 262). I told participants that the drawings could contain variations in how they wanted to depict their lines – squiggly, ascending, descending, snaking, cliffs, spiraling, jagged edges, straight, or wavy (Martin, 1997). These variations could correspond to how they felt about that event/life moment. For example, Martin’s (1997) clients used ascending lines to represent “‘well-being’ and ‘happiness’” while descending lines suggested “‘depression’, ‘hitting bottom’, ‘anger’, and ‘illness’” (p. 262). Jagged edges symbolized “‘stressed out’, ‘anxiety’, ‘rough going’, and ‘frustration’” while spiral lines depicted “‘confusion’, ‘out of control’, ‘going in circles’, ‘dizzy’, ‘going crazy’, and ‘going nowhere’” (p. 264). I told participants to label each event or milestone as a picture, image, symbol, or sign. Unlike Martin (1997), I advised participants that they were free to write down words as some did not feel confident in their drawings and wanted to add lexical markers. Chen (2018) argues that timelines provide insights into how participants view

time in relation to their illness journeys. Ultimately, timelines offer participants a way to make sense of their experiences away from language (Chen, 2018; Kolar et al., 2015; Gramling & Carr, 2004; Guenette & Marshall, 2009; Gutiérrez-García et al., 2021).

By being open about the 'rules' of the assignment, I avoided pre-structuring how participants would depict their experiences, which led to interesting variations in how they drew their lifelines. For example, some participants did not represent their lives in chronological order, with one participant painting a strawberry as a different form of the 'line' and another painting an image of swirling colours (found on page xii of this dissertation), while others drew zig-zag lines with their life events in chronological order with no symbols (see figure 1 and 2 below).

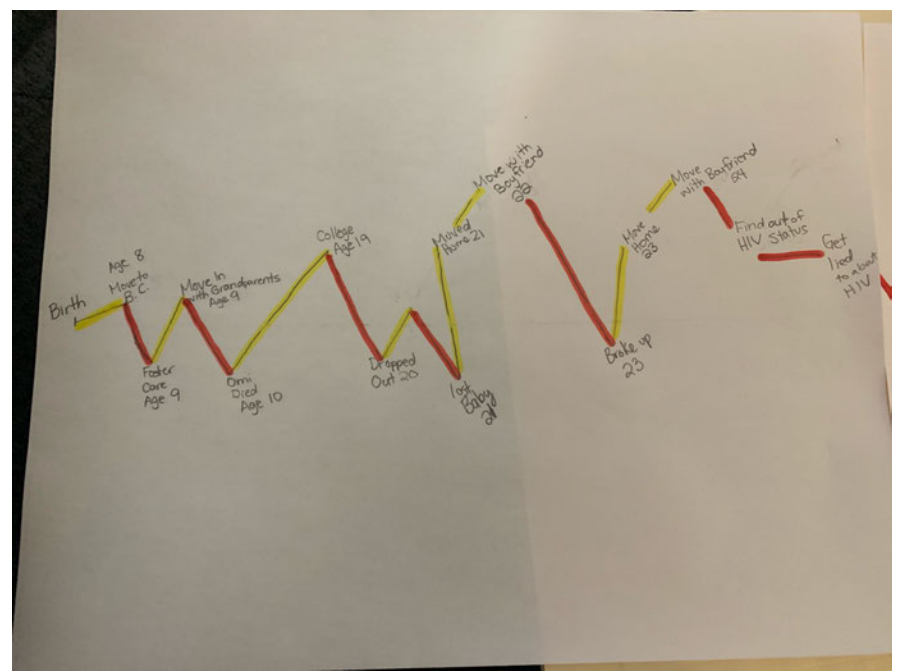


Figure 1. Rose's Lifeline Part One

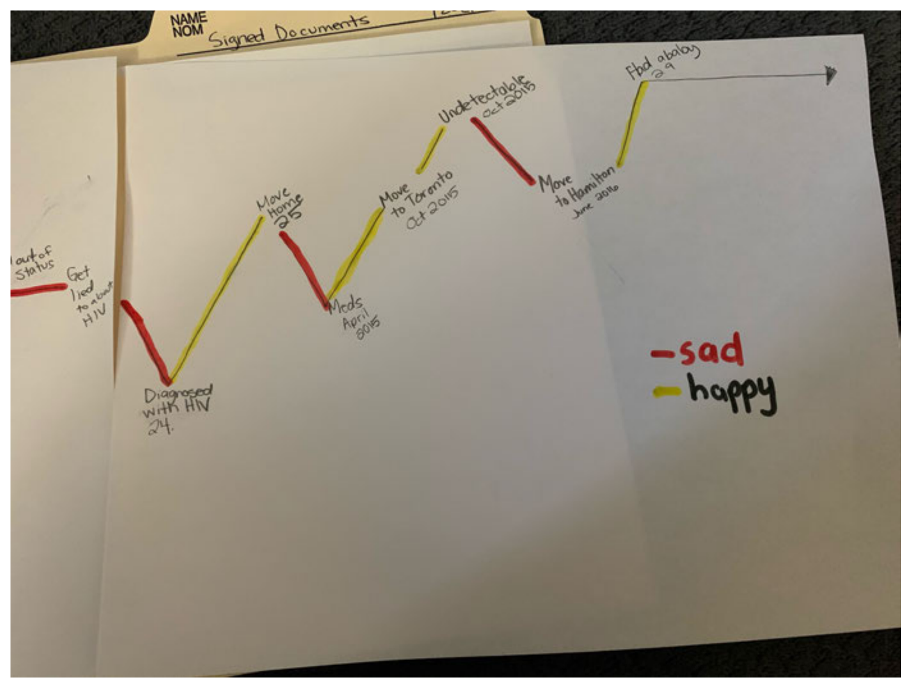


Figure 2. Rose's Lifeline Part Two

Often, lifelines are used in conjunction with other methods, such as interviews, to enhance understanding of participant experiences (Gramling & Carr, 2004; Kolar et al., 2015; Martin, 1997). In these cases, the researcher draws a timeline of events during the interview and sometimes in partnership with the participant (Adriansen, 2012; Bagnoli, 2009; Chen, 2018; Gray & Dagg, 2019; Guenette & Marshall, 2009; Sheridan et al., 2011; Kolar et al., 2015; Monico et al., 2020). For example, Sheridan et al. (2011) argue that the production of timelines encouraged participants to narrate their experiences and explore the content and dimensions of their memories. When conducted in combination with interviews, the timeline "acted as an aide-memoire, focusing attention beyond what is possible through talk alone, thus becoming not only a piece of data in its own right but a vehicle through which further data was produced" (p. 554). Lifelines offered a mechanism through which participants shared their experiences in a visual manner. By doing the drawings, participants were able to open up in ways they did not during the interview, thereby nuancing the stories told by sharing new stories, feelings, or experiences.

For example, Margaret talked about how different it felt doing the drawing compared to when she tells her story, which she has done often as someone who is open about her status and is an advocate:

> I think [doing the drawing] makes you think more about [your story]. […] somehow you connect more to it. I find that I've got my spiel that I tell people what happened. And I've said it so many times— I really, it's funny, I was watching Rudy Giuliani once after 9/11, and they [asked him] "it must be really hard for you to think back on that time." And he said, "you know what? I talked about this so much, it's like I'm dead to it." And that's how it feels for me. But actually drawing it and thinking of how I was drawing it and what happened — drawing to me is much more artistic and much more emotional than giving a speech and just blah, blah, blah. I can do that.

For Margaret, the lifeline exercise brought back the emotions and feelings she experienced when she was first diagnosed and learning how to live with HIV. The drawing allowed her to tap into these feelings that she had suppressed and placed her back in time.[91]

Different from an interview, I asked participants only one question during the lifeline debriefs:[92] "I would like you to take a few minutes to look at your lifeline and think about what it means overall." From there, participants would detail their lifeline, explaining the symbols they used and their reasons for using those images, while others required a bit more prompting. If there were parts of the lifeline that interested me and the participant did not address it, such as a specific colour used, line variation, or location of an event on the line, I would ask about it. The debriefs unfolded more as a conversation about their lifeline than an interview and lasted anywhere from half an hour to an hour. Everyone who drew a lifeline also participated in the debrief interview.

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[91] I asked participants to tell me how they felt drawing the lifeline. Many of them shared that they enjoyed the exercise because it made them take a holistic look at their life from where they were to where they are now, which was often more positive. This aspect of the lifeline activity is an interesting avenue for a future publication.

[92] While I call these debriefs to differentiate from the interview, they did not unfold as debriefs in the traditional sense. They served as an opportunity for participants to explain their drawing and how they felt making it.

### 4.2.3. Data Analysis

In this section I review the steps I took to analyze the data. In the first part I discuss my transcription methods and then I outline the thematic narrative analysis process adopted to analyze the interviews, lifelines, and debriefs.

***Transcription***

Transcription involves a series of research decisions because each speech act can be transcribed in different ways depending on the researcher's theoretical and methodological orientations; it transforms a dynamic conversation into a static form, losing some of the key features of talk (Riessman, 2008). Riessman (2008) discusses two different methods of transcription that assume different theories of the self:

> (1) the act of storytelling in dialogue *constitutes* the autobiographical self, that is, how the speaker wants to be known in the interaction, vs. (2) autobiographical narrative *reflects* a preexisting self; there is constancy across speaking situations because the self exists independently of social interaction. (*Emphasis in original*, p. 29)

The first method theoretically understands the self as co-constructed and produced dialogically while the second is based on the idea of a reflected self (Riessman, 2008). Given that I am defining identity as co-produced between speaker and listener with and through the use of affective narratives, and that I am mobilizing the work of Ricoeur and Frank who contend that it is through narratives and the dialogic relationship that we come to know ourselves and others, I opted to transcribe the interviews and debriefs verbatim using the first method.

This transcription process involved writing down the interactional content such as "back channel non-lexical expressions" (Riessman, 2008, p. 31) (marked as I --Mmm, I--uh huh, I -- ok, I -- yes, I -- right), the break-offs when a person would interrupt their own thought, or would

transition to another idea mid-sentence (marked with --), and long pauses (marked with a 'p').[93] Since I am interested in emotions, these interactive elements also represent the "narrativity of emotions" (Kleres, 2018, 2011). As such, I also made sure to transcribe as many of the prosodic elements of speech that I could identify such as characteristics of the voice (e.g., if someone was particularly soft spoken, reduced or raised the volume of their voice at particular moments, if their voice trembled), emphasis (e.g., if someone stretched out words, sped up or slowed down, paused), and vocal style (e.g., if someone separated their syllables such as 'shame-less' or 'puh-lease'), and verbal planning (e.g., if someone stuttered) (Kleres, 2018, 2011). In addition, I wrote down moments when people laughed, cried, smiled, chuckled, or gestured with their hands in a particular way to note some of the moments of profound displays of emotion.[94] I utilize this method not only because I understand the self to be co-constructed, but also because participants are narrating a particular account of events *for me,* and I recognize that the way they tell their story might change depending on the person they are speaking to and when they are sharing.

To maintain anonymity, I assigned participants pseudonyms and changed all identifying information in the transcripts. For example, if participants mentioned names, I simply wrote [name], if they referred to a city they grew up in or currently live, I wrote 'city' but kept the same province, and if they discussed the country they immigrated from I wrote "X continental country" to make it broader. I also made sure to change any other specific identifying information about a participant's story, such as using three date ranges to identify their diagnosis

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[93] I chose to remove the "back channel non-lexical markers" that Riessman (2008, p. 31) speaks of for the sake of clarity in the presentation of participant's quotes. While these were important in the analysis to help position myself in the interview, they distracted from the content of participant's stories. I endeavour to write a methodological journal article about this transcription process and how participants co-constructed their affective narrative selves throughout the interview talking to a white, heterosexual, HIV-negative, woman.

[94] The prosodic elements of speech and the visible displays of emotion that I noted, are presented in some of the quotes I use in the analysis chapters. Undoubtedly, there are components of participant's speech or emotional displays/performances that I did not capture as I was transcribing the interviews.

date: early in the epidemic and before the invention of ARVs (1980-1995), mid-epidemic and after the invention of ARVs but before the official publication of U=U (1996-2017), and later in the epidemic or post U=U (2018-present). In the write up of participant's stories, I also added words in square brackets to make the written text flow better while deleting words such as 'like' or 'um' that are often used when we speak. By doing this I am transforming participant's speech into written text to align it with the carefully curated text I have written around their quotes.

When I write about transcription in this way, it sounds easy, but it was not. I avoided transcription because it meant re-living the interviews and I did not want to feel the emotional weight of them anymore. In other words, I experienced what I call an emotional blockage. Past research on emotion work and emotional labour in qualitative research highlights the role of emotions in research (Bergman Blix, 2015; Bergman Blix & Wettergren, 2015; Bruckert, 2014; Dickson-Swift et al., 2009; Fabian, 2014; Gammerl, 2015; Gould, 2015; Hannem, 2014; Mario & Bogosavljević, forthcoming; Moran & Asquith, 2020; Munn, 2014; Waters et al., 2020; Wettergren, 2015; Yuen, 2011). But what happens when we don't want to feel? When the surface acting and deep acting fail. When I got to the transcription phase, I felt like my bag of emotions was emptied. So I sat on my data for months not being able to transcribe. Of course, that brought with it a sense of guilt that I was failing my participants by not doing the work I promised I would do. I also felt that I was failing as an academic because I was not being productive.

This can feel defeating, increasing that emotional blockage. I felt like I was trapped in a hole I could not climb out of or as I described to my supervisor, a shame-guilt spiral that kept pulling me under. In other words, I felt depressed and stuck. As Cvetkovich (2012) writes, "being at a 'dead end' or 'no exit,' impasse captures the notion of depression as a state of being

‘stuck,’ of not being able to figure out what to do or why to do it” (p. 20). Like Cvetkovich (2012) I treated this impasse as a state of “potential.” I was unable to engage with my data, so I took a step back. I spent time with family, I hung out with my friends, and I dove into a new relationship. I thought about anything other than my dissertation. This eventually brought me to a space where I was able to transcribe and start the writing process. I found joy in the work again and motivation to do something with the information participants shared with me.[95]

***Thematic Narrative Analysis***

Narrative analysis is used to understand the “storied nature of the self” and thus how people “position and narrate their identities in a *social* context” (Skjelsbaek, 2006, pp. 376-377). I understand narratives to involve long periods of talk or extended discussions about one’s life that participants articulated over the course of a single interview, as well as through the creative lifeline activity, which enabled them to constitute visual narratives. Importantly, I emphasize that narratives are “entities open to constant becomings, stories in becoming” (Tamboukou, 2008, p. 284). In other words, I understand participants’ stories as events woven around “*moments of being* temporarily crystallized into narrative forms” (Tamboukou, 2008, p. 284, emphasis in original).

I analyzed the interviews and lifelines using thematic narrative analysis, which focuses on “‘what’ is said, written, or visually shown” with particular attention paid to content rather

[95] Although I say I found joy, there is little happiness to be found in transcribing. In fact, I hate transcribing because it forces me to confront all those times when I did not do a good job – I spoke too much, did not follow an important thread, forgot something, responded awkwardly, or sounded too much like a therapist. In addition, as someone who was recently diagnosed with ADHD, I also find transcribing incredibly boring – it is probably the worst job to give someone with an inability to sit for hours and pay attention.

than how, to whom, and why stories are told (Riessman, 2008, p. 53).[96] Riessman (2008) discusses three steps researchers take when conducting a thematic narrative analysis. First, the researcher "isolate[s] and order[s] relevant episodes into a chronological biographical account" (p. 57). I did this by first creating a larger code about people's 'HIV story' as a whole (recall that I asked participants at the beginning of the interview to tell me about their HIV story). From there, I further divided their HIV story into different episodes, which include their 'diagnosis stories', 'disclosure stories' 'exposure/nondisclosure stories'[97], 'victim/non-victim stories', 'undetectability stories', and 'criminalization stories'. Sometimes this involved coding long pieces of text, while other times it meant coding only a few sentences because participants often did not talk about their stories in a linear way, moving back and forth between their diagnosis and disclosure stories, for example.

Then the investigator "zooms in, identifying underlying assumptions in each account and naming (coding) them" (p. 57). Once I created the larger category codes related to various aspects of people's HIV stories, I broke down each category code to identify its assumptions, meanings, emotions, and different aspects of their stories. For example, in people's diagnosis story, I had a code about death and loss, which was often paired with codes about grief, sadness, depression, crying, loneliness, difficulty, disgust, deteriorating mental and physical health, reactions to diagnosis such as suicidal thoughts, attempts, and so on. Emphasis was given to the ways in which "emotions are embedded in narratives and are in fact socially learned through narratives" (Kleres, 2018, p. 91). Kleres (2018) argues that the narrative elements of any story

[96] Given that I have chosen to define narratives as a process rather than a sequence (Tamboukou, 2008), I do not conduct a structural narrative analysis (most often used by linguists), which seeks to understand how a narrator uses "form and language to achieve particular effects" (Riessman, 2008, p. 81) and which breaks down a narrative into its component parts and configurations.

[97] This code referred to their experiences of being exposed to HIV since one participant was HIV negative or realizing that they had not been disclosed to once receiving their diagnosis. If they talked about not disclosing to others, I would code this under their disclosure story.

shape and organise emotional experience, and thus that narratives are emotionally structured. As such, there are often specific linguistic manifestations of emotions in narrative accounts. Kleres (2010) describes three broad categories of these emotional indicators, some of which I used to focus my analytic gaze: lexical (words), syntactical (sentences) and prosody. At the lexical level, 'fear' can be expressed as "fear, concern, fright, [or] dread" or expressive words can be used such as "Yuck!, Gross!, Finally!, Darling!" to describe emotions (p. 98). At the syntactical level, there are "direct references to emotions—'I am scared'; double propositions […] such as 'I'm afraid that…'; optative sentences, […] as in 'If only I could ….'; exclamations ('What a day!'); hyperbole ('the worse day of my life'); intensifying, repetitive genitive constructs ('The book of books'); questions and rhetorical questions; finally, comparisons [or metaphors] as in 'I felt about my wife's illness like I felt as a soldier during the war'" (pp. 194-195).

Lastly, specific cases are selected to illustrate the themes and underlying assumptions are compared (Riessman, 2008; Williams, 1984). Once I further divided the larger category codes, I zoomed out and started to look at the different codes that were overlapping to find meaning across cases. This process results in the formation and discovery of what Crépault and Kilty (2017) call a "through narrative" or the "figurative thread and needle that punctures" each interview, lifeline, and debrief (p. 275). For example, the codes mentioned above about death and loss, gave me the impression (per Ahmed, 2004) that receiving a diagnosis was experienced through grief and the emotions often tied to grief (e.g., sadness and feelings of loneliness). It also told me a story about how being diagnosed with HIV ultimately leads to a rupture of one's sense of self, which I examine in detail in chapter 5.

For the lifelines, I engaged in a visual narrative analysis that interrogates the image itself, "asking about the story it may suggest, what it includes, how component parts are arranged, and

use of colour" (Riessman, 2008, p. 144). I did not analyze the images as narratives in their own right but as a secondary component of those produced during the interviews. In particular, I sequenced the images in dialogue with the written texts to tell a story about living with HIV. I coded the image based on the life events participants included in their lifeline, which were clarified during the debrief sessions. For example, if they chose to visualize disclosure, this was coded under 'disclosure story', or if they drew pills, I coded this under 'diagnosis' and then 'health and treatment'. I also coded emotional and other meanings that participants described in their debriefs in relation to the different line variations, symbols, and colours participants used to depict their life events.

Working from a feminist epistemological position, I am particularly attentive to the interpretive authority I, and all researchers give ourselves when we tell and re-tell people's stories (Borland, 1991). I remain cautious about how I tell people's stories as a white, heterosexual, middle class woman with particular views about victimhood. Frank (2010) argues that interpretation or "hermeneutics is clear that the issue is someone else's story, but knowledge of that story always proceeds within the horizons of an interpreter as knowing subject" (p. 96). The interpretations I provide are, therefore, within the realm of multiple possible interpretations, illustrating that all research is epistemologically violent (Raju, 2002; Borland, 1991; Munn, 2014; Bruckert, 2014). For example, Munn (2014) writes about her personal struggles with "appropriating" her participants' stories for her own ends and her "obligation to 'do right' by them" (p. 293). She also recounts her struggle with asking participants to re-tell their stories of success which might bring up harmful memories. As such, I engage in a dialogical interpretation which Frank (2010) describes as,

> …less a matter of decoding stories than of seeing all the variations and possibilities inherent in the story. The narrative analyst opens him- or herself to these

> possibilities, in order to invite others to open themselves. Interpretation seeks not to say: all the story is here, analyzed and stated in clear, explicit terms. Interpretation seeks not to stand over the story, speaking about it. Interpretation aspires to be an ongoing dialogue with the story. (p. 104)

I vehemently claim that my interpretation of people's stories is not finalized or complete for stories are never whole (Frank, 2010). Instead, my interpretations in this dissertation are a retelling (out of many possible retellings) of participant's stories to create new connections and insights.

There are a few points I would like to reflect on in terms of my positionality and how it might affect the ways in which I interpreted my data. First, my positionality as a middle-class white woman often makes me overlook class in my analysis. It seems to always be something I must make a concerted effort to see when analyzing data whereas issues related to gender come so easily as I am able to relate to those struggles. Second, there is the issue of which emotions I chose to focus my analysis on. For example, the ways in which we communicate emotions are culturally delineated which poses problems for how we are to interpret displays of emotion or even emotional narratives. While I did ground my analysis of participant's emotions in the literature, my own interpretations of their words, tone of voice, particular gesture, or facial expression is very much based in my own North American and European understanding of emotions. Third, perhaps my critique of the hopeful biomedical narratives related to HIV treatment in chapter 7 could stem from my own pessimistic feelings about the power of medicine and its associated institutions, having been failed by the medical establishment on numerous occasions when doctors dismissed my health concerns because of my weight. Third, my interpretation of participant's shame at not practicing safe sex could very much stem from my own shame at contracting an STI while still in undergrad. Perhaps participants felt no shame at contracting HIV or not practicing safer sex, aside from those that explicitly mention feeling

ashamed. This was something I very much grappled with as I was conducting the analysis. I was struggling with potentially imposing emotions onto my participants that, without asking them to verify my analysis, I could never know whether they felt.

### 4.2.4. Methodological Rigour and Integrity

Ezzy (2002) contends that rigour in qualitative research is as much connected to the politics of the research topic as it is to the technical aspects of conducting research. While positivist research, particularly that emerging from the natural sciences, relies upon concepts such as objectivity, validity, and reliability to evaluate a study's rigour, a political model of rigour advanced by Ezzy (2002) and which I take up, involves a commitment to being honest about one's positionality and the impact this has on the research; a duty to share research findings with the community for they are the arbiters of quality, and as a sign of respect and acknowledgment of their contributions to the study (Ezzy, 2002).

This model of rigour is akin to what Kilty (2014) refers to as the four principles that every critical feminist social researcher must embrace. First, she contends that critical feminist scholars must attend to voice. Voice in qualitative research means attending to the myriad ways in which individuals, including researcher and participant construct and interpret certain experiences and their position in relation to those experiences (Kilty, 2014; Fabian, 2008). Importantly, one must not claim to 'give voice' for doing so is "born of a desire for mastery, to privilege oneself as the one who more correctly understands the truth about another's situation or as one who can champion a just cause and thus achieve glory and praise" (Alcoff, 1991-1992, p. 29). Second, Kilty (2014) outlines what she calls the three Ps of critical feminist research: positionality in which the researcher must recognize the different social locations of women and other marginalized peoples and thus the "situatedness of their oppressions"; politics in which the

researcher actively politicizes social, economic, scientific, and legal issues; and praxis or the action of taking theory to the streets in ways that will make social change regarding the politicized social, economic, scientific and legal issues at hand (p. 127).

In this vein, I intend to share the results of the project with the HIV/AIDS organizations I contacted as well as through the CCRHC, of which I am currently a steering committee member. The lifeline drawings are going to be presented in a booklet and shared among HIV/AIDS service organizations to use as a resource with service users. As a steering committee member for the CCRHC, I have also been involved in law reform advocacy for several years, having met with Senators, the Minister of Justice, and Members of Parliament to advocate for legislative reform. Most recently, I, alongside other CCRHC members, participated in a press conference on Parliament Hill, calling out the Liberal Government for their inaction and failure to make legislative reforms in relation to HIV criminalization. In this way, I am bridging research with political action (praxis) to open dialogue about the marginalization, stigmatization, and harmful effects of law on PLWH.

In their seminal work on naturalistic inquiry, Lincoln and Guba (1985) articulated a different way of evaluating qualitative research that is separate from the positivist criteria of validity and reliability which are inappropriate concepts to apply to constructivist or critical qualitative work. Specifically, they note four key criteria: truth, value or trustworthiness to replace credibility, transferability to replace generalizability and external validity, dependability to replace consistency or reliability, and confirmability to replace neutrality or objectivity (pp. 294-301). In a more recent work, Tracy (2010) identifies the following criteria: a worthy topic, rich rigour, sincerity, credibility, resonance, significant contribution, ethical research (discussed above), and meaningful coherence.

A worthy topic is one that is relevant, timely, significant, and interesting (Tracy, 2010, p. 840). Given that Canada is currently the world leader in per capita prosecutions of HIV nondisclosure, this research is timely in that it provides insight into the ways in which people who have experienced nondisclosure conceptualize this moment in their life and how this meaning might influence whether they report such an instance to police or not. Rich rigour involves asking questions to provide thick, rich descriptions to support the researcher's arguments, spending enough time collecting data, ensuring an appropriate sample for what the research wants to do, and selecting the appropriate method of analysis for the research questions. By asking participants to tell their HIV story and following up with probing questions, I was able to elicit thick, rich descriptions of people's experiences that will be used as supporting quotes in the analysis chapters. I spent seven months (December 2020 – June 2021) recruiting and interviewing participants and made sure that each participant met the inclusion criteria so that the sample would be appropriate for the goals of this research. In the end, I was able to collect 44 interviews and 25 lifeline drawings. Since I am interested in understanding people's affective narrative selves as they relate to their HIV diagnoses, living with HIV, treatment, and experiences of HIV nondisclosure, I employed a thematic narrative analysis to understand how people construct their identities through emotional storytelling. I spent over a year coding and analyzing the dataset and writing up the analysis chapters.

Establishing sincerity involves what Lincoln and Guba (1985) called auditing. Tracy (2010) specifically argues that for a study to be sincere the researcher must be vulnerable, honest, and transparent about the messiness of the research process; I address these points throughout this chapter. Credibility or trustworthiness is achieved by way of: thick rich descriptions that show the reader the complexity of the data; crystallization, which involves the

use of multiple sources of data; the use of different methods and theoretical frameworks to analyze the issue at hand; multivocality, which involves the use of diverging viewpoints and paying attention to differences in race, gender, class, age, and sexuality; and member reflections in which the researcher seeks input from the community while analyzing the data and producing the research report (Tracy, 2010). By mobilizing different data sources, I facilitate crystallization[98] and thereby generate a "more complex, in-depth, but still thoroughly partial, understanding of the issue" (Tracy, 2010, p. 844). I also use detailed quotes and images of the lifelines to provide thick rich descriptions of the affective narratives I found in the dataset. Moreover, I borrowed from three theoretical fields (affect, narrative, and identity) to facilitate analysis. In the analysis chapters, I make sure to consider participants' races, genders, sexual orientations, HIV statuses, ages, and socioeconomic statuses to trace variations of their stories along these lines. I did not exclude people who had different opinions about the criminalization of HIV nondisclosure and was able to recruit one person who was criminalized for HIV nondisclosure, one person who was criminally charged for nondisclosure, and one person who experienced HIV nondisclosure but remained HIV negative and did not report this instance to the police.

Significant contribution is measured by questioning the theoretical, heuristic, practical and methodological significance while resonance is achieved when the stories presented evoke something in the reader (Tracy, 2010). My hope is that this research will make important contributions to the fields of affect, narrative, and identity, the scholarship on the criminalization

[98] I use the term crystallization rather than triangulation because the latter refers to the establishment of one 'Truth' by way of coming to the same conclusion after analyzing multiple data sources, theoretical frameworks, types of data, and coding with multiple researchers. I therefore reject the term because it originates in realist traditions whose goal was to rid science of subjective bias (Tracy, 2010).

of HIV nondisclosure, and practically, in terms of my work with the CCHRC.[99] By presenting participant's stories in their own words and using their drawings, I wish to make their narratives resonate with readers and make a broader contribution to our understandings of living with HIV in a time when criminalization and HIV stigma continue to harm PLWH. I also desire for this research, with its focus on the politics of victimhood within the HIV community, to stir up the need to move us away from neoliberal rationalities that depict victimhood as individualized, responsbilized, and unproductive ways of being, towards embracing "unproductive whining", passivity, and weakness as "every bit as creative and resilient as strength and activeness" (Koyama, 2011, n.p.).

Lastly, this study has achieved meaningful coherence because it: (a) accomplished what I set out to do (i.e., to understand how people configure their affective narrative selves in relation to their partner's nondisclosure, HIV diagnosis, and living with HIV); (b) aligned my theoretical framework, methodology, and methods by connecting them to affective feminist knowledge production and ways of doing research; and (c) mobilized the substantive and theoretical literature reviewed in chapters 2 and 3 to explain and situate the findings in the three substantive analysis chapters.

## 4.3. Final Thoughts

I end this chapter by reflecting on a quote from Arthur Frank (2002),

> …the social scientist's responsibilities for analysis go beyond those of the folklorist who collects and archives stories that might otherwise be unrecorded and thus lost (indeed, most folklorists do a good deal more). In moving to the tasks of analysis, however, I hope to sustain the recognition that stories are not waiting for social scientists to endow them with sense. Narrative analysis needs all possible humility when asking what it can bring to stories. (p. 114)

[99] I discuss in more detail the theoretical, methodological, and practical contributions of this research in chapter 8.

Frank urges the social scientist to remain humble in how their analysis makes sense of and gives meaning to the stories that participants tell. I find this incredibly difficult to navigate as I often do not know how to strike the balance between having humility and being confident (I tend to be more unassertive and self-deprecating, especially in academic circles). This is particularly challenging because in writing a dissertation, I must defend my research decisions and conclusions while also recognizing that my interpretations are but one reading and configuration of participant's stories. In fact, completing a PhD has only taught me how much I do not actually know.

Throughout this chapter, I presented an honest and transparent account of the challenges and messiness that I experienced while conducting this research. I have described my own positionality and engaged in a discussion about how this impacted my research decisions. I also systematically reviewed the data collection and analytic methods I deployed in this research. I write about these experiences to remain humble and honest in what I was able to achieve and the conclusions I could draw based on my theoretical and methodological frameworks.

I now turn to the substantive analysis chapters in which I present the stories of HIV told to me by participants who so openly and emotionally shared their experiences with me. To do so, I write my own narrative account of people's HIV stories, explaining the complexities of living with HIV as people navigate the challenging terrain of criminal law, public health, and continued HIV/AIDS stigma. I start with chapter 5 where I discuss how people make sense of their partner's nondisclosure.

# Chapter 5.

# The Right to Know and the Right to Tell: The Felt Experience of HIV Nondisclosure

> *Convincing the public and ourselves that people with AIDS can participate in life, even prosper, has been an uphill struggle. The facts are all too clear: people suffer terribly, and we're dying by the thousands. But I'm not talking about not dying; I don't deny the reality that sooner or later most people with AIDS die; it would be foolish not to address death. I'm talking about the business of living, of making choices, of not being passive, helpless, dependent, the storm-tossed object of the ministrations of the kindly well. These are the pejorative connotations of victim that PWAs find unacceptable.*
>
> – Max Navarre, 1988, p. 145

This chapter was a particularly difficult one to 'place' in this dissertation and to write, as nondisclosure, how one acquired HIV, whether someone is HIV positive, and the notion of victimhood, are prickly topics in the HIV community. As Richard, a white, pansexual man who was diagnosed early in the epidemic[100], explains:

> I meet people who are poz who are very pissed off at the non-poz community for asking if they're poz. These guys are running into them more than I am, I guess, within the gay community. I float more in the bisexual community, it's a little different. [Gay] guys ask [this question] more and [so they get] angry and feeling like "why do they get to ask me if I am poz? Why [don't I] get to explain to them that it doesn't matter. That we know how to do this safely?" And that feeling, like he is […] made [to] explain it […] I think […] makes you feel more like a victim.

Richard refuses this kind of 'victim mentality' instead emphasizing that one should not get angry, or feel victimized, for being asked this question. Instead, he says that people need to just accept it, "if you put it behind you, that little bit, and not make it your ace card, it's better and you feel less like a victim." This kind of sentiment, about not accepting defeat and 'powering

[100] Recall that in chapter 4 I placed participant's date of diagnosis within the specific time periods that make up the HIV epidemic. People diagnosed early in the epidemic refers to the time before ARVs were invented (1980-1995), mid-epidemic refers to after the invention of ARVs but before the official publication of U=U (1996-2017), and later in the epidemic references the post U=U era (2018-present).

through', has long been a central feature of the empowered narratives emerging from the HIV/AIDS crisis era and shows the complexity within which the politics of victimhood operates. Being a victim of HIV also implies that there is a victimizer, an uneasy thought when it was essential for people infected with HIV to create community so that they could survive.

Today, similar sentiments remain; for example, the Centres for Disease Control (CDC) (n.d.) produced a guiding document on what language to use to combat HIV-related stigma, which states that rather than using the term 'victim' people should say "person with HIV" because "some people with HIV feel that these terms imply that they are powerless, with no control over their lives…These terms also segregate the people currently living with HIV" (n.p). My exchange with an executive director of an ASO that I discussed in Chapter 4 (section 4.1.1), exemplifies the lingering stigmatic nature of the label 'victim' for PLWH and how ASOs work to protect against its use. Indeed, ASOs participate in the co-production of illness identities taken on by PLWH when counselling PLWH about their responsibilities regarding disclosure and the law on HIV nondisclosure (Orsini & Kilty, 2021). Victimhood within the HIV/AIDS community remains highly controversial because it is equated with how one acquired HIV, intimating that people are more or less responsible for having contracted the virus depending on the method of transmission.

I heard from some participants about how much they hated being asked how they got HIV because they felt the judging gaze of those inquiring. For example, the first thing that Dillon, a strong advocate in the HIV community, told me when we started the interview was that he thought that "this is one of the only times 'how did this happen to you' is an appropriate question" even though I did not explicitly ask him to tell me how he got HIV, but rather to tell me his HIV story. He went on to explain his diagnosis story and that he does not know from

whom he acquired HIV which, he says, is “very frustrating for some people because they want you to have a very a good story, like you were a haemophiliac, or your partner cheated on you, or somebody didn’t disclose to you. And I simply don’t have one. It is what it is.” He went on to describe that a very good story is a *sympathetic* story in which the PLWH,

> […] is not culpable […] which is the opposite of empowerment. So, […] you’re encouraged and you’re […] socially pressured to tell a *version* [emphasis] of your story that makes *you* [emphasis] the innocent victim? I mean, that’s not an empowering place to be. So, you have to be a victim in order for people to feel good about your situation, right? And this notion that it’s my obligation to make people feel less bad about my life is— that’s a burden […] [smiles]. (white, gay male, diagnosed late in the epidemic)

As evidenced by these quotes, Dillon feels a certain pressure to take on a victim identity because people would have sympathy for him, alluding to the notion that being a victim entails an always-already subject position of innocence and blamelessness for the harm that befell them (Carrabine et al., 2004; Christie, 1986/2018; Dunn, 2010; Holstein & Miller, 1990; McGarry & Walklate, 2015). Dillon speaks to how sympathy is attached to victim status in ways that are politicized, creating an affective narrative that shapes how people ‘read’ HIV nondisclosure.

Dillon’s story references the negative relationship many PLWH have with ‘victimhood’ and hearkens back to the Denver Principles that were developed by HIV/AIDS activists in 1983 as an empowering manifesto that would later structure important policies around research and healthcare for PLWH.[101] The first line in the manifesto states: “we condemn attempts to label us as ‘victims,’ a term which implies defeat, and we are only occasionally ‘patients,’ a term which implies passivity, helplessness, and dependence upon the care of others. We are ‘People With AIDS’” (n.p.). When the Denver Principles (1983) were first created, the criminalization of HIV

[101] For example, the Greater Involvement of People with HIV (GIPA) which promotes the meaningful participation of people living with HIV/AIDS in political decision making around the response to HIV.

nondisclosure in Canada did not yet exist[102] and therefore 'victims' of nondisclosure did not exist as a legal subjectivity. Yet, narratives of "AIDS victims" abound during this time and were used to refer not only to those who had died from AIDS related complications, but to differentiate the innocent, passive, and unknowing recipients of HIV (e.g., victims of tainted blood transfusions and hemophiliacs) from the reckless, wanton, blameworthy, diseased Other who failed to adhere to the ideals of white middle class respectability (Treichler, 1999; Watney, 1987). Writing about mothers whose babies were born with HIV, Treichler (1999) describes how they were framed as both "not women" and "not normal":

> If they acquired the virus "unknowingly" and "innocently," they were seen as passive victims or invisible transmitters. But, if they were found/alleged/believed to have gotten (or stayed) pregnant knowing that they were HIV positive, they acquired instant agency-and sinister agency at that, transformed in a flash from passive receivers to culpable agents invidiously transmitting infected blood to their unborn babies. (p. 65)

The victim identity HIV advocates employed in the Denver Principles was couched in the affective narratives of the HIV/AIDS crisis at the time, wherein the 'victim' label was not only associated with notions of defeat but as a tool of differentiation and oppression, or what Carrabine et al. (2004) call a "hierarchy of victimization" to describe the ways in which some victims have a higher status in discourses about 'crime' which allows their experiences of victimization to be taken more seriously (p. 115).

Interestingly, this rejection of victim identities by HIV/AIDS activists in the crisis era occurred at roughly the same time as victim-feminists were strategically constructing women as blameless victims of male violence to win public sympathy and gain advances in enshrining sexual assault and intimate partner violence in law and policy (Doe, 2012; Dunn & Powell-Williams, 2007; Dunn, 2010; Goodmark, 2011; Lamb, 1999; Leisenring, 2006). For victim-

[102] The first criminal case of HIV nondisclosure occurred in 1989 (Hastings et al., 2022).

feminists, being a victim is not a sign of defeat. In fact, constructing 'battered women' *as* victims was a discursive move made by activists to change understandings of 'battered women' as blame*less* thereby fighting back against rhetoric that responsibilized women for the abuse they suffered (Dunn, 2007). As Holstein and Miller (1990) argue, "calling someone a victim encourages others to see how the labelled person has been harmed by forces beyond his or her control, simultaneously establishing the 'fact' of injury and locating responsibility for the damage outside the 'victim'" (p. 106). As such, "the term 'victim' became a unifier for policy initiatives […] that simultaneously 'celebrates' some victim's experiences and erases others" (McGarry & Walklate, 2015, p. 21).

The normalization of victims within law and other related policy arenas, what I called legal and psychiatric victimhood in chapter 2, gave way to the idea of a 'legitimate' victim as the norm upon which all others will be judged. The legitimate, or ideal victim is someone who was harmed and to be designated or treated *as* a victim, must not be perceived as responsible for their own victimization (Christie, 1986/2018)[103]. These narrative moves made sense for victim-feminists at the time, although feminists later criticized the association of victimhood with women because it implied that women were always-already weak, passive, and powerless leading to narrative reconstructions of victims as survivors, a more empowered and positive tone that signifies a sense of resilience after harm that should be celebrated (Alcoff & Gray, 1993; Gavey, 1999; Larson, 2018; Stringer, 2014; Walklate, 2007). This too was the thinking of HIV/AIDS activists during the height of the crisis in the 1980s who wanted to stress a more

[103] See section 2.2.1 on *Recognizing Victims Through Law* for a more detailed discussion. I do not suggest we should blame victims for the harm inflicted upon them, but rather articulate what Schulman (2016) describes as a conflation between feelings of discomfort and feelings of threat: "at many levels of human interaction there is the opportunity to conflate discomfort with threat, to mistake internal anxiety for exterior danger, and in turn to escalate rather than resolve. […] Conscious awareness of these political and emotional mechanisms gives us all a chance to face ourselves, to achieve recognition and understanding in order to avoid escalation towards unnecessary pain" (p. 17).

empowered narrative about living with HIV (Callen & Berkowitz, 1983; Crimp, 1987; Navarre, 1987; Watney, 1987).

In this chapter, I take up nondisclosure as an affective practice, a human activity that is not *just* an individual action but a "recurring, spreading and evolving pattern of practices which carry their agents and are at the same time carried (out) by them" (Reckwitz, 2012, p. 248). Nondisclosure as an act of secrecy, of withholding information from others—that may also sometimes involve self-deception—is "inevitably a relational practice" shaped by specific cultural norms of truth-telling and historical power dynamics (Hardon & Posel, 2012, p. 3). Affects are rooted within the practice of nondisclosure, given that "affects are always embedded in practices which are, in turn, embedded in tacit schemes of interpretation. Affects are thus not psychological or mental processes, but they constitute an integral part of the practical activities within which human bodies relate to other objects and subjects" (Reckwitz, 2012, p. 251). Given this relational practice, I concentrate on the partner who was not disclosed to, the recipient of this practice, to explore how people give meaning to nondisclosure, an affective practice on its own. I contend that the transition into the era of HIV normalization, and intensifying criminalization of HIV nondisclosure has reignited a politics of victimhood in which claims to innocence/guilt, responsibility/irresponsibility, and blamelessness/blameworthiness are readily made along virological and moral lines, thus assembling different "schemes of interpretation" (Reckwitz, 2012, p. 251).[104] These schemes of interpretations are embedded in different ways within two interrelated affective narratives that make up the prefigured "practical field" (Ricoeur,

[104] In Chapter 7, I discuss this in relation to the hopeful narratives of the biomedical field that participants take up to configure their affective narrative selves into the undetectable self who is responsible because they adhere to their treatment plans and reach undetectabibility. The undetectable self stands in opposition to the detectable Other who is irresponsible in their failure to become/stay undetectable.

1983/1990, p. 53-54) from which people configure (Ricoeur, 1983/1990) their stories about nondisclosure and their sense of self.

First, the transformation of safer sex from a community practice rooted in care, compassion, eroticism, and pleasure (Kinsman, 2024, Watney, 1997, 1998/2002) into a personal obligation under the "new public health" in which medical, legal, and moral modes of regulation are enacted to manage, surveil, and punish individual bodies in the name of 'risk' prevention (Armstrong, 2005; Crawshaw, 2012; Petersen & Lupton, 1996). The new public health model was established and is maintained, in part, through the mobilization of shame, fear, and disgust to make judgements about what and who is risky, responsible, innocent, and blameworthy (Gagnon et al., 2011; Lupton, 2015, 2013). In chapter 2, section 1.3.1, I reviewed the ways in which health is productive of new subjectivities with regards to the responsibilizing and self-governing practices mandated by medical, legal, and moral modes of regulation. I specifically discussed the multiple and competing narratives of safe sex messaging during and proceeding the era of the HIV/AIDS crisis in which different notions of responsibility were invoked to regulate behaviour. Here, I frame these as the affective narratives that prefigure (Ricoeur, 1983/1990) participant's configurations of their sense of self, of *who* is responsible and *how* that responsibility is achieved. These affective narratives create the conditions ripe for some to view themselves *as* victims with certain "rights."

It is important to note that out of the 44 participants, 16 did not feel like a victim, 22 felt like a victim, 3 were unsure, and 3 felt that they were and were not victims. I made the question about victimhood broad to ensure that I was not imputing in people's minds that they *could* be victims of nondisclosure with legal recourse. I was particularly concerned that this line of questioning could lead to a framing of their experiences within the legal victimhood that I am

trying to oppose. I also left it broad to get a sense of the events in people's lives that could lead to the use of this label, outside nondisclosure. Given the non-specific nature of the question, the people who said they felt like a victim did not necessarily identify this with the act of nondisclosure. People felt like victims of stigma, the law on HIV nondisclosure, disclosure, circumstance, immigration policies, sexual assault, and abusive partners. As such feelings of victimization and/or victimhood are complex and often multi-layered.

The second affective narrative involves "vocabularies of victimization", which are the "melodramatic, eventually well-known stories about victims and victimization told by victims, their advocates, and their opponents" (Dunn, 2010, p. 6), that predominantly construct victims as women who are damaged, weak, passive, always-already innocent, and in need of saving by the legal and psy professions (Christie, 1986/2018; Dunn, 2010; McGarry & Walklate, 2015; Holstein & Miller, 1990). This includes the more recent affective narratives of victims, or "vocabularies of surviving", as empowered and strong survivors (Alcoff & Gray, 1993; Dunn, 2010, p. 7; Gavey, 1999; Larson, 2018; Stringer, 2014). Narrativizing victims as weak and powerless evokes strong emotions, particularly sympathy, which enables the creation of criminal justice policies (McGarry & Walklate, 2015; Rock, 1988), and organizations such as rape crisis centres and battered women's shelters (Dunn, 2010; Gottschalk, 2006; Ricordeau, 2019/2023). Yet, these constructions of victims "serve to remind us that victimhood is contested and a product of processes that can produce and reproduce particular social relations, encouraging the assignation of blame and victimhood in particular ways" (McGarry & Walklate, 2015, p. 24).

The two main themes in this chapter juxtapose the competing emotions and interpretations of HIV nondisclosure. First, I discuss the feelings of shame expressed by participants through their articulation of self-blame and responsibility for acquiring HIV. Their

stories invoke multiple and complex notions of responsibility wherein the neoliberal rational actor co-exists alongside collective responsibilities in which people care for each other. I contend that shame in this instance does the work of binding people to a time of crisis when responsibility to each other was paramount to survival but also works to reinforce and (re)produce the very boundaries between responsibility and irresponsibility, and thus victims and victimizers (section 6.1). Second, I shift to the feelings of anger and betrayal that some participants feel towards partners who were abusive, philanderers, and who did not disclose their serostatus (section 6.2). These feelings inform people's configuration of an affective narrative self that is a victim, although they did not always use this term, of their partner's refusal to give them a choice in decisions about having sex with someone who is HIV positive. Together, these configurations form the affective practices people engage in to understand nondisclosure and their responsibility to others.

## 5.1. "I am responsible for me": Stories of Shame that Promote Multiple and Complex Notions of Responsibility

Shame is a productive emotion in the way that it turns the self both against and towards the self: "shame is an experience of the self by the self. At that moment when the self feels ashamed, it is felt as a sickness within the self" (Sedgwick & Frank, 1995, p. 136). Shame is thus a reflexive affect (Sedgwick & Frank, 1995), tethered to the practice of self-recognition (Ahmed, 2004) and "our relations to others" (Probyn, 2005, p. 35).

Shame is also a social emotion implicated in social control and regulation (Ahmed, 2004; Probyn, 2005; Sedgwick & Frank, 1995; Sedgwick, 2003; Scheff, 2003). As Ahmed (2004) argues, "in shame, I expose myself that I am a failure through the gaze of an ideal other" such that one may view herself *as if* she *were* the other (p. 106). Judgments about who has failed or

succeeded in abiding by prescribed ideals, norms, or standards are made *because* people's actions are read through affects such as shame and pride (Ahmed, 2004). Such conclusions therefore "not only respond to how we live up to ideals, they also shape the ideals in the first place" (Ahmed, 2004, p. 109). Said differently, ideals are saturated with shame and pride which create the very boundary between a failure and a success; feelings of shame and pride determine *who* is read and whether one reads *oneself* as having failed or succeeded in the attempt to approximate an ideal or norm. Shame becomes the "affective cost of not following the scripts of normative existence" yet it also "confirms and negates the love that sticks us together" (Ahmed, 2004, p. 107).

Shame's cousin, guilt, involves the "deed done, the transgression of an obligation-imposing rule" including the law or other social norms (Hacker, 2017, p. 219). Guilt is thus about moral responsibility for "a deed" that one must atone for either through suffering retribution or endeavoring to repair the situation (Hacker, 2017, p. 220). Sedgwick and Frank (1995) contend that the underlying affect when feeling guilt is the shame one may feel about moral matters that are internalized, what they would call, self-contempt. I focus explicitly on shame in this section because guilt and shame are not exclusive emotions, for one can feel these at the same time (Hacker, 2017) particularly given that "an emotion is above all a relational pattern and […] is automatically distributed and located across the psychosocial field. Affect is never wholly owned, always intersecting and interacting" (Wetherell, 2012, p. 24).

I contend that shame is central to safe sex narratives in the new public health as it works to reinforce and (re)produce the boundaries between responsibility and irresponsibility that operate at the intersection of medical, moral, and legal modes of regulation. Participants narrativized acquiring HIV not in terms of their partner's shame for not disclosing, but in terms

of their own shame, for in feeling shame, one associates with the badness of an action such that one feels oneself to *be* bad instead of attributing the 'bad feeling' to an object or other (Ahmed, 2004).[105] By shifting the blame for their partner's nondisclosure to themselves and denying a personal sense of victimhood, shame about acquiring HIV works to fortify narratives that suggest there *is* a responsible and irresponsible person, when HIV should be conceived of, as Weait (2016) puts it, an "effect of the ecological assemblage of which HIV is a necessary but insufficient component" (p. 32). In other words, HIV should be understood like the pioneers of safe sex intended, as a normal potential aspect of engaging in sexual relations, and unsafe sex as "part of the normal conflicts and contradictions that signify being flawed and mortal, i.e., a person" (Schulman, 2016, p. 122). Nonetheless, shame's self-reflexive and social quality *also* opens these boundaries, creating cracks and fissures, to make room for different forms of responsibility rooted in relations of care, empathy, and understanding for the other.

The shifting narratives about safe sex (reviewed in chapter 2) are evident in the stories participants told me when I asked them whether they felt victimized by their partner's nondisclosure. Each participant narrativized themselves as a rational actor responsible for acquiring HIV, blaming themselves for their circumstances, and taking on the shame that they should have known better, that they should have been more responsible sexual citizens. Their assertations about responsibility reinforce the binary opposite of irresponsibility, that there is some*thing* to be ashamed about thus raising "complex issues about citizenship, and especially about the degree to which the execrated and threatening person with a life-threatening syndrome who nevertheless fails to engage in 'safer sex' can be fully included in the social" (Weeks, 1998,

[105] It is important to note that I do not believe it is shameful to not disclose one's HIV status. I am invoking here the prescription by law and public health that one *should* feel ashamed for not disclosing because not doing so makes one a failed self-governing subject.

p. 44). Yet, their stories also show an ethic of care as they refuse to moralize their partner's actions thus rejecting the discourses of moral regulation which "impute blame and assign responsibility" (Hunt, 1999a, p. 411) to their partner.

For example, Dillon, a ferocious HIV/AIDS community advocate, spoke at length about responsibility for one's own health. He began by telling me about his feelings of shame for getting HIV. He feels ashamed because he was told his entire life that as a gay man he would die from HIV, signalling the lasting effects of discourses from the HIV/AIDS crisis era when gay men were shamed and blamed for HIV (Crimp, 1987; Gould, 2009; Kinsman, 2024; Kippax & Race, 2003; Patton, 1989, 1996; Treichler, 1999). His sense of shame stems from his belief that he failed to be the responsible gay man that took care of his own health:

> It feels like shame […] because this is something that has been talked about my whole life. It's something that I grew up [….] in the 80s hearing about. It's the way people predicted I would die. So even though I'm very educated on HIV, there's still the emotional weight of that.

Speaking specifically about nondisclosure, Dillon flip flops between configuring his story about acquiring HIV as an everyday risk of being a sexual citizen with his feelings of personal responsibility. He equated getting HIV through a metaphor of a sports injury, stating that he does not feel like he was victimised in the way that someone who is injured during football would not feel victimised. This metaphor reinforces the position that acquiring HIV is a natural risk born from engaging in sexual activity. He then suggests that we each have an obligation to ourselves, signalling how he takes up the affective narratives of personal responsibility to configure his self as a rational actor who refuses to take on the passive victim identity:

> I did not feel victimized by anybody. […] I would have felt the same way if I had got a sporting injury. That's a great […] thing to compare it to. I would feel the same way if I was playing football with someone and got injured while playing football. […] it's unfortunate. It's not something [you wish to] happen, but sometimes when you play football, these things […] happen [smiles]. So, for me, I

> did not feel victimized in that context […] that just wasn't a part of my personal narrative […] We […] all have an obligation to ourselves to advocate for our own sexual wellness, and if you don't ask for something, you can't get it. So […] I did not feel like a victim in that sense, I felt like I had been acting unempowered […]. I should have prioritized that conversation. So if anybody victimized me, it was me […] by not holding my own interests at heart […]. (white gay male, diagnosed late in epidemic)

Dillon's sense of shame for acquiring HIV shows how narratives of collective and personal responsibility for safer sex practices from early HIV/AIDS activists and institutionalized forms of responsibility that seek to assign blame to someone, including the self, co-exist.

Yet, what Dillon leaves out in this narrative of self-blame is that decisions to have unsafe sex are not made based on simple risk calculations, but rather on the everyday challenges that come up for people engaging in sex that might make them engage in 'unsafe' sex. This includes not wanting to wear condoms to help resolve erectile difficulties, being in a monogamous relationship, heat of the moment decisions, mental/emotional state, or intentionally engaging in unsafe sex because of disclosure or an intuitive sense that one's partner is 'safe' (Adam et al., 2008, 2005). For Ethan, there was no choice in how he was going to have sex because he was using drugs at the time and having sex with other people to help pay for his drugs:

> To be honest, I wanted to go and kill the guy […] [that] was my first thought, but I don't know […]. I was pretty pissed off. But he's in his late 60s, the guy was old […] I just had a feeling that it's him, but I don't know for sure. […] I haven't confronted him or asked him or anything, but I mean, he's probably dead by now. […] I felt kind of betrayed […] I put the blame more on me. I should have […] questioned […] because I had a feeling […]. But […] my addiction took control and it was all about getting the money to get my drugs. I didn't care and now I kind of wish [in] hindsight that I did care more, and I didn't care […] [but] I did what I had to do [or I would get] sick from not having drugs, [so] it wasn't really a choice. I don't know. It's hard to explain. (white, heterosexual male, diagnosis date uncertain)

While Ethan speaks about feeling angry and betrayed at his client for not disclosing his serostatus, his sense of shame for not asking more questions, for "not caring", for not being the

responsible sexual citizen that is demanded of him, emerges as the more dominant emotion in this affective narrative. In this way, people are *made* to feel shame for not engaging in safer sex through medico-moral modes of regulation that demand personal responsibility for one's health despite systemic and structural barriers to making those decisions. Shame thus works to create the very boundary between responsible and irresponsible through the reading of some as shameful and others as shameless.

Alex, a very recently diagnosed gay Latino man, spoke about knowing many people who are HIV positive, which he believed made him more knowledgeable about the risks of HIV transmission and thus more responsible for not acting recklessly, stating he "should have known better." His association with other poz folks indicates his situatedness within the prefigured cultural field in which the affective narratives about mutual responsibility for sexual health circulate, invoking feelings of shame for not following the social scripts of safe sex:

> For some reason or another, I always had friends who are HIV positive. […] I was well informed [about HIV transmission] and because I was going through […] a phase where I was being reckless—I wasn't thinking. I should have known better to take care of myself.

Similarly, Jeffrey, a white gay male stated that he never felt like a victim because he strongly believes that people must take responsibility for their actions, that they are responsible because they made the decisions that led to them acquiring HIV:

> I never really felt bad about the person that [gave] it to me. I didn't hold them responsible. I had to hold myself responsible. I guess I'm not looking at the "victim", but I don't necessarily see people as victims anymore. If you're responsible, then you take responsibility for your own actions as well. […] maybe I'm feeling this way because I never felt that I was the quote unquote major victim of somebody giving it to me. (diagnosed mid epidemic)

Alex and Jeffrey's narratives about taking responsibility for getting HIV conjures an affective narrative that bifurcates people into the shameless and the shameful. Those who are responsible

have nothing to be ashamed about because they adhere to a heterosexualized safe sex ethic and, presumably, would not acquire HIV, while those who fail to take care of their own health should be ashamed for their 'choices.' For example, Alex told me, "I kind of hate myself because I know a lot about the virus, I should have known better." This statement suggests that Alex feels a deep sense of shame for not avoiding acquiring HIV because he had all the knowledge about the virus and about how to prevent transmission. This sentiment is also evident in how Clay, a white gay male diagnosed early in the epidemic, describes not feeling mad or upset at the person who gave him HIV but that "this is what I was supposed to go through [...] this is my burden in life to carry to learn from or whatever." That Clay feels his HIV status as a "burden" he must learn from signals his sense of shame for not conforming to normative standards of sexuality and behaviour for which he now must be punished by carrying the moral weight of his 'sins'.

Clay's insights are reminiscent of Gould's (2009) "trope of responsibility" inherent in what she calls the "heroic narrative" that speaks to the valiant organizing of HIV/AIDS activists during the crisis era who crafted an image of gay respectability to counter the dominant discourses that blamed and shamed gay men for HIV/AIDS. She contends that expressions of gay pride in this narrative drew from, were implicated within, and reinforced dominant heteronormative values by portraying gay individuals as responsible and mature caregivers. As a result, "it was a pride that was largely premised on an agreement with dominant views about what is shameful…" (Gould, 2009, p. 236). Shame thus operates as a central tenant of the diffuse and interlocking modes of medical, legal, and moral regulation in that it not only creates the very boundaries between good and bad, acceptable and unacceptable, healthy and unhealthy, guilty and innocent etc., but in how our feelings of shame or the shame we are *made* to feel keeps us locked within these boundaries so that we are not marked with a "spoiled identity" (Goffman,

1963). That Clay must learn from his mistakes by carrying this burden, that Dillon feels victimized by his own decisions, or that Alex feels he was being reckless, invokes the shame narratives produced about gay men acting irresponsibly through their promiscuity, for engaging in sexual acts that were not ‘safe’, and therefore for failing to “control their behaviour” like heterosexual citizens (Patton, 1996, p. 98).

Yet, their decision to practice unsafe sex could also be *read* as a “responsible choice among adult men”, something to not feel ashamed about, given the complexity of negotiating sex and the vulnerabilities inherent in human intimacy and interaction with all the tough dilemmas that people face in their daily lives (Adam, 2005, p. 344). Indeed, Richard refuses to feel ashamed of his choices (although there is a sense of shame when he hits his head with his hand and yells “idiot!”) stating that he does not want to “torture” himself over decisions that he did or did not make years ago. He describes actively working on himself to not feel like a victim particularly because he does not want to be portrayed as a victim to his child:

> I did not want to present myself as a victim to my kid, even if I died. I wanted to try and be […] as strong as possible. I recognize that if I let myself feel victimised by it, one evening's events that lasted only moments, for the rest of my life, as opposed to just dealing with the rest of my life, it would be much harder. And looking back in retrospect, I'm bright enough to go [hits hand on head] “Idiot!” I mean, we were both responsible that night, we were both responsible and I failed my responsibility. But am I going to torture myself? No, I'm not going to torture myself for that because it happened, got to deal. And I see a lot of guys torture themselves over it. […] I mean, yeah, you can be a victim in many ways. You can be a multilayered victim. But I mean, it doesn't help. [chuckle] It doesn't help and that's sort of where I took it from and […] the mantra of making myself feel stronger and better on behalf of myself and other people, yeah that helped me not feel like a victim. (white, pansexual man, diagnosed early in the epidemic)

For Richard, remaining strong and not dwelling on the past kept him alive. He recognizes that as a sexual actor he must take responsibility for the risks that come with engaging in sex with

others. In this way, he intimates the sense of communal and individual responsibility that many gay men felt at the height of the HIV epidemic as well as a desire to move on with his life.

Interestingly, narratives about responsibility were not only told by gay men but also by some of the heterosexual women I interviewed and one man who identified as pan-sexual, albeit in different contexts, and with less of a sense of shame. For heterosexual women, nondisclosure stories were configured through the narratives of safe sex promulgated towards heterosexuals, namely: the prevention of unwanted pregnancies, choosing the right partners (i.e., not engaging in sex with men who have sex with men or other 'high risk groups'), condom use, and monogamy.

While not talking specifically about his experience of nondisclosure but about safe sex practices among the bi-sexual community, Richard expresses how these heterosexual safe sex narratives continue to exist today when he describes that bi-sexual men, particularly those who have not come out as bi-sexual and are married, rarely ask about their sexual partner's HIV status. He articulates how most of the bi-sexual men he has had relations with, feel that a wedding ring acts as a "magic pill that stops all diseases" while gay men take more action when it comes to their sexual health:

> In the weird world of closeted bisexual men, right up to today, they don't ask. […] the thought that you might possibly have something that might hurt [married men] is not even on their radar. It's something that I've always found magical. That wedding ring? Married guys look upon [it] as a magic pill that stops all diseases [laughs] because any time I've played with gay men in the community, there's an awareness, they ask questions, they decide whether they want to play. (white, pansexual man, diagnosed early in the epidemic)

While the men that Richard describes are not openly bi-sexual, they are openly heterosexual and, as such, seem to make (according to Richard) sexual health decisions based on this understanding of their sense of self. Richard thus describes the historical legacy of HIV/AIDS

prevention campaigns in which HIV/AIDS education about risk reduction was directed almost exclusively toward gay men and other 'risk groups' such that heterosexuality became associated with an inherent safety (Patton, 1996) and straight men and women focus on avoiding pregnancy while giving less attention to STI prevention and testing (Breny et al., 2023). While bi-sexual men are at an increased risk for HIV and other STIs, they are similarly not the focus of much HIV/STI prevention campaigns, are less likely to use prevention services than gay men with limited interventions being developed to address their unique needs, and are less likely to use prevention tools like PrEP than gay men (Feinstein & Dodge, 2020).

Heterosexual safe sex narratives not only negate the risk reducing sexual practices employed by gay men (e.g., engaging in different kinds of sex acts with lower levels of risk for HIV transmission and after the advent of ARVs, taking PrEP and PEP[106]), but also signal what Cindy Patton (1989) warned us about long ago:

> Women […] in the absence of a strong women's movement, must fight their battle for safer sex on the carefully guarded and privatized domain of relationships with individual men. Gay men can find empowerment among a community of men who demand the practice of safer sex. Safer sex norms will ultimately be more difficult to achieve among heterosexuals than in the urban gay world. (p. 242)

We see how this narrative of safe sex as advertised to the heterosexual community structures Margaret's story when she speaks about feeling naïve regarding sexual health practices.

[106] In the TasP era, medicines such as PrEP and PEP are used to prevent the transmission of HIV, yet the use and advertisement of these as preventative tools have not resulted in reductions in first-time HIV diagnosis rates among cis and trans women despite seeing a decline for gay, bisexual, and men who have sex with men (gbMSM) (Orser et al., 2023). Studies examining the feasibility of PrEP and PEP use among women identified key barriers to its adoption including concerns about stigma such as how others, including one's sexual partners, perceive their HIV risk or serostatus, challenges related to accessibility and affordability such as difficulties in finding providers who prescribe PEP or PrEP and covering medication costs, and a lack of awareness including limited promotion and education of HIV prevention services for women (Bass et al., 2022; Ogunbajo et al., 2021). Additionally, the uptake of HIV prevention measures may be influenced by healthcare providers' uncertainty about when and for whom to prescribe these interventions without broadly categorizing all women in priority populations as being "at risk" for HIV (Bass et al., 2022). Indeed, Orser et al. (2023) found that "…current estimates of HIV acquisition indicate that 20% of new HIV diagnoses are in women, but 10% or less of PEP or PrEP use is by this group…" (p. 294).

Margaret believed she was safe because she was not engaging in sex with gay men and asked her partners if they were HIV positive. Her naïveté exonerates her from feelings of shame because, unlike the gay men above, she did not know any better:

> At the time, I remember, [scoffs, smiles through teeth, shakes head], I was so naïve when it came to sex because I got married right out of school. It was my first boyfriend I ever had that I married. […] when I got divorced, I didn't know what kind of questions you're meant to ask guys […] so I heard a sex show saying you should always ask somebody if they've got a disease. So, when […] one of [the guys I was seeing said], do you want to do it? I said, "well, I've got to know, do you have a disease?" [chuckles] I think I must have been one of the few people who ever said that to people. [chuckles] They said, "no, are you on the pill?" And I said, "yeah, I am." [He] said, "okay, we're fine then." And in that day, it was whether you're on the pill or not. […] That was the big thing. So I was on the pill, I figured I was safe from having kids […] so that was it. I was so naïve. [chuckles] […] I knew that HIV was out there. […] When I went to see [a] specialist […] he said to me, "be very careful because the newspapers are saying that the HIV crisis is going down." […] And of course, I didn't pay attention to him. I thought, well, […] I'm not having sex with gay men. (white, heterosexual middle-class woman, diagnosed early in the epidemic)

I specifically asked Margaret about her feelings towards the partner who did not disclose his serostatus. She describes the circumstances of this encounter as resulting from her choice to have sex without a condom, employing the ethos that the only exception to this rule was if she had been raped. Margaret also stated she feels a sense of control over her life by taking on the blame for being infected and that blaming someone else only gives the illusion that one is in control:

> My feelings [about criminalizing nondisclosure] are really strong. I feel like I am responsible for me, for my decisions. When I made the decision not to have this guy wear a condom, I made that decision […]. I could have said […] we're not having sex. As far as I'm concerned I have to take care of my health. He has to take care of his health. […] I have always felt, from day one, I never blamed [the] guy. If the guy had known [his status], I still wouldn't have blamed him. Because I made my own decision. The only caveat to that I'd say is if he raped me, that's a whole different ballgame because then, I'm not responsible for having sex. That's a whole different thing. But if he knew and didn't tell me, I just can't go down that road, because then […] in a way, I feel like I'm trying to control the situation by blaming someone. […] it's a great way of having control if you can blame someone else, then you feel like this happened to me by mistake, this guy knew. I mean stupid

> guy. I have to be responsible for me and that is the way I have control of my life. (white, heterosexual middle-class woman, diagnosed early in the epidemic)

That Margaret takes responsibility for her decision to not encourage her partner to wear a condom and describes blaming herself as the only way for her to have control of her life is a declaration of identity: that she is a responsible and rational actor who is in control of her body and her life. Yet, Margaret also feels a lot of shame about being responsible for her decisions (which, also signals that she feels irresponsible) because this resulted in her passing on the virus to her daughter who then passed away as a result, something she feels deeply ashamed of:

> I thought I knew that freaking disease was around. I made some decisions [p] and because of that, my daughter is dead. People said, oh, everybody, […] [the] psychiatrist would say to me, "oh, everyone […] is having sex without condoms, […] it's very common, […] don't beat yourself up about that." I said, no, but I knew. I was warned and I didn't listen, so I will forever carry that on my conscience. So *that* I do blame myself for, but [….] it wasn't intentional, right? It just […] happened—I'm upset that I wasn't [p] that I didn't [p] I guess [p] I'm upset that I didn't listen more. (white, heterosexual middle-class woman, diagnosed early in the epidemic)

Indeed, Margaret later describes not feeling like a victim of nondisclosure but rather of "circumstance":

> I felt like I was in the wrong place at the wrong time. […] I feel like, wow, the chances of me getting it as a woman […] from a man, I believe was very low. And then […] to pass it on to my daughter, incredibly low chance that I would pass it on to her. (white, heterosexual middle-class woman, diagnosed early in the epidemic)

Margaret's narrative here reflects a feeling of being unlucky which she expresses throughout the interview, sometimes in a joking manner.[107] This feeling of being unlucky seems to be paradoxical to her description above of taking responsibility and taking on the blame for acquiring HIV and passing on the virus to her child. Margaret at once feels as though no one but

[107] See section 6.3 where I discuss Margaret's story about losing her child and the humor she mobilizes in the telling of this story.

unfortunate circumstances are to blame for what happened to her yet placing the blame solely on a particular context and set of events is an uneasy feeling, which is evidenced by her statement: "I have to be responsible for me and that is the way I have control of my life."

Similarly, Jenny discussed how she does not feel like a victim for acquiring HIV because she consented to "everything", presumably meaning that she agreed to not use a condom. She takes on the shame of her past errors by ascribing the blame to herself, using these feelings to learn and become a better, more responsible person. Jenny too, was concerned only with not getting pregnant:

> I never felt like a victim for getting HIV because I don't even know, like I say [...] I consented to everything. [...] I don't think anybody had any [...] ill intentions [toward] me. And not knowing [...] [whether] the person that I got HIV from actually knows or not. But then again, I wasn't really— I was trying to be as protective as I can. [...] I was only thinking about pregnancy [...] I feel like you're only a victim if you let yourself be one. And I always try to turn it around and go "No, everything I've done, I've done." I take ownership and responsibility for it. And you learn from it, right? And [...] people will only treat you how you allow them to treat you. So, you don't put yourself in those situations. (Jenny, heterosexual white woman, diagnosed mid epidemic)

Jenny invokes in this rejection of victimhood narrative the notion that victims are passive and thus one must actively work to refuse being a victim when she states: "I feel like you're only a victim if you let yourself be one." Victims, for Jenny, are people who let things happen to them, do not take "ownership" or "responsibility" for their actions, and do not "put [themselves] in those situations." In the case of HIV nondisclosure, this understanding of victims might make sense for some people like Jenny, but neglects the reality that sexual health decisions are, at times, made in situations where there are unequal power structures.

For Genevieve, the harm of safer sex narratives for women (Patton, 1996) is evident in the rape myths she employs to describe the moment she believes she acquired HIV. She explains taking responsibility for her infection, not because someone did not disclose to her, but because

she takes on the blame for drinking too much at a party and for putting herself in a position to be raped. In essence, she feels responsible for being raped:

> I was infected […] long before they thought women could be infected with HIV. [I was infected] at a party […] where I took a lot of the responsibility because I had more to drink than I should have had to drink. […] I realize I was raped at the party but at the time I just thought it was my bad decision to be at the party and drink. […] I was working in [African country], we had a really successful day, and we were celebrating. […] from my perspective, it just got out of hand, and I became infected with HIV [but I] did not know I was infected with HIV. (heterosexual white woman, diagnosed early)

In Genevieve's narrative account of her rape, she feels the need take on the responsibility for not just acquiring HIV but also for putting herself in a situation to be sexually assaulted. Genvieve's account shows how narratives about innocent victims prefigure people's understandings of their experiences and sense of self. Genvieve's description points to how the politics of innocence comes to define who gets to be a victim and who does not and who sees themselves as victims.

That none of the women's and men's stories I presented in this theme indicate that they feel like a victim for getting HIV signals their identification with non-ideal victims, for a legitimate victim is always-already innocent (Dunn, 2010; Holstein and Miller, 1990) and the Denver Principles (1983) articulation that PLWH are not victims. Their sense of shame and guilt about getting HIV brings up notions of a communal responsibility for transmission which demands their refusal to configure their affective narrative selves as victims in a legal sense; they refuse to read themselves as the law reads those whose partners did not disclose. They reject the criminal legal discourse that constructs a bifurcated model of active and passive citizens where a harm is committed by one person against another, "the person producing the effect is responsible for the [bodily] change and the person changed – damaged, injured, however one wishes to characterize it – is simply a passive object, a receptacle, a victim" (Weait, 2001, p. 450).

Yet, these accounts also invoke the narrative that “in the marketplace of life, the rational actor is a conscious, informed calculator of risk and gain” (Adam, 2006, p. 169) governed by the shame of failing to be respectable sexual citizens conforming to a safer sex ethic, having self-control, and in Genevieve’s case, a failure to be a respectable self-governing woman who does not put herself in risky situations. By articulating these notions of choice and personal responsibility, participants uphold the binary between ‘good’ and ‘bad’ citizens; those who are capable of “caring for the self” (Foucault, 1988, p. 41) and those who are not. The two narratives of responsibility (personal and communal) co-exist in participants’ configurations of their identities as non-victims. These narratives provide the sense-making with which to understand shame in the context of HIV infection and nondisclosure thus signalling how feelings of shame “might be dependent on past interpretations that are not necessarily made by us, but that come before us” (Ahmed, 2004, p. 171).

## 5.2. “I’d love to smack a book of legalities in [their] face”: Stories of Anger and the Right to Know

Unlike shame, which is a self-reflexive emotion that “makes our selves intimate to our selves” (Probyn, 2004, p. 331), anger is an emotion directed outward at some*thing* or some*one*, including oneself (Ahmed, 2004; Henderson, 2008; Keeping, 2006; Sedgewick & Frank, 1995; van Ingen, 2011). Although I separate anger and shame in these two themes, it is important to note that they are not dichotomous emotions. They can be felt at different times or together and can be mediated by other affects. For example, Victoria speaks about feeling angry following her diagnosis because she was not sure who had infected her. Her feelings of anger quickly turn to feelings of shame as she describes not having “self-worth”, not caring about herself, and thus

that she does not blame her former partner for transmitting the virus. Victoria thus experiences shame/anger about the circumstances surrounding the story of how she got HIV:

> There was a little bit of anger after that. Because at that time, I didn't know who had infected me. So I was mad, I was angry […] [ but then I found out that] I got infected by him. I found out that he was positive and two of his brothers were positive as well. […] he was [an] injection IV drug user; that's how he believes he got it. He didn't know his status […]. I don't blame him. I think back then I just had a lack of self-worth and [I] didn't care about myself. [I was] trying to find a good man to be there […] not as a father but be there as a role model for my kids hoping that things are going to work out […] And so yeah, I got infected […] by him and I basically brought him back to health, and then he left. Asshole. [laughs]. (Victoria, white heterosexual woman, diagnosed early in epidemic)[108]

Her shame/anger is directed at her desire to find a "good man" who could be a "role model" for her children, a desire that made her more trusting in the hope that she would find love.[109] Victoria's desire describes a state of optimistic attachment to the fantasies[110] of a normative nuclear family life. When these fantasies fail to come about (at least in the way she envisioned), she feels a sense of anger/shame for not being able to provide this fatherly figure for her children and for not taking better care of herself. In this way, desire creates a particular subjectivity in the way that our desires are shaped by things, such as narratives, that make an impression and which can be felt as confusion, shame, fear, or even hope as it "reassembles one's usual form in any number of shapes or elaborations [such as] in stories about who one is and what one wants, stories to which one clings so as to be able to re-encounter oneself as solid and in proximity to being idealizeable" (Berlant, 2012, p. 76). When her former partner leaves after she nurtured him

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[108] See footnote 77 on page 149 for a description about why I decided to include Victoria despite her partner not knowing his status. In addition, while Victoria asserts that her partner did not know his status she may never know whether he truly knew or did not know.

[109] During the interview, Victoria and I complained about how difficult it was to find partners and commiserated over the uncaring men that we have had the displeasure of being with over the years. Victoria and I connected very well in the interview, which made me sympathize with and understand the shame/anger she feels when her desires for love betray her.

[110] Lauren Berlant (2012) describes fantasies as "many incommensurate things, from unconscious investments in objects of all kinds to dreams inculcated in collective environments" (p. 8).

back to health, her anger re-surfaces, which she brushes off with a laugh, making the pain sting less or perhaps a nervous laugh acting as an "embarrassment-shield" (Hacker, 2017, p.214) as she reveals to me her failed desires. In what follows, I concentrate on the emotion anger to juxtapose these two emotions and how they shape people's understandings of HIV nondisclosure, with the caveat that no person feels only one emotion at one time and that these stories can be read as different feeling states.

Anger is a reaction to pain, injury, and harm in that it is an "interpretation that this pain is wrong, that it is an outrage, and that something must be done about it" (Ahmed, 2004, p. 174). Ahmed (2004) contends that anger is a form of "against-ness" (p. 174-175), which suggests that in narratives of betrayal one's expression of anger is a way to stand up to one's 'betrayer' (Keeping, 2006). Anger emerges when reading a particular action or inaction as a wrong that violated one's expectations such that "anger is itself the intuition of injustice" (Eatough et al., 2008; Keeping, 2006, p. 478). In feeling angry, one also constitutes the harm in question *as* a *moral* wrong (Keeping, 2006). Emotions, therefore, are not just reactions we have to a particular event or moment, they also 'surface' the event or moment into existence through particular readings based on past contacts with discourses and narratives that make an impression (Ahmed, 2004). Ahmed (2004) describes this process in relation to pain:

> If we feel another hurts us, then that feeling may convert quickly into a reading of the other, such that *it* becomes hurtful, or is read as *the impression of the negative*. […] the 'it hurts' becomes, 'you hurt me', which might become, 'you are hurtful', or even 'you are bad'. These affective responses are readings that not only create the borders between selves and others, but also 'give' others meaning and value in the very act of apparent separation, a giving that temporarily fixes an other, through the movement engendered by the affective response itself. (p. 28)

Through anger, we convert the one who wronged us into the 'bad one' who betrayed us and we may be mobilized to avenge the violation (Keeper, 2006). There are also moments when we do

not desire revenge, but rather recognition (Srinivasan, 2018). We feel this way most readily with people that we are close with because we hold higher expectations regarding their loyalty that we do not necessarily have with strangers or acquaintances; betrayal by people close to us *feels* more intense (Keeper, 2006). This anger is not justified simply because we are closer with some people than others, for "the thought that we can only be aptly angry about things that are sufficiently close to us in space and time, or to which we have some specific personal connection, can shade into a troubling moral parochialism" (Srinivasan, 2018, p. 130).

Anger also has a racial and gendered history in terms of who is *allowed* to feel angry, whose anger is thought to be a sign of their danger or disreputableness or whose anger is used to discredit their claims by way of negative stereotypes, such as "the angry Black woman" (Thompson, 2017; Walley-Jean, 2009). For example, Thompson (2017) contends that the anger and rage expressed by Black people in their fight against the injustices of police brutality, are "viewed as incompatible, or even dangerous, to the operation of American democracy; meanwhile, the anger expressed by dominant groups (especially heterosexual white men) is easily incorporated into political discourse, normalized as politics as usual" (Thompson, 2017, p. 460). Yet, anger is often mobilized in political struggles for justice in several (sometimes) interlocking social movements including HIV/AIDS advocacy, anti-racism activism, and feminism (Ahmed, 2004; Cvetkovich, 2003; Gould, 2009; Lorde, 1984; Srinivasan, 2018; Thompson, 2017; Wood, 2019). As Audre Lorde (1984) so aptly put it,

> Every woman has a well-stocked arsenal of anger potentially useful against those oppressions, personal and institutional, which brought that anger into being. Focused with precision it can become a powerful source of energy serving progress and change. And when I speak of change, I do not mean a simple switch of positions or a temporary lessening of tensions, nor the ability to smile or feel good. I am speaking of a basic and radical alteration in those assumptions underlining our lives. (p. 127)

What interests me is anger's capacity to confer negative meanings to situations and people, to perpetuate existing moral codes and norms through the assignment of someone or something as *bad*, to focus on individual interests at the expense of collective obligations to each other, and its attachment to modes of action that can be punitive. Participant's 'readings' of nondisclosure as a moral wrong and a violation are configured through the prefigured public health narratives about safer sex and the victim-feminist narratives around gender-based violence (GBV) that individualizes victimhood. As I have argued elsewhere, "the more we view acts of victimization as individual events, the more detached they become from the larger structural problems of racism, patriarchy, misogyny, sexism, homophobia, transphobia, and/or classism that inevitably shape them" (Kilty & Bogosavljevic, 2021, p. 188).

The participants stories I outline here and the sense of betrayal and anger they express seems (mis)directed[111] at their partner's nondisclosure which is, in turn, transformed into a moral wrong that they feel is a violation of their right to be told their partner's HIV status and their *choice* in whether they want to engage in sex with someone who is living with HIV. Their anger is a reading of their partner's nondisclosure as a failure to be a properly self-governing HIV citizen who gets tested, knows their status, takes their medications so that they are undetectable, and always discloses. Below, I present Jamie's lifeline and story which exemplifies this well. Figure 1 shows Jamie's entire lifeline while Figure 2 is a close-up of the first image page on which she portrays her feelings about learning of her diagnosis and her partner's nondisclosure.

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[111] I write 'mis' in brackets here to signal that in some cases nondisclosure is one aspect of the struggles that participants faced in their relationships. Some of the stories also discuss abuse and violence in which nondisclosure becomes an aggravating factor.

Figure 3. Jamie's Lifeline

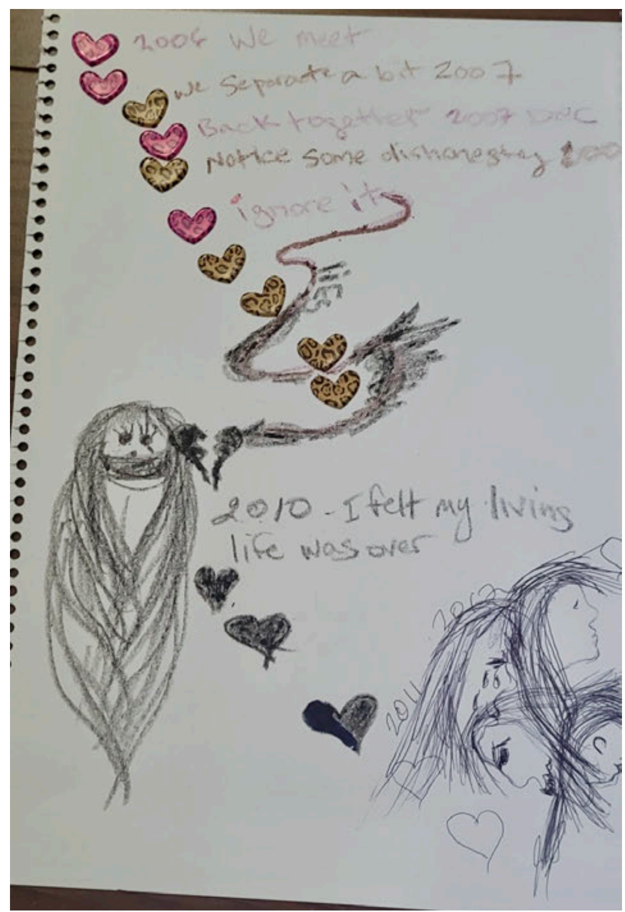


Figure 4. First panel of Jamie's Lifeline

Jamie begins her lifeline when she met her former partner. From there, she explains that the black hearts lead to a "big cluster of different emotions mixed in together" that she felt at the beginning of her HIV story. She describes these as a "rollercoaster of emotions of hate, anger, depression, emptiness, loneliness." The faces, representing a cluster of these different emotions, all merge and seem to flow from each other, depicting how one moment "I was feeling okay [and] then split seconds [later] I was feeling so mad and just so frustrated. And then parts of me felt […] so empty of any kind of emotions. [I didn't] really know what to do with them." Describing the feeling of anger she states,

> The anger felt […] like I think I was so betrayed and lied to and I can't say manipulated, because he didn't manipulate me, he just didn't come forward and tell me the truth of what was going on. […] A lot of my trust issues went out the window because I didn't know if anybody was going to be honest and real with me. A lot of that anger was balled up more [with] the lies and the secrets he kept from me for so long. And then I think the biggest part of it was that he just disappeared and left me alone to deal with all this on my own […] But that [is] a process from when […] I found out that I was [HIV positive] to [thinking about] the person that gave it to me without disclosing. One, I felt so violated. I felt […] my trust was broken for a long time […] this whole thing has been […] a roller coaster of choices that have been taken away from me […]. But it's the choices that have been taken away from me [such as] when or how […] I disclose what I have is the toughest. (Indigenous heterosexual woman, diagnosed mid epidemic)

Jamie links her feeling of anger to betrayal, that her partner lied to her led to her having trust issues and feeling like he took her choices away. This signals the way that "anger presents its object as involving a *moral violation* not just a violation of how one *wishes* things were, but a violation of how things *ought* to be" (Srinivasan, 2018, p. 128). Jamie feels that she *ought* to have been given a choice about whether she wanted to have sex with someone living with HIV, a reading she makes despite her own difficulties with disclosure. This suggests that perhaps anger regarding nondisclosure is not apt (Srinivasan, 2018) given the injustices faced by people who disclose (Allard et al., 2013; Kilty & Orsini, 2017, 2019a; Symington, 2009).

Participants' anger, while directed at their partners, also surfaces the problems inherent in patriarchal and classist systems and structures in which women are often disempowered to negotiate safer sex, particularly women of colour, poor women, sex workers, and women who are in abusive relationships (Alexander et al., 2011; Frimpong et al., 2022; Hahm et al., 2022; Patton, 1989; Worth, 1989). As Patton (1989) contends, "no major campaign has insisted on the responsibility of heterosexual men […] meaning that women must ask men to wear condoms. Women exist in a sexual economy where they have unequal power in relationship [*sic*] to potential sex partners; this inhibits their ability to make a risk evaluation and reasonable changes" (Patton, 1989, p. 243). Women from Africa have a particularly difficult time negotiating safer sex because HIV stigma remains a major barrier to prevention, treatment, and testing efforts (Liamputtong, 2013; Njokwe & Kijima, 2025; Wyrod, 2013) especially in relationships where abusive husbands impose risky sexual practices on their partners (Dunkle et al., 2004; Jewkes et al., 2006).

This was the case for Bisa, a Black-African heterosexual woman whose former husband transmitted HIV to her which she then passed on to her two children. Transmission and diagnosis happened while Bisa was still living in Africa, as such, her anger is situated in a social context in which she felt the power to negotiate safer sex practices was taken from her. Her anger was apparent throughout the interview in the way that she talked, raising her voice at several points as she recounted her story, in the way that the interview felt, to me, like an hour long rant, and her vociferous proclamations that people should be criminalized for nondisclosure. She explained how her husband pitied her when she was diagnosed with HIV (an affective orientation she hated), yet, she found out, that he was in fact living with HIV and had most likely infected her. This enraged her and she expressed wanting revenge:

> I reached out to a doctor there and it was the doctor that disclosed to me that my husband was also positive. And I was like what? This man made me feel that he was negative, that he was married to me because he's pitying me [because of my HIV status], that he loves me, whereas HE WAS THE ONE THAT PASSED THE VIRUS TO ME! That day my whole world shattered. I didn't know what to do and I was so done. I was destroyed. I was feeling I wanted […] revenge. […] I was so angry. But thank god I was not in [African country] then because I wouldn't have known what I would have done. I would not have this kind of life that I'm having right now, I wouldn't be having this conversation that we're having right now, maybe I would be somewhere in jail [...] So for criminalisation, they are fighting for it to go away. I am in support of it. I want people to be criminalised. I want people to disclose […] because if I was disclosed to, I [would] not be in this situation today. I [would] have [had] my right to choose. (diagnosed mid epidemic)

After she explained the circumstances surrounding her infection, I asked Bisa whether she felt like a victim and if she did, what that subject position meant to her. She said that she did feel like a victim because her former husband's nondisclosure removed her choices regarding whether she wanted to have sex with someone who was living with HIV or to use a condom. She was particularly angered by the removal of her decision-making power because it meant that she could do nothing to prevent passing on the virus to her children.

> Feeling like I didn't get to make my choice […] During the time I was with my late husband […] if he had told me [of his HIV status] we would have been able to save me and the kids. […] we would have been having sex with a condom and there would be a way that I could have kids with him without him passing the virus [on] to me [and] me passing the virus to the kids. Every day my own status does not destroy me, but my kids' status does destroy me [...] So a victim of not making my choice to be with a positive person […] So I'm a victim. (Bisa, Black-African heterosexual woman, diagnosed mid epidemic)

Bisa assumed that because she was in a monogamous relationship she was safe to have sex without a condom and would have engaged in sex with a condom if she'd known her former husband was living with HIV. Yet, as Mol (2011) reminds us, choice is an ideal that "carries a whole world with it: a specific mode of organising action and interaction; of understanding bodies, people and daily lives; of dealing with knowledge and technologies; of distinguishing

between good and bad" (p. 7). In other words, choices are rarely made free of systems of oppression that limit our options or from relational contexts (Wendell, 1990).

Roxy expressed anger at being duped by her partner regarding his sexual orientation. She stated that if her former husband had told her that he was having sexual relations with men, they could have come to some kind of compromise.

> I think the anger that you're talking about, the anger not so much with the diagnosis, but that how could we have been in this relationship, and I didn't know about this, and it could have all been avoided […] It was an unknown, I didn't know. […] It took me such a long time to even know what happened. […] I guess my initial reactions […] [were] how did I not know? And had I known, could this have been worked out? Because I don't think that most women are going to just up and leave their partner or have some crazy reaction just because their partner's having sex with other men? (white heterosexual woman, diagnosed early in the epidemic)

Roxy feels she has the 'right' to be told her husband's sexual orientation since she believes that most women will not have an intense reaction to this disclosure. Yet, research indicates that women have many reactions including, anger, feelings of betrayal and loss, and even empathy (Daly et al., 2018). Many try to stay in the marriage because they do not want to break up the family but most eventually separate as the burden of carrying a double life weighs on them including the fear of stigma and rejection from other family and friends who may disagree with their decisions (Daly et al., 2018). The safer sex narratives about the 'inherent' safety of monogamous relationships are "model stories" (Meuter, 2013) that participants mobilized to orientate their lives and actions, as evidenced by Roxy's anger and shock that her former husband stepped out of the marriage and then transmitted the virus to her. This reflects something Crimp (1987) predicted long ago:

> It is the lack of promiscuity and its lessons that suggests that many straight people will have a much harder time learning 'how to have sex in an epidemic' than we did. This assumption follows from the fact that risk reduction information directed at heterosexuals, even when not clearly antisex or based on false morality, is still predicated upon the prevailing myths about sexuality in our society. First among

> these, of course, is the myth that monogamous relationships are not only the norm but ultimately everyone's deepest desire. Thus, the message is often not about safe sex at all, but about how to find *a* safe partner. (p. 253)

Whereas the participants in the previous section felt responsible and blamed themselves for the decisions they made, Jamie, Bisa, and Roxy felt they made the *right* decisions, that they were proper self-governing individuals who protected their sexual health by engaging in a monogamous relationship with (seemingly) straight men.

Such narratives are problematic, and angering, especially when considering that the ability to engage in safe sex is structurally and socially determined. For instance, low-income women who use drugs are at heightened risk for HIV due to their limited power to demand safer sex practices, which only increases their risk of physical and sexual abuse (El-Bassel, Gilbert, 2005; El-Bassel, Terlikbaeva, et al., 2010; El-Bassel & Strathdee, 2015; Wechsberg et al., 2008). This issue was exemplified by Ava who described staying in a relationship with her abusive partner because he was a drug dealer whom she depended on to supply her with the drugs she needed to avoid withdrawal. She directs anger both toward herself and her partner, stating that she was "stupid" and "blinded by love" and that her former partner had "no respect" for her. Ava described feeling like a victim because she had little control or choice in whether to engage in sex with someone who was living with HIV, to negotiate condoms, or to leave the relationship.

> I met this guy, [he] was introduced to me and he was definitely not my type normally. But he had something about him and I just […] fell head over heels. We spent 10 years together and […] it was just horrible, he was abusive. […] he was a drug dealer and [a] heavy addict. [sighs] And [so I] stayed with him because he held the bag. And I could access drugs whenever I wanted, but he fucked around on me all the time. Broke my heart. I wasn't used to anybody like that, he lied, he got me into stealing. I was stealing and I never had a charge ever in my life. And then I got this criminal record, and it got worse and worse and worse and worse. […] So it ends up that […] he had HIV and […] I had no idea. And I mean, I should have clued in. I was just fucking stupid and blinded by love, what I thought was love. […] I feel I was destroyed. I mean, I used to teach Sunday School, I went to a private girl's school, I was destroyed that this guy […] didn't tell me. And it

> changed my life. I just kept on using and using. I've had very little clean time. Even to this day. I was a victim. I was a victim of an asshole [chuckles]. […] I had no control. This person just fucking had no respect. He could care less about someone else's life. He didn't give a damn and that makes me a victim right there. (white heterosexual woman, diagnosed mid epidemic)

Given that women, have limited power in negotiating safer sex (Alexander et al., 2011; Frimpong et al., 2022; Hahm et al., 2022; Patton 1989; 1996; Worth, 1989), particularly among women of colour and women who use drugs (El-Bassel, Gilbert, 2005; El-Bassel, Terlikbaeva, et al., 2010; El-Bassel & Strathdee, 2015; Wechsberg et al., 2008), it is not surprising that they invoke the language of *choice* to describe their desire for agency in decisions to have sex and that anger becomes a response when this option is taken away. This narrative of choice is couched within feminist mobilizing around issues of consent in sexual assault more broadly as well as in feminist legal doctrine on HIV nondisclosure that is concerned with protecting women's right to choose *how* she wants to have sex (LEAF, 2019).[112]

Natasha expressed this legalistic way of understanding nondisclosure, using the term "non-consent" to describe HIV nondisclosure. When I asked her why she was speaking about nondisclosure in this way, she described reading articles about the issue and concluded that

[112] Feminist legal scholars recently critiqued the legacy of *R. v. C* (1998) and the impact on sexual assault laws more generally. Grant (2020) argues that HIV nondisclosure cases have impacted the laws on sexual assault in two ways: "first, the contours of sexual fraud have evolved almost exclusively in the context of the risk of disease transmission. Second, because of concerns about the possibility of prosecuting HIV nondisclosure without resorting to fraud, the interpretation of consent in the Criminal Code has been limited in incoherent ways" (p. 63). As LEAF (2019) argued, the use of sexual assault law in cases of HIV nondisclosure changes the meaning, scope, and nature of sexual assault laws by potentially eroding "the gains made in establishing an affirmative standard of consent, which protects the right to determine 'who touches one's body and how'" (LEAF, 2019, p. 9). This issue was debated in a case heard by the Supreme Court of Canada. In *R. v. Hutchinson* (2014) the accused sabotaged the condom which resulted in the complainant becoming pregnant. Since she wanted to leave the relationship, she had an abortion that led to an infection which included extreme bleeding and severe pain for about two weeks. The accused told the complainant he had poked holes in the condom and the complainant contacted the police who then charged Hutchinson with aggravated sexual assault. The core issue in this case and the site of much contention between feminist legal scholars and those advocating for reforms to HIV nondisclosure laws is whether the definition of consent, as outlined in s. 273.1(1) of the Criminal Code, includes not only the nature of the sexual activity but also how that activity is carried out (including the use of condoms) (Grant, 2020; Gotell & Grant, 2020; Gotell, 2020). The reliance on law by some feminist groups to deal with issues of sexual assault shows evidence of the continued legacy of "carceral feminism" (Bernstein, 2012). I heed Smart's (1989) call on feminists to de-centre law wherever possible because law is "juridogenic" in that it may cause harm while purporting to extend rights and remedies.

nondisclosure equals non-consent. When I asked her how she felt about the criminalization of HIV nondisclosure she said she would be inclined to press charges (which she re-affirmed in a second call to me outside the interview)[113] because her former partner takes no accountability for his actions. This signals how the law has the power to define situations (Smart, 1989), creating affective narratives that people may take up to configure narratives of nondisclosure:

> I don't feel that the non-consent thing is as big as the individuals which are involved...the first time that I had intercourse with [partner's name] I was not consenting to being intimate with someone with HIV. And so, the consensual part of it is a factor there as well […] I guess maybe in my mind I was blurring the difference between disclosure and consent in some ways. But now I know. What I'm reading with these articles is that consent and disclosure, non-disclosure and non-consent are somehow linked to each other. I mean, why would you, I mean, really? Do you think "Oh yeah, just give me AIDS. That's just what I really want." I mean, it's just not like that. So non-disclosure, it automatically follows that there is non-consent. I mean, that's a given […] [and] to tell you the truth, I'd love to smack a book of legalities in [partner's name] face and say, […] "here, what do you think you were doing and are you still doing it?!" […] he doesn't care, even down to the last time I saw him.

It was not just women who invoked this language of choice. Some of the gay men I spoke with also felt like victims, although they described empathizing with their partners and blaming themselves for acquiring HIV. For example, Karam said his partner did not care about his well-being and that he felt like a victim because he felt he did not have a chance to negotiate the parameters around the sex he engaged in with his previous partner. While Karam does not blame himself, it is unclear from the interview whether Karam's reference to his partner "not knowing" is about not knowing his status or about his partner not knowing his partner's status. It appears Karam is stating that his partner was a victim too because he was also not disclosed to by someone else:

> He was aware that he was hooking around and he didn't even care […] to tell me let's use a condom […]. So that's where I have this anger […] [towards] him. Definitely. Because at first, of course, I thought I'm the victim here, I was crying,

[113] See Chapter 4 section 3.1.1.

> it's not my fault. Why did I get this? How did I get it? But then thinking about it, he was the victim too, for not knowing. So of course you have these feelings […] it's still there, I still feel it because it's not something I chose to have. […] It's not something I got the chance to bargain about […] Of course, sometimes I still have this feeling [of] victimization. (Karam, gay Middle Eastern man, diagnosis date not specified)

Karam points to the messy nature of HIV and other disease transmission in that we can be both victim and vector which makes distinctions between victims and perpetrators, responsible and irresponsible, and guilty and innocent in the legal sense more complicated, as we are always-already biologically and socially connected to each other (Battin et al., 2009). As such, Battin et al. (2009) describe people as "way-station selves" who "exercise autonomy that is embedded in a web of biological relationships" (p. 77). Yet, as Karam intimates, not being disclosed to and acquiring HIV can feel deeply victimizing because, as he describes, "it's not something I got the chance to bargain about". People want the chance to exercise their autonomy and agency regarding their sexual health and when they are not disclosed to, they feel betrayed and angry because this choice was taken away from them.

In the era of TasP and intensified criminalization of HIV nondisclosure, anger plays a central role in the politics of victimhood, especially around access to safer sex and issues related to sexual violence, sexual autonomy, and a woman's right to choose. These are sites of struggle where anger and frustration have long been felt and mobilized by feminists to bring attention to the continued failure to believe women who have been victimized by GBV (Phipps, 2021; Ricordeau, 2019/2023; Walklate, 2016). Angry narratives about betrayal, not being disclosed to, and not being given the 'choice' to negotiate the 'how' of sexual encounters, create the conditions for the configuration of narratives that highlight one person's *right* to be told about their partner's serostatus and another's *duty* to disclose, "thus defining the emotional contours surrounding (non)disclosure, including the extent to which 'victims' are legitimately able to

express anger about nondisclosure, the direction of their emotions (anger toward their partner and/or themselves), and the duration of that feeling" (Kilty & Orsini, 2019a, p. 11). The criminalization of HIV nondisclosure invokes these angry politics of victimhood which serve as the "cultural unconscious" (Venn, 2006, p. 111) that some heterosexual women and gay men take up to give meaning to the affective practice of nondisclosure as a victimizing and morally wrong act.

## 5.3. Final Thoughts

Scholars have long pointed to how the criminalization of HIV nondisclosure changed notions of shared responsibility for sexual health and culpability for HIV exposure and transmission (Adam, 2005; Kinsman, 1996, 2024; Race, 2001; Weait, 2001). Mutual responsibility for sexual health enshrined during the HIV/AIDS crisis (Callen & Berkowitz, 1983; Crimp, 1987; Patton, 1989, 1996) was individualized, making "certain actors (such as HIV positive individuals) … culpable for HIV transmission, while certain others (in this instance negative and untested individuals) … as externalities—that is, considered external to the culpabilities at hand" (Race, 2001, p. 330). PLWH bear the burden of responsibility for preventing HIV transmission thereby negating the agency of the 'victim' in these cases to accept the risks that come from sex (Race, 2001; Weait, 2001, 2007).

As others have already indicated, but not quite explored in relationship to the politics of victimhood (Adam, 2005; McClleland, 2024; Race, 2001; Weait, 2001), this shift in responsibility is produced through the affective narratives of legal victimhood whereby the legal victim of nondisclosure is always-already innocent and blameless for the act of exposure and thus deserving of sympathy, while PLWH are the blame*worthy,* always-already perpetrator. We see this most prominently in cases where women living with HIV are in abusive relationships

whose partners threaten them with criminalization if they choose to leave the relationship, forcing many women living with HIV to stay in these relationships (Annamanthadoo et al., 2019; Csete, 2005; LEAF, 2019; Symington, 2012). In these cases, women are victims of intimate partner violence just as victim-feminists have argued, yet the law emphasizes nondisclosure as the more harmful act in this scenario, negating women's victimhood, instead ascribing this status to their abusive HIV negative partners who then garner the sympathy attached to the label victim. Weait (2001) contends that "the criminal law's approach to the question of responsibility is one based on a model of subjectivity that will, and must, deny the specificity of individual human experience" (p. 204). With these two juxtaposing narratives about nondisclosure, my aim has been to show the specificity of individual human experience that Weait (2001) alludes to, including the emotions felt by those whose partners did not disclose. I also endeavoured to make the case that the very emotions participants felt have a history of contact with wider affective narratives about safer sex practices and the politics of victimhood, such that they end up creating the very boundaries between guilty/innocent, responsible/irresponsible, blameworthy/blameless.

Given this, I propose a framing of nondisclosure as an affective practice configured by the prefigured (Ricoeur, 1983/1990) narratives about victimhood, safe sex, innocence, blamelessness, culpability, and responsibility. Venn (2020) describes Ricoeur's notion of prefiguration as "the corpus of the already-known and the already-said, the stock of narrative understandings of the world and of subjects, 'inscrypted'—that is, at once inscribed and encrypted—in the lifeworld" (p. 46). These create "a cultural unconscious" (Venn, 2006, p. 111) that is affectively charged and which informs and structures the configuration of one's sense of self and the meanings one attaches to certain life events. This "cultural unconscious" (Venn, 2006) as it relates to nondisclosure, I contend, is made up of the two affective narratives

discussed above. These are the repertoires and archives from which PLWH "grasp together" (Ricoeur, 1983/1990, p. 66) their storied lives, "constructing the horizon of expectation [and] instructing the subject about what he or she is meant to anticipate and desire…" (Venn, 2006, p. 111). Therefore, understanding HIV nondisclosure as an affective practice allows for fluidity rather than rigidity in how people not only make sense of not being disclosed to, but also how others refigure (Ricoeur, 1983/1990) or interpret stories about HIV nondisclosure. Conceptualizing nondisclosure as an affective practice configured within narrative opens-up "worlds of feeling" (Plummer, 1995, p. 155) that are ignored, 'misread', or sublimated within law.

In the next chapter, I continue to explore this world of feeling and the specificities of living with HIV that are often neglected by the law, which positions PLWH as dangerous vectors of disease, and emerging narratives about a post-AIDS world where HIV is a personal responsibility one must manage (Race, 2001). I do this by focusing my analysis on the moment of diagnosis, which I theorize as a narrative plot twist in people's lives. I explore the emotion of grief, which has long structured narratives emerging from the HIV/AIDS crisis (Crimp, 1989/2003; Cvetkovich, 2003; Gould, 2009), creating a kind of practice in the way we come to know life with HIV. The grief of the HIV/AIDS crisis never went away but has been silenced or forgotten about in the normalization era, subsumed under hopeful narratives of a post-AIDS world. Yet, as participants' stories show, grief persists in the present as a sense of melancholia at the continued losses of self, relationships, and a healthy body, and social death.

# Chapter 6.

# Registers of Grief: HIV Diagnosis as Narrative Plot Twists

> *It was only when [partner's name] died, when my partner was killed suddenly that I started going to counsellors and I began to realize that I'd been grieving for a number of years and I didn't recognize it as grief. But when I lost my job, there was grief when I lost my ability to play soccer, there was grief, there was just loads and loads of grief in my life that I hadn't recognized. I would recognize grief when I lost someone, a human, but I didn't see that it was all around me, all the time, just because [I was] living with a disease that was stripping me of the things that helped me identify myself. So my job, soccer, my friends, things were just changing really quickly. So it took a death to help me realize that there's a lot of grief associated with living with HIV, and now I kind of acknowledge it [….].*
>
> *– Genevieve, white female, heterosexual, diagnosed early in epidemic*

In this chapter, I examine participants' stories about learning they were HIV positive and as they live with HIV in the era of HIV/AIDS normalization (Juhasz & Kerr, 2022; Squire, 2010). Receiving an HIV diagnosis, like many other chronic illnesses, acts as a rupture in one's life, one that may create further ruptures, forcing people to grieve their old self and configure a different affective narrative self (Charmaz, 1983; Ciambrone, 2001; Williams, 1984). I theorize this rupture as a narrative plot twist in one's affective narrative self that is shaped by the "refiguration of time by narrative" (Ricoeur, 1985/1988, p. 248) or how narrative not only reflects reality but actively reshapes time and our place within it. While I do not theorize time explicitly in this dissertation,[114] I think about time in relation to the disruption that illness causes (Bury 1982; Charmaz, 1983; Gardner, 2022; Riessman, 2015) and the eras of the HIV epidemic: the era of crisis and the era of normalization (Juhasz & Kerr, 2022). I place participant's stories of their diagnosis and the subsequent challenges of living with HIV *in* time. Specifically, I am interested in the affective narratives that structured the epidemic during the crisis, an era marked by

[114] See chapter 8 for a discussion of future research directions that may take up this question in more detail.

suffering, pain, grief, and anger (Crimp, 1989/2003; Gould, 2009; Juhasz & Kerr, 2022; Sycamore, 2021).[115] As Buttercup, an HIV/AIDS activist who was diagnosed early in the epidemic explains,

> There was a huge disruption during that period in people's lives […]. They were displaced. Their jobs [were] gone, their partners [were] dying, their health [deteriorated]. They had to go home to die, there was […] a funeral every week. […] I was helping people [p] actively and [stutters] but quietly because I didn't want [my] work to find out or I wouldn't have a job. And it's rather a sad time because you just […] watched everybody die. And here we are still alive 40 years later. (white, gay man)

Buttercup details the affective atmosphere (Anderson, 2014) of that epoch as saturated with feelings of fear about losing one's job and health, sadness and grief at the loss of friends and partners, and even relief and/or shock, as he proclaims in the last sentence how he is still alive "40 years later." While these affective narratives no longer represent the reality for many PLWH in Canada and other countries where there is access to medications to treat HIV, participant's stories in this chapter show that similar feelings persist today. Indeed, I was quite overwhelmed with how much participants recounted stories of pain, death, sadness, grief, fear, shock, loneliness, and isolation.

I focus this chapter and the next, specifically on grief and hope, which are central emotions that make up the affective narratives that characterized the HIV/AIDS crisis, as scholars before me have explored (Crimp, 1989/2003; Cvetkovich, 2003; Gould, 2009; Juhasz & Kerr, 2022; Sycamore, 2021). For example, Gould (2009) has shown in her work documenting the emotions underpinning AIDS activism, how grief was expressed in the form of anger amongst members of ACT UP, which propelled the group's formation and organizing. Anger, she contends, became the primary feeling as the epidemic progressed (Gould, 2009) at the

[115] I recognize that there were more complex emotions and feelings experienced during this time.

expense of grief's suppression or the way that PLWH were required to shut off "just to exist in day-to-day experience" (Sycamore, 2021, p. 16). By suppressing grief, you also silence it, and "that's what dominant culture, gay culture, queer and trans cultures" have done in the context of the losses sustained to HIV/AIDS (Sycamore, 2021, p. 16). This silencing internalizes grief, which can have devastating intimate, interpersonal, cultural, and communal consequences (Sycamore, 2021) as people are expected to *just* move on as the hopeful narratives about normalization emerged.

I am interested in how these affective narratives puncture into the present, shaping people's lived experiences of HIV. In this chapter, I therefore explore how these affective narratives make up the "'affective repertoires' [that] emerge in bodies, in minds, in individual lives, in relationships, in communities, across generations, and in social formations" (Wetherell, 2015, p. 147) to form the structures of meaning-making by which PLWH come to understand their sense of self, their place in this world, and their experiences. Specifically, I examine different registers of grief that make up life with HIV. By registers of grief, I am referring to the kinds of affective practices that are experienced as "a semi-continuous set of background feelings which are more long-lasting, moving in and out of focus as a steady shifting accompaniment to one's days, perhaps shifting now and then into more intense phases dominated by the body" (Wetherell, 2012, p. 12). I contend that while the intensity of grief felt during the crisis may not be experienced today by some,[116] a melancholic feeling nonetheless persists, configuring what it means to live with HIV in the present. While the urgency and crisis feeling during the HIV/AIDS epidemic in the 1980s shifted following the advent of ARVs, it is important to recognize that some people may still experience crises of different kinds (e.g.

[116] This may also be the case because the majority (44%) of participants in this study identified as middle class.

related to economic precarity). This chapter attempts to show these shifts and place it in a time when HIV/AIDS is increasingly being normalized.

Genevieve's point in the quote above intimates how grief has been silenced in the way that it can still be felt without being recognized as grief. The unconscious feeling of loss situates grief as an absent presence (Hetherington, 2004; Maddrell, 2013). As Broom and Peterie (2024) contend:

> Grief, too, has a problem with lingering. Or, perhaps has a tendency to join the unwillingness to fulfill the swift departure. But is grief lingering? Or, is it affective attachments that continue on, spilling into the present? Is the extended presence of grief in fact an act of intimacy that flies in the face of the cultural pull toward moving on and (in the lexis of recent clinical research) achieving 'post-traumatic growth'? (p. 13)

Grief may give the impression that it has departed but has only "moved on beyond our field of vision, or perhaps our willingness to view" (Broom & Peterie, 2024; p. 1). As time passes, it simmers just below the surface until it erupts as anger, shame, guilt, fear, uncertainty, disbelief, sadness, sorrow, shock, numbness, remorse, anxiety, and relief, only to recede and explode again, or at least make its presence felt (Charmaz & Milligan, 2006). Grief manifests in different forms that affect our bodyminds and makes it difficult to recognize or name (Broom & Peterie, 2024; Holinger, 2020; Jacobsen & Petersen, 2020). For this reason, very few participants described their experiences of being diagnosed and living with HIV using the language of grief; grief is what makes up the unsaid and unconscious affective narratives that impinge on the lives of PLWH and is felt as disgust about one's body or shock at the news of one's diagnosis. Nonetheless, their narratives describe loss in many areas of their lives, signalling the ways in which grief is experienced even if it is not recognized or named *as* grief. As Ahmed (2010) writes about melancholia, "what is lost is withdrawn from consciousness. This does not mean

that the feeling of loss is unconscious but rather than [*sic*] we can be unconscious of what is lost even when we feel we have lost it" (p. 140).

Citing Freud's work in *Mourning and Melancholia*, Eng and Kazanjian (2003) differentiate between mourning as a psychic process in which the "past is declared resolved, finished, and dead" from melancholia as "mourning without end…the inability to resolve the grief and ambivalence precipitated by the loss of the loved object, place, or ideal" (p. 3).[117] To be clear, I do not use melancholia in the clinical sense or to refer to a pathological state. Instead, I align with Eng and Kazanjian's (2003) depathologized description of melancholia as not only social "but also […] creative, unpredictable, [and] political […]" (p. 3). As they articulate, "melancholia might be said to constitute […] an ongoing and open relationship with the past—bringing its ghosts and specters, its flaring and fleeting images, into the present" (Eng & Kazanjian, 2003, p. 4). Melancholia, as a state in which one does not move on, allows for a continued and open relation with the past where new and different perspectives and understandings of that which is lost can be gained (Eng & Kazanjian, 2003). For Eng & Kazanjian (2003) melancholia becomes an important concept for exploring the political, economic, and cultural aspects of how loss is understood and history defined, producing "a world of remains as a world of new representations and alternative meanings" (p. 5). They argue that in asking what is lost, we invariably also question what remains (Eng & Kazanjian, 2003). In this chapter, I use the term melancholia to encompass the lingering quality of grief not as a negative affective state but as the affective practice which makes up life with HIV, structuring the

[117] Mourning also involves the active aspect of experiencing grief such as performing rituals and other mourning practices (Jacobsen & Petersen, 2020). I do not engage with mourning in this chapter as that requires an analysis of the specific practices people engage in as they mourn the losses they experience. In keeping with my theoretical framework on the affective narrative self, I was more interested in how the narratives of the HIV/AIDS crisis structure participant's sense of self in the present as they come up against the insidious traumas that continue to be felt in the era of HIV/AIDS normalization. Nonetheless, this is a fruitful topic for further exploration in a separate piece of writing.

configuration (Ricoeur, 1983/1990) of people's sense of self as they come up against the "traumas [that] the AIDS crisis continues to enact…" in the present (Sycamore, 2021, p. 14).

I frame participants stories of loss within a feminist and critical understanding of trauma (Brown, 1991; Cvetkovich, 2003a; Stevens, 2016; Wertheimer & Casper, 2016; Westengard, 2019) which explores forms of insidious trauma described as those "every day, repetitive, interpersonal, [and institutional] events" (Brown, 1991, p. 129) and "the everyday precariousness and brutality of the social" (Stevens, 2016, p. 27). Traumas of this kind are frequently diminished and ignored such that acknowledgement of one's trauma is often reserved for dominant groups who "can participate as a victim rather than as the perpetrator or etiology of the trauma" (Brown, 1991, p. 122). Insidious traumas are therefore manifestations of violence (Cvetkovich, 2003a) and the effect of diffuse modes of regulation which create the norms upon which PLWH are judged.

Trauma is also productive in how it gives way to particular forms of subjectivity and how it conditions and directs affective responses that are then regulated, managed, and redirected into broader political projects, serving as a mechanism for the mobilization of collective sentiment and social action (Cvetkovich, 2003a; Stevens, 2019). As a cultural object, trauma is invoked as a "set of practices that provide explanatory narratives, organize interpersonal and material relations, and establishes meaningful frameworks for understanding relatedness, temporality, and embodiment vis-à-vis 'overwhelming events'" (Stevens, 2019, p. 26). Keeping with this articulation of trauma, I consider the traumatic legacies of the HIV/AIDS crisis as forming a particular affective narrative with which to understand the insidious traumas of living with HIV in the present epoch.

I document the stories told to me by participants about loss and death that configure their sense of self in a time when normalizing narratives about a post-AIDS world attempt to silence and foreclose the ways in which the moralized narratives of HIV continue to construct PLWH as dangerous and a threat and HIV as a deadly disease. Based on the interviews I conducted, living with HIV was often described with reference to living alongside grief; a melancholic life that makes one's Otherness stand out, a sense of "misfitting" represented as the "discrepancy between body and world, between that which is expected and that which is […]" (Garland-Thomas, 2011, p. 593). Grief and melancholy expressed by participants through stories of death and loss form an affective connection to the era of HIV/AIDS crisis giving rise to a sense of longing for the world promised by biomedical narratives about a post-AIDS world.

I show this by juxtaposing the stories of participants who were diagnosed during the HIV/AIDS crisis with those who were diagnosed after the advent of ART and U=U. In doing this, I wish to connect the cross-generational narratives of HIV in which those diagnosed early in the epidemic feel as though they "have the […] the grief, and the duty, and the burden" while younger generations are believed to be "more free from suffering due to the people that came before" (Juhasz & Kerr, 2022, p. 108). Yet, PLWH today are not free from suffering and harm as HIV continues to be a "highly stigmatized illness that disproportionately burdens communities neglected and hurt by systems that should be designed for care and service" (Juhasz & Kerr, 2022, p. 222). The traumatic legacies of the HIV/AIDS crisis persist such that "the past does not stay in the past but ruptures through to the present, and the present looks to a future that is already possessed by the past" (Mann, 2023, p. 390).

The analysis resulted in four themes that make up this chapter: stories of the loss of self where participants describe an HIV diagnosis as a death sentence; stories about the loss of one's

body where participants describe the disruptive effects of taking medications daily and the side effects of these medications; stories about the loss of others where participants discuss witnessing death and losing friends, relationships, and family when they disclose their status; and stories about social death where participants grapple with the disruptions brought on by HIV stigma. I contend that encountering the loss of self, one's body, and one's social identity are the moments when the failure to assimilate one's affective narrative self into a normal, responsible, and healthy self are felt. They signal the moments when PLWH feel as though they do not belong in a post-AIDS world and a "return to the materiality of suffering and loss" (Westengard, 2019, p. 112) that has since been forgotten.

## 6.1. Stories of Loss of Self: Diagnosis Feels like a Death Sentence

In this theme, I show how the affective narratives of HIV as a death sentence pervade participants' experiences of receiving an HIV diagnosis regardless of the era within which they were diagnosed. Getting the diagnosis was narrated as 'life ending' both in the literal sense as the possibility of death felt imminent during the era when no medications to treat HIV were available and in the sense that participants felt a loss of self. Being near death in these ways not only exposes the rupture that HIV represents in participants' affective narrative selves but is felt as an affective intensity that reverberates throughout one's life with HIV and as they experience other aspects of their lives that might create new ruptures.

This is not unlike the experience of other chronic illnesses (Bury, 1982; Cluley et al., 2023) or experiences of violence (Brison, 2002; Mann, 2021). For example, in describing the sexual assault she experienced, Mann (2021) writes that "fear was central to the assault and the aftermath of the assault, but I wasn't afraid of literal, physical death. I was afraid of the annihilation of the meaning of my life as I understood and claimed it" (p. 383). Facing death,

whether through the potential eradication of one's physical body, the meaning of one's life, or the passing of loved ones, makes real the frailty of the human body and identity. As Bury (1982) argued, "chronic illness involves a recognition of the worlds of pain and suffering, possibly even death, which are normally seen as distant possibilities or the plight of others" (p. 169). Grief lingers on in these encounters with death, shaping how people understand the shifting meaning of their lives and how they are to respond to this loss. This theme is best shown by Margaret's lifeline in figure 5.

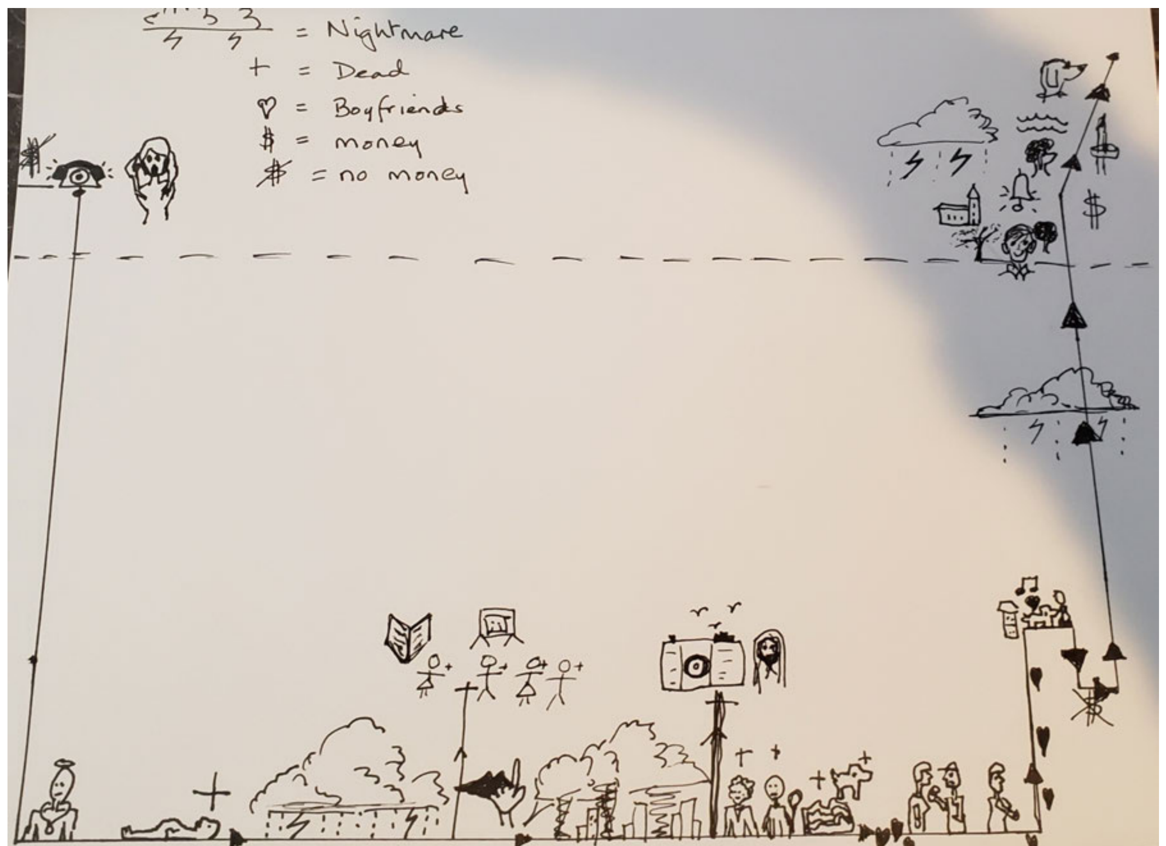


Figure 5. Margaret's Lifeline

The most profound aspect of Margaret's lifeline is the distinction between a "normal life" and a "chaotic life," which is differentiated by the dotted line, representing "ground level." Everything above the line represents happier moments in her life and the life she has now lost. The images below the line represent different moments in her life after being diagnosed, which are filled with

heartache, depression, stress, nightmares, loss, sadness, and uncertainty – this is where grief lives, shaping and altering the events in her life and their meaning. In the debrief about her lifeline, Margaret states,

> […] that little dotted line shows ground level, I feel like, normal living. And I was above that for sure. I was having a very good life. And then just before I found out, I was laid off my job. So I did a dollar sign, that's not very clear, but the dollar sign with a strike through it meant suddenly I had no money. And then […] [child's name] got sick and I got the phone call to say that [child's name] had AIDS […]. And, that is me incredibly shocked. So from that point down, everything fell out of my world. And where […] you might think that there's highs and lows [that] follow. And I've done a little stick up where there may have been a high, but mostly I think I was at an incredible low. All of that period of time, even when things seemed good, it wasn't good for me because my depression lasted well after the meds came in and everything.

Most poignantly, she states that this part of her lifeline could more readily be represented with a cloud over it. The metaphor of the cloud in Margaret's description alludes to the hovering effect or absent presence of grief (Hetherington, 2004; Maddrell, 2013) masquerading as depression and sadness. Margaret describes how she "went into a cloud of depression" as she experienced nightmares regularly:

> […] anywhere where there's clouds, and probably there could be a whole big cloud over the whole thing, there are continuous nightmares and I went into a cloud of depression. It was very, very bad. When I look back on it, I'm amazed I got through that. […] And I kept having nightmares, tornadoes, where I was in a building and tornadoes were going into the buildings and destroying everything. But I was still there. And I'm sure that was like HIV was coming and killing my friends. And I was still standing, which was very scary because I felt like the tornadoes were still out there after I came out the building. The tornadoes are still there and where do I go? […] Then lots of people I know died. […] that's kind of stacks and stacks of people I know who are friends of mine who died. […] So that period was really difficult. […] [Margaret, white heterosexual woman, diagnosed early in the epidemic]

Margaret's story is one of significant loss: the death of her child, which prompted repeated thoughts of suicide, PTSD, and depression; the loss of her career, partner, and friends; and financial stability – culminating in the death of her old self. That Margaret speaks about

tornadoes in her nightmares signals the chaos narratives told by people diagnosed with a chronic illness (Frank, 1995) and the tsunami and wave effect of grief that people with chronic illness experience (Taladay-Carter & Gunning, 2024). As a tsunami, grief comes on strong but dissipates quickly, while as a wave, it is never-ending, resurfacing from time to time (Taladay-Carter & Gunning, 2024). Being in a tornado means not knowing up from down as things are thrown about and as the centrifugal forces pull one up, creating disorientation. As the tornado passes, it leaves a mess and those in its path have to rebuild. For Margaret, being diagnosed with HIV was one aspect of her life that made her feel disorientated, like being sucked into a constant state of depression as the tornado killed her friends, her child, and her sense of self. Alongside their diagnosis and living with HIV, participants describe several other events in which they experienced loss that coalesce with HIV to create layered narrative plot twists in their storied self.

Genevieve was a university student when she was diagnosed with HIV at the height of the epidemic. She got the call that she was HIV positive while on the university campus in a common room using the computers. She described how hearing that she was HIV positive made her feel like everything had dropped around her, including the colour in her face and life from her body. Just hearing the words HIV/AIDS made her instantly feel like she was going to die and subsequently black out, as she did not know what else her doctor said at that moment. She explains,

> At the moment, all I heard was HIV-AIDS, I'm going to die, […] that's what I heard him say. I don't know what else he said. […] I never got calls at the university. I was a pretty dedicated student and I was focused on my studies. But, I […] felt like everything dropped, the colour dropped from my face, the life dropped from my body. I was supposed to go on a field trip that afternoon and I remember walking across the hall to the dean who was doing the field trip and saying, “I can't come on the field trip this afternoon.” I'm not feeling well. He said, “you look like death.” […] he did not know what he was saying, but he said, “You look like death, go

> home.” And I got home. I went on the bus home. I didn't talk to anyone on the bus. I walked upstairs to my bedroom in the house that I was living [at] […] and lay on the bed to die. I literally thought I was going to die that night, that's how horrible that news was. (Genevieve, white heterosexual woman, diagnosed earlier in epidemic)

That Genevieve felt these “drops” signals the heaviness of grief as she comes to terms with her new reality, the possible death of her physical body, and the death of her old self.

For people who were diagnosed after 1996, when HAART was created, death continues to permeate their thoughts as they live with and grieve the traumatic legacies of the AIDS crisis. Sycamore (2021) describes this feeling as “living between certain death and a possible future” (p. 14-15). Indeed, that participants diagnosed later in the epidemic encountered death even though medications make living with HIV manageable, is evidence of the sticky quality of the affective narratives about HIV/AIDS that depict the illness as a death sentence which shapes people’s sense of self in the present. Death, loss, and grief thus become a normalized part of living with HIV regardless of when one was diagnosed, for “it is the damaging aspects of the past that tend to stay with us, and the desire to forget may itself be a symptom of haunting” (Love, 2007, p. 1).

For instance, Jamie described her diagnosis as feeling like she got tasered; the instant shock of hearing those words, ‘you have tested positive for HIV’, coursed through her such that emotions left her body and she became numb and zombie-like. As Jamie states:

> And when I was in the office and he had told me […] you […] tested positive for HIV […]. […] I honestly froze for a while. […] . […] it's like I just got tasered. The huge shock of voltage of information that I'm HIV positive was [p] very shocking and very like, oh, shit! […] [p] almost every part of my emotions left my body. And I was just left with this empty box of not knowing how to feel, not knowing any choices, just feeling like this black hole of just not knowing, for […] what felt like a long time […] Once I left the doctor's office, I was […] like a zombie walking. I literally walked from the doctor's office right home. I didn't even want to go anywhere else after that because I didn't know how to handle it. […] all my decisions and all my thought patterns were gone because I didn't know what the

> next move was. […] those initial moments in the doctor's office after finding out that I had [HIV] [made me feel] very empty […] and very alone […] for a while.

She described this feeling of shock in greater detail later in the interview stating:

> […] the initial shock waves were pretty devastating. [I felt] emptiness and really not knowing what to do and not knowing how to handle it. […] [The feeling of diagnosis is like] you get shot by an electric voltage […] and then you kind of sit there and wait until the tingling is over to feel-- to see, am I okay? (Jamie, Indigenous heterosexual woman, diagnosed mid epidemic)

While Jamie never says she felt suicidal, she describes leaving her doctor's office as a zombie – the literal embodiment of living death and what has been depicted in American cinema as a "convenient bogeyman representing various social concerns" (Lauro & Embry, 2008, p. 86). Jamie's identification with a zombie represents her fear that she has lost herself but also her fear that she now represents this 'bogeyman'. As Lauro and Embry (2008) write,

> The terror that comes from an identification of oneself with the zombie is, therefore, primarily a fear of the loss of consciousness. As unconscious but animate flesh, the zombie emphasizes that humanity is defined by its cognizance. The lumbering, decaying specter of the zombie also affirms the inherent disability of human embodiment—our mortality. Thus, in some sense, we are all already zombies […] for they represent the inanimate end to which we each are destined. Yet the zombie is intriguing not only for the future it foretells but also for what it says about humanity's experience of lived frailty and the history of civilization, which grapples with mortality in its structure as well as in its stories. Humanity defines itself by its individual consciousness and its personal agency; to be a body without a mind is to be subhuman, animal; to be a human without agency is to be a prisoner, a slave. (p. 90)

Jamie feels a deep sense of lost agency because of her diagnosis, as she is uncertain about how her life will unfold moving forward. She told me several times throughout the interview that she feels her choices about relationships, friendships, and health have been taken away from her. Grief, in this sense, has a corporeality: "like physical pain, grief is the experience of damage to the self, and it is felt as an injury to the lived body" (Fuchs, 2008, p. 46).

The death sentence feeling is represented in both Genvieve and Jamie's accounts but in differing ways. Genvieve was diagnosed in the early days of the epidemic. She describes feeling a heaviness and that she did not talk to anybody right after finding out her serostatus, opting to go home and lay on the bed to die. She knew there was no medicine at the time of her diagnosis to treat HIV, resulting in an immobilized feeling. Jamie, even though she was diagnosed mid epidemic when ART was available, articulates similar feelings to Genevieve; she felt like a zombie and a sense of shock coursing through her body. Both refer to the sense of loneliness and isolation that follows an HIV diagnosis and living with HIV (Austin et al., 2023; Blanco et al, 2025) signalling how "grief—as a privately felt emotion—can still be a lonely feeling that leaves" those who are grieving isolated (Jacobsen & Petersen, 2020, p. 8). Yet, grief is also social (Jacobsen & Petersen, 2020) in the way that it connects the stories of PLWH. It alludes to a sense of "feeling backwards" (Love, 2007, p. 4) to a time when people were dying of AIDS in critical numbers, and grief and collective mourning were salient features of affective life for PLWH and their friends and family (Cvetkovich, 2003a; Gould, 2009). In the present, grief is experienced through this feeling backwards, with participants describing their HIV diagnosis as a significant moment of rupture in their affective narrative selves regardless of normalizing rhetoric that constructs HIV as 'just a manageable illness' (Squire, 2010; Walker, 2020; see also chapter 7 of this dissertation).

Cara similarly describes a sense of sadness and loneliness when she received her diagnosis as she would hide her crying from family. She also articulates how learning that she was HIV positive made her feel dirty signalling how disgust operates as a moral judgement such that "its presence lets us know we are truly in the grip of the norm whose violation we are witnessing or imagining" (Miller, 1997, p. 194). In other words, feeling dirty is a sign that Cara

feels her Otherness, as a “misfit” (Garland-Thomson, 2011, p. 593), and the “violence of the norm” (Cole, 2016, p. 261). Cara also felt fear because she did not know much about HIV other than what she saw on television, which depicted scary images of children and adults dying of AIDS. She felt as though she was all but dead. She states,

> I was living with my mother at the time and I felt dirty. […] I felt betrayed […] I felt sadness, a lot of sadness, because I used to go outside and sit just so I could be alone, and I would cry. […] everybody else was inside the house and I didn't want to do that in front of anybody. […] I would cry myself to sleep at nighttime […] because […] I didn't understand anything. […] the only thing that stuck out in my head […] were [those] […] commercials [that would] come on about African babies and adults having HIV and AIDS. And that's what I thought I was. I thought I was a goner. […] I'm a pretty big person. […] I'm not small. And I was just thinking to myself, how would I look in skin and bones? […] Losing all that weight? It's not a healthy thing to see [especially] […] getting stuck in a bed and not be able to move or anything. (Cara, interview, Indigenous heterosexual woman, diagnosed mid-epidemic)

Cara’s imagination of her body withering away to match the images she saw on television signals the ways that grief in the aftermath of a diagnosis allows one to “relate to death, to our own [and other’s] finitude and the temporality of life” (Lund, 2021, p. 190). It also reveals the way depictions of HIV/AIDS as a death sentence in the early days of the epidemic leave behind affective impressions that continue to shape the narratives used by PLWH to understand their sense of self today. Grief manifested itself in her fear and uncertainty about what her future holds, an ambiguity that was deeply isolating for her.

Dillon explains that he felt a profound sense of despair and self-blame when he was diagnosed. He felt his “ruined” body was tainted and believed his diagnosis to be a death sentence even though he was aware that there are medications to treat HIV. It took him a while to accept that he could live with HIV:

> [...] there were moments when I first got diagnosed where I was like, well, why don't I try meth? I mean, it's not something I've ever done before, but since you ruined your body and nobody is going to see you as someone of value, why not?

> Who cares? [shrugs shoulders] kind of a deal. So I mean, it left me thinking […] it's game over, dude. Even though logically, I did not believe that and I knew about medications and stuff. It took a long time for that to feel real. (white gay male, diagnosed later in epidemic)

Dillon feels a deep sense of despair linked to his diagnosis that negatively impacts his perception of himself and how he feels others will see him. This description of how being diagnosed with HIV feels references the felt experience of social death which refers to the systematic exclusion, dehumanization, or erasure of individuals or groups of people from social, political, and legal recognition (Ghane et al., 2021; Králová, 2015; Mann, 2021). We see this in the quote when Dillon articulates the feeling that he is no longer "going to [be] seen as someone of value." This sense of a social death reveals the way that receiving an HIV diagnosis is a rupture in his biographical life and an affective intensity felt as hopelessness and grief that facilitated the configuration (Ricoeur, 1983/1990) of his sense of self as 'not worth it'.

Dillon's statement that "it took a long time to feel real" alludes to the time it took to grieve the life he once had and to come to terms with having to re-imagine his life, one where his body may change, he has to take medications daily, go to regular medical appointments, and deal with HIV-related stigma on top of the stigma he already faced as a gay man. For example, he explains: "again, suddenly after […] 30 plus years of being an active gay person, I was back to being worried about my personal safety, about my legal status, about my relationships, […] about being a human biohazard and stuff" (Dillon, white gay male, diagnosed later in epidemic). His description thus signals how some PLWH "never cease to reinterpret the narrative identity that constitutes" them (Ricoeur, 1991b, p. 32), particularly in light of the histories of HIV.

Explaining an HIV diagnosis as a death sentence for both those who survived the height of the epidemic and those diagnosed after the advent of ARVs meant being "painfully suspended between a full life and a potential death" (Broom & Peterie, 2024, p. 9), a state of liminality

affectively charged by different registers of grief and fear. Next, I discuss participant's accounts of experiencing the loss of their once healthy bodies.

## 6.2. Stories of the Loss of One's Body: The Disruptive Effects of Medications

PLWH negotiate and make meaning of the effects of HIV and HIV medications on their bodyminds in different ways, including having negative body image and quality of life, feelings of loss of control over their bodies, and fear about changes to their bodies acting as visible markers of their status (see Chapman, 1998; Guaraldi et al., 2008; Huang et al, 2006; Kelly, Langdon, and Serpell, 2009; Tate and George, 2001). Those diagnosed earlier in the epidemic expressed feeling like "guinea pigs" as studies were conducted to determine treatment options. These drugs were often toxic and resulted in permanent side effects. In fact, some doctors and patients during the AZT trials[118] were skeptical about the drug's benefits and even argued that the drug was destroying the very properties the body needs to resist the annihilation of the immune system (Treichler, 1999). As Ariss (1997) writes, "having a disease that is little understood opens the body to the exploratory gaze of medical science" such that the individual becomes an experimental subject first, and a patient second (p. 91). For many who were diagnosed early in the epidemic, participating in HIV studies was the only way to access therapy in the absence of approved treatments (Ariss, 1997).

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[118] Zidovudine, or AZT as it is more commonly known, was for several years the only approved drug to treat HIV/AIDS in the 1980s. It was first derived from herring sperm and used in the treatment of cancer in the 1950s only to be abandoned when it was deemed too toxic and expensive. It was later, re-used as the American Federal Drug Administration (FDA) moved to test the drug on its effectiveness at treating HIV/AIDS. It reached full FDA approval in 1987 as a prescribed and insured medication for PLWH to use. Although trials of AZT showed that it improved short-term survival, reduced frequency and severity of opportunistic infections, and delayed progression to AIDS, it was also at the same time very toxic to PLWH. People suffered from nausea, muscle ache, headache, fever, skin rash, and dementia and because it interrupted cell replication, especially in bone marrow, in some cases it severely depleted red and white blood cells, causing fatigue, shortness of breath, and severe anemia. Some patients also experienced severe leg pain due to muscle wasting. (Treichler, 1999).

For instance, Victoria describes feeling like a guinea pig when participating in HIV trials, a sacrifice she was willing to make to also help others:

> I got on treatment. That wasn't fun, either, because I had to try different drugs. I was in a lot of studies, a lot of trials, some worked, some didn't work and then there were times that I was sick as a dog because back then all we had was AZT and 3TC. So the protease inhibitors weren't out yet. They didn't come out until 1995. […] so they had to put me on drug trials to find out what drugs would work. I was basically a guinea pig for the longest time. But I wanted to do it, not just [because it would] help me, but helping others who are living with HIV because I figured if it can help me, it can help others. However, there's some trials [or] studies [that] weren't so pleasant. [I had to have] a spinal tap and [I didn't know] how much of the drug actually goes to your brain and all that. And it's like, oh my gosh, […] I would never do that again! So that was kind of a nightmare.

I asked Victoria how these treatments affected her, and she spoke about having to live with neuropathy in her legs and the constant re-occurring pain she experiences as a result:

> Of course, my body has changed dramatically. I mean, these treatments are not easy on your body. I took a drug many years ago and I have neuropathy in my legs, which is very painful. It's in the nerve and there's no treatment for it. So this was a side effect that […] after so many years, there's still no treatment. And I guess they didn't know enough about the drug to find out […] years later that you would have this problem. So I have had neuropathy for years [it feels] like a tingling and burning sensation in your legs. And sometimes you have a hard time walking. But you know, I still get up and do what I've got to do. I've got responsibilities and I do what I have to do. But there's some days that it's very painful.

Victoria continues in a slightly joking yet serious manner, describing how she both grieves and feels disgusted with her changed body, and fears what the toxicity of the drugs she is on will make her feel and look like in 10 years:

> The body fat distribution goes to my gut. Like my legs and my arms are quite thin, so my body fat distribution all goes to my belly. I don't like that. I don't like my body image, I don't like it at all. I find it sometimes gross. But [sighs] that's hard to deal with. I lost my ass. Got no ass. I had a nice bum, now it's gone. It's gone flat. […] Like all these medications that I take are toxic, very toxic. It eventually is going to affect my liver or my kidneys, because that's what these meds do. So I'm concerned in regards to what I'll be like 10 years from now. I don't know what's going to happen 10 years from now. […] I don't know how these meds are going to affect my body. I don't know. I have no idea. I just live for today. The treatments are working well. I don't have any side effects other than headaches, I get a lot of

> headaches. But other than that, my treatments are working well. But I've been on […] several different treatments. One of them, I was allergic to. That almost killed me. That was a while back. […] when I was first diagnosed I was taking 18 pills twice a day. Yeah, now I'm down to three pills a day, plus my vitamin supplements […]. So we've come a long ways in regards to treatment. Thank God, because it was brutal. I mean, brutal. […] I've had some good experiences and not so great experiences. But today I'm doing OK. I manage, but it has changed my body image. […] (white heterosexual woman, diagnosed early in epidemic)

Although Victoria manages the pain of neuropathy and her poor body image, there is a sense of sadness at the loss of her body and the things it could do before she was diagnosed with HIV. As Eng and Kazanjian (2003) question regarding the corporeal origins of melancholia "how are embodied losses registered as historical events—at what costs and for what purposes?" (p. 8). In Victoria's story we see how the history of HIV is inscribed on her body as the effects of the HIV drug trials continue to be felt. This history is one in which "race-based systems of domination established by colonialism and slavery provide the grounds for biopolitics to work here, leaving [some] women without health care and inferior treatment options, where they were passively left to die" (Manning, 2020, p. 246). While Victoria accessed treatment through these trials, the insidious traumas of those studies continue to be felt as a temporality, a "lived time [that] is not bound to linearity, like clock time [but is] an entanglement of or even infusion of past, present and future […]" (Mann, 2023, p. 391).

The different registers and intensities of grief are reflected in Victoria's story as oscillating between a sense of sadness at the loss of her body that once was and the sense of purpose when she describes her experiences with earlier medications as a worthwhile disruption since they helped science progress to the benefit of others. Grief over her loss is mediated by her feeling of 'doing good' as she volunteers her body to finding treatment and dedicating her life to working as a peer support worker for newly diagnosed women. Yet, she continues to feel fear about what the medications will do to her 10 years from now suggesting that "interpreting the

meaning of being HIV-infected is a continual process of assessing one's health, one's probability of progression, of rendering medical information intelligible" (Aris, 1997, p. 55). Victoria's ongoing struggle with medication side effects exemplifies how biographical disruption is not felt only at the initial diagnosis but at different times throughout one's life (Cluely et al.. 2023), as new pains and side effects emerge, as one ages with HIV, and as new life events are experienced. Her attempt to avoid feeling the weight of grief by focusing on "living for today", is a mechanism of overcoming biographical disruption where she ignores or avoids thinking about her future in great detail—doing so is too painful.

Such avoidance is also seen when participants spoke about forgetting they were HIV positive until a side effect from their medications flared and they felt pain, or they had to take their medications. Ava discussed the side effects from her medications at length, stating that she feels pain all over her body and that it often travels:

> I have chronic pain. I have constant pain, and it moves all around my body like right now, I have […] a problem with my heel. And once this is healed, […] I'll have something else and it's constantly like that every single day, not a year goes by that I don't have something and then it goes to somewhere else and goes to somewhere else and somewhere else. It's constant chronic pain. Other side effects, gaining weight, [p] [sighs]. At first, I had vivid dreams, really vivid. When I first started on one of my meds, like my eyes, everything went bright and my heart started pounding really hard. But for the most part, I must say that the meds have been good for me. […] I'm lucky that way. I got to say my immune system's pretty good. So they're doing something for me. (Ava, white heterosexual woman, diagnosed mid epidemic,)

When I asked Ava to tell me how she feels about having to manage these side effects, she spoke about trying to ignore the pain to get through her day.

> It's horrible. […] I'm just getting used to it […] but it's when I sit down and when I have time, it sinks into my head. It gets me really down. Like right now. I usually don't think about it […] and I just carry on and [I say] "okay, my heel is sore […] just go on. Just carry on. Because […] fuck, I don't know, I just carry on. But, now thinking about it and everything [the pain in] my leg is just going up and down. […] I try not to think about it too much. But at a point like now, when we're

> discussing it, […] it gets me down. It's just [p] it's brutal. (diagnosed mid epidemic, white heterosexual woman)

Karam, emphasized that the act of taking daily medications is a constant reminder of his HIV status.

> When I started medications […] it's a reminder every day [that] ok, you got HIV. Even through the day I don't think about it […] And it's, I wouldn't say triggering, but […] it's always […] kind of a reminder. (Middle Eastern, gay male, diagnosed later in epidemic)

Ava and Karam's stories signal the affective intensities of living with HIV that register as intense pain (physical and psychic) felt by Ava as it travels up and down her leg and she experiences nightmares, as a heaviness exemplified by Ava's sigh, relief as Ava describes feeling "lucky" that the medications are working for her, and the haunting feeling that the virus lingers in one's body as Karam is reminded of his diagnosis every time he takes his medications. Their stories show the continuous disruptions brought on by living with HIV including chronic pain and the requirement to take their medications daily and diligently and thus never able to forget that they now must live with and manage a virus in their body. For Ava, this is something that is deeply upsetting and difficult for her to talk about.

Victoria and Ava's descriptions of their pain and how they cope with it intimates the "emotion work" (Hochschild, 1979, p. 560) that is involved in managing how one feels. By emotion work Hochschild (1979) means the "act of evoking or shaping, as well as suppressing, feeling in oneself" and not necessarily whether such emotion work is successful (p. 561). They both talk about, in one way or another, carrying on, moving on, or being present. These are attempts to manage the grief caused by the side effects of medications. Moreover, pain sensations demand attention to "embodied existence" and thus how one "inhabit[s] the surfaces of the world in a particular way" (Ahmed, 2004, p. 27). Their pain is thus a sign of their

Otherness, of their ‘out of placeness’ from the norm of a healthy body. Lastly, Ava’s story shows that grief is experienced in moments of different kinds of biographical disruption, signalling that we must be cautious when thinking about biographical disruption due to HIV for those whose lives were already marked by instability (Thompson & Abel, 2016; Wells, Murphy et al., 2023).

As time and the science of ARVs progressed, these side effects were felt less and became more tolerable (Horne et al., 2019). Alex’s story exemplifies this well and is shown in his lifeline drawing in figure 6; modern day ARVs allowed him to recover from the effects of seroconverting and to feel better with minimal side effects, although other events can also comingle with HIV to create disruption (Wouters & De Wet, 2016):

> […] things seemed to start getting better. But then 2020 happened, and a bunch of things just went into chaos, that's what the explosion is supposed to mean. […] I started feeling off with everything, just mentally and physically. […] I started coughing and that's what the mask is supposed to mean. And yeah, so I started feeling sick and […] in [month] was when I was admitted to the hospital and eventually, I was told that I had HIV and that's what the exclamation mark is supposed to mean [chuckles].

When asked why he chose to represent his diagnosis with an exclamation mark, Alex stated that he felt a sense of relief and closure because, for so long, the doctors did not know what was wrong with him:

> When they gave me the diagnosis, it was like, finally I know what it is, […] yay?! But it was sort of a relief to know what was going on with me and to know that there was something that could be done because that was […] the other thing. I was worried […] that […] they don't know what is going on and how long it's going to get for me to get better and get back to some normal. So yeah, for me it was a relief to know what this is, this is what you have, and this is what you need to do to get better. […] in 2017 I put out a question mark because that's […] when the weird symptoms started. And then the exclamation mark, meaning that OK, it's kind of a closure. (Alex, Latino gay man, diagnosed recently)

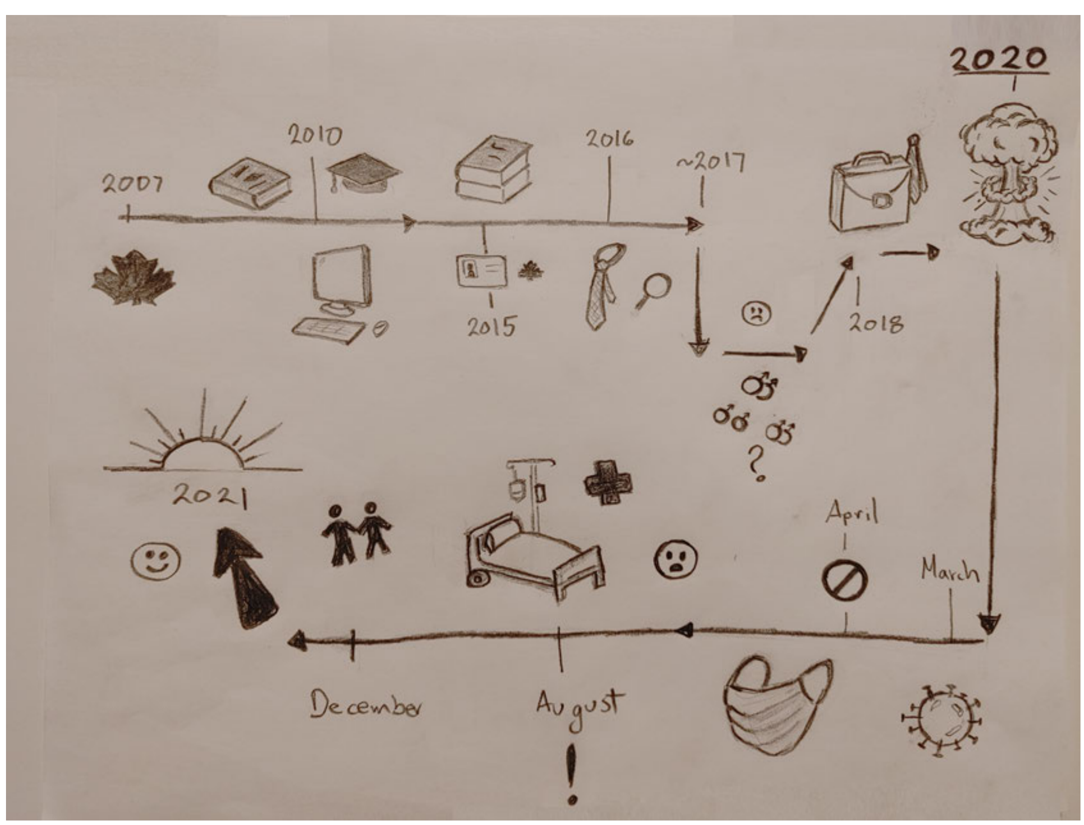


Figure 6. Alex's Lifeline

For Alex, who was the most recently diagnosed person I interviewed, the HIV diagnosis was experienced as a sense of relief which stands in stark contrast to the narratives of Dillon, Victoria, Cara, Jamie, Margaret, and Genevieve. His diagnosis was not felt as a disruption but rather as "closure" to the disruption caused by the effects that untreated HIV was having on his body. Closure as an emotion has come to mean "the constellation of feelings—peace, relief, a sense of justice, the ability to move on—that comes with finality" (Bandes, 2009, p. 2). Receiving an HIV diagnosis gave Alex a sense of certainty; he now knew what was going on with his body, and that meant knowing how to manage it. Wouters and De Wet (2016) explain that an HIV diagnosis is not always felt as a rupture in one's biography as people would go from denial to acceptance and thus incorporation of HIV within their sense of self. Alex was well-connected with the HIV community and had several HIV-positive friends, situating him within

present understandings of HIV as a chronic but manageable illness thus making him less fearful of what it means to live with HIV. His sense of closure and relief signals how "human experience is mediated by all sorts of stories we have heard" (Ricoeur, 1991b, p. 29) thus rooting the self in relations of time and space.

The embodied aspects of HIV represent the historical traces of the era of the HIV/AIDS crisis and the feeling of "misfitting" (Garland-Thomson, 2011, p. 593) which signals a temporal juxtaposition in which PLWH experience a loss of one's healthy body in a time of HIV normalization. Said differently, their pain surfaces the borders between healthy and ill that characterizes the experience of living with HIV in the "second silence" (Juhasz & Kerr, 2022, p. 11). Next, I discuss the stories of grief experienced because of losing loved ones.

## 6.3. Stories of the Loss of Others

Those who survived the epidemic in the 80s and 90s experienced their HIV diagnoses as death sentences, actively living through the years in which no medications were available and loved ones were dying. Death presented itself everywhere and grief was felt at lost friends, lovers, and family alongside feelings of survivor guilt and anger that propelled some participants into advocacy. For instance, Buttercup, an older gay man diagnosed early in the epidemic, describes how he witnessed many of his friends dying:

> It's kind of sad when you watch all your friends die and certain ones stick out and the suicides-- there was a number of people who committed suicide during the 80s, that I knew. People jumping out of buildings, people overdosing intentionally, some dreadful occurrences. And then there was the other people who committed suicide they just came and said goodbye. And then they'd commit suicide. This is all history now. It's kind of forgotten when there's only a handful of us left from that period.

Buttercup expressed concern that early stories of suffering are being forgotten as time passes on. His feeling that the memories of friend's stories are lost to time and insistence that they be

remembered signals what Broom and Peterie (2024) call the spectrality of grief or the ways in which grief lingers. Grief's haunting effects are felt such that,

> relationality does and should not end at death, despite the pressure […] to sever connections and let the dead be. In this sense, partitions between the living and the departed are experienced as incomplete. […] To remember, after all, is to *be-with* and to *grieve-with*. (p. 15)

Grief is an important feeling that keeps those we have lost alive through the impressions they have made on us. These impressions shape "our bodies, our gestures, our turns of phrase: we pick up bits and pieces of each other as the effect of nearness or proximity" (Ahmed, 2004, p. 160). In other words, as Buttercup grieves the loss of his friends, he carries their impressions with him, keeping their memory alive through him, as he provides care for others who are also grieving and suffering.

The most profound story of death and grief's enduring quality was told to me by Margaret, whose lifeline drawing was included in the opening of this section. She spoke at great length about how her diagnosis was unique because she was pregnant at a time when medications that allow women living with HIV to safely give birth to HIV-negative children were not available. Her child was born HIV positive and very quickly passed away, leading to intense feelings of self-blame and PTSD:

> […] I was scared! […] I was told I was going to live five years at the most! Well, they actually said to me, some people live five years with this. So in other words, you're lucky if you live five years. And [chuckles] I thought, well, I wonder if I should wear my seat belt anymore […]. That would be quicker. I went into a deep, deep depression after [child's name] died. I was […] really looking for ways to kill myself. And actually, before she died, I was trying to figure out how I could kill her. Say we go out in the canoe, fall over the edge, in a cold lake and die like that with her. And then I thought, knowing my luck, I'll probably live and I'll be mentally damaged for the rest of my life because that's how lucky I am… I feel so guilty that she got infected from me. I was so stupid. (Margaret, white heterosexual woman, diagnosed early in epidemic)

Maragret's story intimates the ways in which grief involves "the *foreclosure* of longstanding embodied intimacies" (Broom & Peterie, 2024, p. 8). In this case, Margaret experienced the fracturing of the mother-child relationship, the most intimate of bonds for some women. Her grief is also registered as self-blame for passing on the virus to her child, a pain that surfaces her sense of failure to abide by gendered expectations of women to be proper mothers who take care of their bodies and keep their children safe (Schmidt et al., 2023; Whitehead, 2016).

Even with all the pain and suffering she experienced around her diagnosis; Margaret told her story with some humour. While describing the vivid nightmares she experienced and her plans to end her life, she was able to chuckle her way through the telling of this account. She stated several times throughout the interview how unlucky she was, so any attempt at suicide would most likely be unsuccessful. The comic narrative form Margaret employs allows her to manage when she lets the affective intensity of her daughter's death be felt as grief or as something to chuckle about and lighten the mood. Humour is often also used to cope with feelings of grief (Wilson et al., 2024). Margaret often used sarcasm, humour, and wit as she told her story.

Loss of others was not just felt when those closest to participants passed away. It was also felt when participants lost relationships, friendships, and family members when they would disclose their status. For example, Frank discusses how telling his partners that he was undetectable did not change their opinions about him and that they would still reject him. He speaks about how they did not "care" about him or the fact that he was able to remain undetectable for 19 years:

> […] when you try to go out and meet somebody and all of that, and then you disclose to them, and you disclose that you're undetectable, at the same time, they still don't give a damn! [elevated voice]. They still don't want anything to do with

> you. Even though you're undetectable. I have been undetectable for 19 years, but they don't care. (white gay male, diagnosed mid epidemic)

Richard describes how the people in his life, including his in-laws but not his wife, abandoned him once they found out that he was living with HIV: "…everyone in my life bailed on me, except my wife. My in-laws didn't want anything to do with me" (white pan-sexual male, diagnosed early in epidemic). For Pup, the opposite was true in that his in-laws were very accepting of him while his own family shunned him and wanted him kicked out not only because he is living with HIV but also because he is gay:

> I got more acceptance from my partner's family than I did from my own family. […] My parents, unbeknownst to me, […] my brother, my other brother and sister, and my nieces and nephews too, […] [said] "oh, you should kick Pup out, he's gay, he's positive, you should kick him out." That went on for years and it all came out, […] in the wash after my mom passed away […]. The only person that […] I'm in contact with from my actual blood family is my sister in Vancouver. [I] lost contact with my dad, with my brother, my sister, my other sister disowned me.[…] Do I regret it? Do I feel sad about it? Yeah. (Indigenous, two-spirited, gay, diagnosed mid epidemic)

For Pup, being disowned by his family makes him incredibly sad, yet he also told me in the interview that he had to just move on with the support that he did have, including from his long-term partner. Rose also articulates how she lost many friends and contact with her more distant relatives because of her HIV status. She describes how her friends chose to refrain from interacting with her because HIV is "too much drama" for them:

> […] I have lost a few friends because of my HIV status, because they can't get over the fact that I have HIV. […] I don't necessarily talk to anybody from my family other than my immediate family. Friends, they just stopped talking to me because it's […] too much drama to have HIV and it's [p] [shakes head and rolls eyes] and, you know, like I can educate you, I can tell you, and they're like, "no, no." They're fine with [chuckles] […] not talking to me, which is fine, I've come to accept it. You either want to be in my life or you don't. Plain and simple. (white heterosexual female, diagnosed mid epidemic)

Clay explains how disclosing is a deeply personal decision and practice because not everyone is accepting. He talks about having to really trust the people that he is disclosing to because in the past, when he did disclose to friends, they stopped talking to him:

> There was only a couple of people that I disclosed to. That's a very personal thing because you have to really trust the people that you're disclosing to. Back then and now as far as I'm concerned because people still discriminate and there's still people […] that I have disclosed to today that […] don't talk to me anymore. It's like really? But anyways, it's their issue, not mine [chuckles]. (white gay male, diagnosed early in epidemic)

For Rose, Clay, Pup and many other participants, disclosing acted as a mechanism to weed out the people they wanted to trust and build a friendship with which resulted in deeper and more committed friendships. This is evidenced when Rose states, "you either want to be in my life or you don't" and Clay says it is "their issue". With these narrative twists, Rose and Clay seem to brush off their friend's negative reactions to their disclosure and the feeling of rejection by stating that it is their problem for not wanting to learn about HIV and PLWH, for not wanting to accept them, and for remaining ignorant.

But this was not always the case for some participants who described refusing to engage in relationships and sex all together to avoid the burden of having to disclose. For example, Pieter articulates his decision to refrain from relationships because he does not want to feel rejected:

> I always felt I had a secret. […] I felt also, holding back from making relationships because I didn't want to share my diagnosis. […] just the fear of rejection, I guess. I would have been rejected many times in the past […] in my life, and […] no one wants to feel rejected. (white gay male, diagnosed mid epidemic)

For participants like Pieter, living with HIV and the burden of disclosure also meant experiencing a loss of one's own sexuality and intimacy with others to avoid the negative repercussions like ostracization, rejection, and even violence that so often accompanies

disclosure. Living with HIV meant living with a secret that weighed heavily on Pieter and others as they navigated decisions about when, how, and if to disclose. Every disclosure thus represented the possibility of further disruptions to their lives as friends and family disowned them and intimate partners rejected them.

Seeing others die, the incredible pain and grief that is felt by those who survive, and the loss of relationships, friendships, and family when one discloses their status shows that as humans we are deeply connected. Indeed, "grief discloses the fact that as human beings we are fundamentally related to, and in need of others, that […] ourself is permeable and open to them" (Fuchs, 2018, p. 48). Loss of a loved one means a "*contraction* or even *partial loss of self*" (Fuchs, 2018, p. 49), for we identify *with* the people we come into contact with, taking on their characteristics or actions just as we take on other's stories in the creation of our own narrative self (Plummer, 1995; Ricoeur, 1996). Buttercup's stories of death remind us of the pain and suffering of PLWH who have died and the importance of remembering those who have gone to provide better care to those who live with HIV. Grief thus acts as a "motivational well" (Plummer, 1995, p. 39) in the configuration of one's affective narrative self. Plummer (1995) describes a motivational well as a "source point for explaining what is going on, who one is, why one is the way one is" (p. 39). This is evident in the way that Buttercup describes himself as a "renegade," not afraid to push the boundaries and stand up for other PLWH through his advocacy work during the HIV/AIDS crisis of the 1980s. Grief has always been a motivating factor for HIV/AIDS activists even when it was felt as anger (Crimp, 1989/2004; Cvetkovich, 2003; Gould, 2009). As Crimp (1989/2004) famously wrote in his essay *Mourning and Militancy*,

> Upholding the memories of our lost friends and lovers and resolving that we ourselves shall live would seem to impose the same demand: resist! […] But we

> must recognize that our memories and our resolve also entail the more painful feelings of survivor's guilt, often exacerbated by our secret wishes, during our lovers' and friends' protracted illnesses, that they would just die and let us get on with our lives. We can then partially revise our sense…of the incompatibility between mourning and activism and say that, for many gay men dealing with AIDS deaths, militancy might arise from conscious conflicts *within* mourning itself… (p. 138)

As such, the stories of the loss of others I discussed in this theme highlight how "death has its own vitality – a life of its own […]" (Broom & Peterie, 2024, p. 15) such that death and loss are not always the end and grief is not only disruptive to happiness, but also a moment to refigure (Ricoeur, 1983/199) the self, one's relation to others, and a motivational force towards political and social action. Next, I think about social death as a feeling brought on by HIV-related interactional stigma and the contemplation of suicide as a response to this feeling of social death.

## 6.4. Stories of Social Death: The Insidious Trauma of Stigma

PLWH contend with changes to many aspects of their life, including to their bodies, mental health, relationships, and families. These disruptive effects are well documented in the literature (see Alexias, Savvakis, & Stratopoulou, 2016; Ezzy, 2000; Carricaburu & Pierret, 1995; Ciambrone, 2001; Orsini & Kilty, 2020; Wouters & de Wet, 2016). These changes make 'normalizing' HIV in one's daily life difficult precisely because HIV is not *just* disruptive at the point of diagnosis but rather continues to disrupt throughout one's life (Squire, 2010). The concept of biographical dialectics[119] (Cluley et al., 2023) exemplifies this well and helps to

[119] Biographical dialectics, as discussed in chapter 2, is the notion that disruption to one's biographical life does not occur at one point in time (Cluley et al., 2023). Rather, that disruptions are continually experienced throughout one's life with chronic illness (Cluley et al., 2023). These disruptions often lead to other issues that require problem-solving on the part of those experiencing chronic illness (Cluley et al., 2023). Cluley et al., (2023) explain, "this recurrent pattern of *issue*, *problem*, *answer*, is known as a dialectics. The coming together of two things (generally opposites), in this case life before dialysis and life with dialysis, creates something new. In creating something new (the solution), other issues arise that also have to be considered and solved. These issues may not be immediate but may arise over time" (p. 7).

describe how PLWH must continually configure their affective-narrative selves as the personal, social, and cultural impressions of HIV make themselves felt through grief.

These continuous disruptions in the lives of PLWH are most acutely felt in relation to experiences of stigma and particularly "anticipated stigma" which results in a "deeply felt realization of 'otherness'[…]" (Bruckert & Hannem, 2012, p. 3). The social death felt by participants is the effect of interactional or interpersonal stigma defined by Goffman (1963) as not just an attribute but the "relationship between attribute and stereotype" (p. 4). Hannem (2014) defines the process by which interactional stigma unfolds more specifically as when,

> …an individual possesses a particular attribute (i.e., the quality of having a conviction for a criminal offence) defined by others, based on stereotypes, as an undesirable or negative characteristic. This attribute, then, and the perception of it, result in avoidance or discriminatory behaviour directed toward the sitgmatized person. Stigma is not inherent in the individual attribute but is realized in interaction with other non-stigmatized ('normal') persons. To be present, stigma need not be realized in overtly discriminatory action, but often operates on a sub-surface level, colouring interactions and creating tension or avoidance behaviour. (p. 15).

In other words, interactional stigma is experienced when a person possesses an attribute, like living with HIV, that is perceived by others, based on stereotypes and assumptions, as an undesirable or negative characteristic. People then respond to this characteristic and their judgement of it by avoiding the person or engaging in other discriminatory behaviour that is directed at the stigmatized person. In this theme, I contend that interactional stigma is experienced as an insidious trauma (Brown, 1991; Cvetkovich, 2003a; Stevens, 2016) that reverberates throughout the lives of PLWH shaping their relations with others and how they configure (Ricoeur, 1983/1990) their affective narrative selves. I show how the affective narratives of the HIV/AIDS crisis act as stereotypes or metanarratives that inform people's understandings of HIV and PLWH and that continue to be applied to PLWH and HIV today.

These experiences seem to show that, in our present moment, HIV/AIDS is anything but normalized.

As a disease of signification (Treichler, 1999) and one in which metaphors abound (Sontag, 1977), HIV discourses variously categorize PLWH as dirty, dangerous, immoral, bad and therefore people to be feared (Crimp, 1987; Patton, 1990; Treichler, 1999; Watney, 1987). Stigmatizing discourses are exclusionary and are very closely attached to the emotions of disgust and fear, the impacts of which are felt in very real and often dis-abling or disruptive ways by PLWH. These may include: a loss of social identity and status, disenfranchisement from communities they once knew, and unjust treatment (Herek et al., 2003; UNAIDS, 2007); negative health outcomes (Lo Hog Tian et al., 2021); reduction in access to HIV prevention, testing, treatment, and care (Mahajan et al., 2008; Newman et al., 2006), criminalization (McClelland, 2019b, 2024); discrimination in the workplace (Ontario HIV Treatment Network, 2016; Liu et al., 2012; Perri et al., 2021) and healthcare settings (Lacombe-Duncan et al., 2020); mental health challenges (Turan et al., 2017); and overall quality of life (Earnshaw & Kalichman, 2013). These effects can be felt even more depending on one's race, class, sexuality, sex (Logie et al., 2011; Turan et al., 2017; Woodgate et al., 2017), what some have called intersectional stigma or the "alignment of structural systems of oppression" (Malama et al., 2023, p. 116). As a disease of signification, I am thinking about stigma as socially produced, something that gets attached *to* an individual rather than something an individual *has* (Hannem, 2014; Link & Phelan, 2001).

Like Dillon in section 6.1., Jamie expressed feeling a deep sense of stigma throughout her HIV journey. When I asked her to explain how the moment of being diagnosed felt, she talked about the uncertainty of how she was going to live with HIV. She was afraid that she would have

to isolate in her room because no one would want to be friends or be close to her. While she did not feel suicidal, she feared that the diagnosis would hinder her efforts to refrain from using drugs. Jamie was sober 20 years, so a relapse would be a significant setback for her. She says,

> Sitting there, it was a very, very rough shock to comprehend. I was going into my doctor's office thinking, I'm going to get another green bill of health and then coming out […] I felt like my life was over. […] I didn't want to end it, I didn't ever think I want to kill myself, because I've got this. It [just felt] like my life is over. I'm not going to have any friends, I'm not going to have anybody that wants to be near me. I'm not going to ever have a happy lifestyle. I mean, this is what I thought at the time. I thought my life was going to be my room and maybe once in a while, I'll go for coffee or something […]. I probably isolated myself a good four years, trying to adjust […], I had a lot of counselling, I had a lot of support, which is really good because I know if I didn't have that, I wouldn't have made it. I probably would have relapsed […] thinking that […] my life is over. (Jamie interview, Indigenous woman, diagnosed recently)

Jamie describes how after she was diagnosed, she isolated herself for four years. This articulation of how she felt upon receiving her diagnosis intimates the loneliness of grief (Broom & Peterie, 2014) and one of the primary features of social death in which people are socially excluded, leading to a loss of connectedness with their communities and society (Chavez, 2021; Ghane et al., 2021; Králová, 2015). Jamie describes the feeling of social death as like being "put in a box":

> After the initial shock was over, I felt like I was put in a box and that I was only able to go out in certain parts of the city, because I was so afraid that anybody was going to find out that I was HIV positive. Because I'd seen the stigma out there. I am now part of that stigma. […] it was very controlling, meaning that I let the stigma control me and that fear of, oh my god, some people are going to find out! […]

That Jamie uses the metaphor of a box is telling of the felt experience of social death as 'actual' death in which we bury those who have passed in a coffin. When I probed her specifically about her experiences of being an Indigenous woman living with HIV, she described feeling doubly marked:

> I believe that being an Aboriginal woman with HIV has more of a stigma to it. […] Doesn't matter where I am or who I may be with, if that disclosure comes out […]

> when people like me [p] come forward and say “yeah I'm HIV positive”, [even] undetectable HIV positive, people will automatically step back three or four steps. It's like the virus is going to jump out of my body and jump onto them somehow, like a bedbug or a cockroach or something. […] [As an] Aboriginal women [when] I walk into a place with a group of people […] for some reason I get centered out. […] I am a well-educated person and I know my culture and my language, I know my boundaries, and I am very respectful of other people, but yet you still have a picture of me standing on the corner with a needle in my arm. I [don’t] understand that. I still don't understand it. Like [why do] some people have that image of Indigenous women? Considering there's like the majority of us that were in positions like myself, where the person didn't disclose or other people who got it from blood transfusions or from work when they got stuck by a needle by somebody that was in psychosis. […] Indigenous women get the stigma the worst. I don't know. I think that's really unfair. Everybody else can live with the label of cancer and Hep C and anything else. But for some reason HIV is like, holy shit! Run for your life! What is it about that one? Considering [it] has moved [on] from [being] a deadly disease, people still see it as a disgusting disease where they just want to stand back. (Jamie, Indigenous heterosexual woman, diagnosed recently)

Here Jamie describes how she deeply feels other’s perceptions of her as a dirty and savage Indian woman. These are stereotypical assumptions often invoked to deem Indigenous women as disposable and to justify their increased regulation, control, and punishment (Monchalin, 2016; Razack, 2000). This is all amplified as an Indigenous woman living with HIV, an attribute in and of itself that is deeply stigmatized as those who live with the virus are regarded by others as dangerous, dirty, immoral, and risky. Jamie also talks about how people avoid and distance themselves from her when she discloses that she is living with HIV. This is an example of the ways in which interactional stigma is not always realized in overtly discriminatory ways but in the subtle behaviours of those with whom stigmatized individuals interact.

As Cohen (1999) contends, “feelings of alienation and distance result not from a one-time or single-domain, experience of marginalization, but instead are rooted in a historical experience of exclusion across domains” (pp. 49-50). In describing Ricoeur’s notion of prefiguration, Dowling (2011) explains that this involves “the way any individual consciousness inhabits its culture as a symbolic whole. In very basic terms, this means that I am able effortlessly to

understand, as I understand my native language, the sign systems of my own society" (p. 15). As symbols, affective narratives about HIV and Indigeneity form the stereotypes that prefigure our understandings of HIV and the people who live with the virus. This conception of affective narratives as the mechanism through which interactional stigma is enacted, intimates Frank's (2010) assertion that stories have the capacity to "make TROUBLE for humans" (p.28) as they produce stigmatic understandings of the virus and PLWH.

As an Indigenous woman living with HIV, Jamie experiences the insidious traumas of interactional stigma through the historically racialized and gendered narratives that depict Indigenous women as the non-human, dirty, savage, and disposable Other (Monchalin, 2016; Razack, 2000) in addition to those of HIV and PLWH. As a result, Jamie positions herself as an innocent victim when she states, "the majority of us […] were in positions like myself, where the person didn't disclose or other people who got it form blood transfusions or from work when they got stuck by a needle by somebody that was in psychosis." She articulates throughout the interview that it is unfair for others to stigmatize her particularly because she is also undetectable and thus a responsible HIV citizen.

Beth, also an Indigenous woman, described the stigma she faced from certain family members. Although most of her family was quite accepting, some made her feel dirty and disgusting. Despite this, Beth sympathized with them because she felt they had little knowledge about how HIV is transmitted:

> Sure, there's days […] that I was looked down upon because of my HIV by my family, but they didn't mean to make me feel anything different. It's just that they're scared too. They didn't know what it was and what could happen, and they're trying to be protective of their kids […]. So, I had to sit down and I had to learn on my own and try to teach them about HIV, even though I was teaching myself what it was. Today, it's okay. It's not as bad as it was because at first, I wasn't allowed to use anybody else's straw. Like everybody else's [toothbrush] was out of this one bottle, but I had to get a cup. But today I just share.

Beth manages her behaviour around her family members to make them feel more comfortable. She does this by keeping her toothbrush separate from the other toothbrushes in the bathroom even though she is fully aware that HIV cannot be transmitted by eating from the same bowl: "I do little things like that just to make sure that my family is comfortable with me." Yet, when I asked how stigma made her feel, Beth explained that it made her feel alienated:

> It made me feel so degraded, unwanted, unhuman. Like I wasn't even a part of the family, like, I didn't exist. And the look that [my sister] gave me was so, hurtful, [p] I wouldn't wish something like that on anybody. You know it, it tears, tears a person. (Heterosexual, diagnosed mid epidemic)

Beth and Jamie's experiences show how others can read someone in ways that they may not read themselves thus conferring a particular affective narrative self onto the person who is being judged. Jamie describes this when she talks about not understanding "why […] some people have that image of Indigenous women" and when she states that she knows her culture, language, and boundaries, and that she is "very respectful of other people." Beth's narrative that experiencing stigma from family tore her apart, as well as Jamie's sense of unfairness and frustration at people's lack of education about HIV, speaks to how grief can be registered as anger, frustration, loneliness, and sadness. In other words, "to grieve [is] to reckon with and rally against" (Broom & Peterie, 2024, p. 10) the violence of HIV stigma borne of the affective narratives from the HIV/AIDS crisis that configure PLWH as 'dirty' and dangerous (Treichler, 1987/1989; Watney, 1987, 1997) even when they do not configure themselves in this way.

Margaret experienced several physical changes to her body: "I have high cholesterol because of HIV. I have […] this bladder thing [which] is totally tied into HIV. I mean, how much medication can you put through your kidneys before it's going to affect it? I've put on weight where […] I wouldn't usually put on weight, like on the back of my neck" (white woman,

diagnosed early in the epidemic). These changes to her body meant that she is constantly on alert in terms of how she presents herself, trying to hide that she has HIV. She continues,

> I'm very, very conscious of how I look when I go out. I try and look my best all the time. If I'm doing a speech, I'll try and look my best. Depending on who I'm doing it to. If I'm doing it in [an area with high levels of poverty and homelessness], I'm not going to go really dressed up […]. But I always try and look my best because I don't want it to look like [HIV is] part of me. (Margaret, white heterosexual woman, diagnosed early in epidemic)

This statement illustrates the way that PLWH can feel that HIV is inscribed on the body, intensifying fears about 'looking like they have HIV' and being exposed (Kelly, Langdon, & Serpell, 2009). HIV leaves its mark by way of changes to appearance which can mean further disruptions to people's lives as they manage masking their medication side effects, to be perceived as HIV negative and thus healthy or at least untainted. Here I am reminded of Goffman's (1963) notion of "passing" in which stigmatized individuals work to keep secret the discredited parts of themselves. The extent to which one passes can vary "from momentary and unintended at one extreme to the classic kind of deliberate passing" (Goffman, 1963, p. 101). In trying to pass, there is a sense of grief registered as anxiety that is associated with the loss of one's ability to be open about who they are.

Being diagnosed with HIV can also disrupt one's previous understandings of PLWH, alerting us to our prejudices. Bruckert (2012) identifies this as the shedding of "stigma baggage" (p. 71). For instance, Margaret, a white heterosexual woman, describes developing sympathy and empathy for gay men as HIV was no longer a distant disease of the Other.

> Well, I was absolutely shocked. […] I've been diagnosed since with chronic PTSD, so how did it feel? It felt like, how could this happen? I felt so sorry for the people who were gay. […] I said […] to the doctor […] down at the [redacted] Children's Hospital, I said I can't even imagine being gay with this illness because […] first of all, you're going to have to tell your parents you're gay and then you're going to have to tell them you've got HIV and the stigma of it with your friends. […] But my first thought was, I've just crossed over like a fence or a line. *It was them and*

> *now it's us. That's how I felt.* (Margaret, white heterosexual woman, diagnosed early in epidemic)

Margaret's identification with gay men shows how "narrative identities link self and other" (Lawler, 2014, p. 35) as the self is embedded in the social world. Prior to her diagnosis, Margaret produced her identity narrative amongst a predominantly heterosexual community (as seen in chapter 5 regarding her understanding of safe sex); after her diagnosis, she came to see herself in the stories of gay men and other people who were dying from AIDS. In this way, the stories of Others are part of "our social milieu [and] also provide […] a set of *resources* on which we can draw to produce our own stories" (Lawler, 2014, p. 33).

That said, not every person diagnosed with HIV will change their general perception of PLWH, particularly if these Others also occupy another discredited status (e.g., someone who uses drugs or works in the sex industry). Shared feelings of grief around an HIV diagnosis do not always link other's stories with one's own sense of self. Speaking as a heterosexual woman whose former partner was a bi-sexual man that cheated on her with another man, contracted HIV, and then passed it on to her, Roxy expresses frustration that she does not feel like a member of the HIV community because her transmission story is so different from the ones that are most discussed. In her frustrations, she actively stigmatizes people who use drugs and sex workers for courting risk, while others, like her, were *innocent*.[120]

> The other thing that I observed a lot when I go into the clinic, and the waiting room sometimes is full of women. […] I have this different feeling, I'm not afraid or uptight or traumatized anymore, I almost feel this compassion and I thought […] it sort of reinforces my thoughts and my […] hypotheses around women. There's no way that all these women in the waiting room were at one time intravenous drug users or in the sex industry or whatever else. […] some of them [were] like sweet little ladies that just got caught up in a situation. And it was the same when I went

[120] This was also evident in Jamie's description of her experience with stigma as an Indigenous woman living with HIV. She invokes a politics of innocence as she states feeling frustrated with people's stigmatic assumptions about PLWH given that she acquired HIV through nondisclosure and thus of no fault of her own. She also describes that those others who acquired HIV from blood transfusion or a needle prick at work should also not have to be stigmatized.

> to some summits with [HIV organization] because I would sit with different women […] and I found myself at a table with about, I guess, 10 other women and […] they remind me of my mom […] or my aunt or me. And I think they're just like me, […]. There's a segment of our HIV population that have HIV through other circumstances other than what we constantly hear about. (Roxy, heterosexual white woman, diagnosed early in epidemic)

When I asked what she meant when she said that she did not feel like part of the community upon her HIV diagnosis Roxy replied,

> […] our service organization here in [city name] […] I don't go there, because they don't really have anything that I need or want, but when I have gone there and all the time, it's me and 20 gay men, or it's a man's organization, it's not for women. We don't have much for women, but yet we're constantly being told "oh we're all in this together" and I thought, well, if we're all in this together, why is this discussion about issues with men, and that event is for men, and this one and that one and once in a while, they'll have some event for women and then two women will show up and they'll have to cancel it because none showed up […]. In that way, I think […] think women's issues are so different from men's that if we say we're all in this together and lump us all together, we'll get lost in that shuffle and we'll […] be a separate entity within the bigger group. If that makes sense. Health wise and just our roles, too, as women. I mean […] we're partners, we're mothers. […] although some people wouldn't [agree], I don't know how they can disagree— that women are marginalised already? Women, not individuals, but as a whole we're marginalised so to get this diagnosis, it puts further layers of stigma and marginalization on us that men would not necessarily experience. […] when men are discussing men's issues […] they want to do it with men. Same with women, I think. (Roxy, heterosexual white woman, diagnosed early in epidemic)

Here, Roxy expresses her wish that she could access women-only HIV services, separate from other groups within the HIV community, namely those of gay men, IV drug users, and sex workers (as she states in the previous quote) because they do not share her experiences. Interestingly, although she situates women's issues as being different from men's, she does not seem to consider sex workers and people who use drugs as members within this group. Unlike Margaret, who let go of previously held stigmas related to gay men and people who use drugs by identifying with their shared experiences in having HIV, Roxy very much sees her situation as distinct, going so far as to want separate resources designed for 'respectable' women. In Roxy's

narrative, we see how “affiliation with, or separation from, [her] more evidently stigmatized fellows” leads to ambivalence about her sense of self (Goffman, 1963, p. 107). As Goffman (1963) contends, “the more allied the individual is with normal, the more he will see himself in non-stigmatic terms, although there are contexts in which the opposite is true” (p. 107). Her narrative also shows how people manage their stigma by legitimating the stigmatic assumptions about others by distancing herself (Goffman, 1963).

By framing the affective narratives borne from the HIV crisis as stereotypes that inform people’s understandings of HIV and PLWH and thus lead to experiences of interactional stigma, I show how HIV is not only disruptive to one’s narrative self, but also how these historical narratives mark one out for social death and thus exclusion. PLWH continue to be constructed as dangerous threats regardless of the normalizing and hopeful rhetoric of initiatives like U=U.

## 6.5. Final Thoughts

Being diagnosed with HIV acts as a rupture, a narrative plot twist in the lives of PLWH. The narratives of loss I discussed in this chapter signal how historical affective narratives of HIV as dangerous and PLWH as morally depraved manifest in the present, as emotional memories that construct people’s narrative accounts of how it feels to be diagnosed with HIV. As Frank (2010) argues, stories “do not cease to perform when they are not being told” (p. 40). Even though the story of HIV has changed so that people live long lives *with* HIV, stories from the height of the HIV epidemic in the 80s that depict those living with the illness as all but dead persist. These affective narratives have, over time, calcified such that even in the present, when HIV is considered a manageable condition, they continue to be mobilized in the configuration of selves and press upon the lives of PLWH to such a degree that they intensify the feelings associated with their diagnosis.

I detailed in this chapter how the different kinds of loss throughout one's life with HIV, which include the potential eradication of one's own physical body, the meaning of one's life, the passing of loved ones, the loss of relationships, and social death awakens one to the painful reality of the frailty of the human body, one's own sense of self, and one's Otherness. The death of the old self, the one that was HIV negative, is transformed into a life *with* HIV. This life is configured through different registers and intensities of grief and melancholia that may show up as anger, frustration, disgust, and sometimes, may shift into feelings of relief. As critical disabilities scholar Ellen Samuels (2017) describes about living with a disability:

> Crip time is grief time. It is a time of loss, and of the crushing undertow that accompanies loss. […] What I have found much harder to let go is the memory of my healthier self. With each new symptom, each new impairment, I grieve again for the lost time, the lost years that are now not yet to come. This is not to say that I wish for a cure—not exactly. I wish to be both myself and not-myself, a state of paradoxical longing that I think every person with chronic pain occupies at some point or another. I wish for time to split and allow two paths for my life and that I could move back and forth between them at will. (n.p.)

Participants narratives of their diagnosis show how living with HIV means never leaving the grips of a time when HIV was considered a deadly disease. Their stories are shaped by this time such that their affective narrative selves are "entangled in stories" (Ricoeur, 1991a, p. 435) of a past marked by crisis, death, suffering, pain, and community (Cvetkovich, 2003a; Gould, 2009). As Mann (2023) describes: "living legacies are booby-trapped with historical meanings" (p. 388).

In the next chapter, I explore how grief gives way to feelings of hope as people engage with biomedical narratives in the configuration of their undetectable selves. The undetectable self is one who actively combats HIV disruptions/ruptures, perseveres when HIV threatens one's health, and who shapes the affective narrative self through medico-moral-legal narratives that continue to bifurcate PLWH into healthy/unhealthy, good/bad, and innocent/guilty. I use the

notion of the undetectable self to discuss how participants negotiate disclosure(s) in their relationships and the implications this has on the production of the affective narrative self.

# Chapter 7.

# "Whatever nice stories you want to tell yourself, you're damaged goods": The Undetectable Self and the Cruelty of Hope

In Chapter 6, I discussed how grief lingers over people's stories of being diagnosed and living with HIV as they refigure or re-interpret their affective narrative selves. In Chapter 7, I build on this argument by exploring how the grief felt at the loss of one's sense of self gives way to feelings of hope, notably as medicines to treat HIV emerged and narratives of a 'post-AIDS world' began to take shape. As one of my participants humorously described this post-AIDS epoch, "AIDS is now largely relegated to history. The 1980s will be remembered for two things: AIDS and spandex, and I don't know which is worse [chuckles]" (Buttercup, diagnosed early in the epidemic, white gay male). In this chapter, I explore how hopeful post-AIDS narratives are taken up in the configuration of participants' affective narrative selves, including who has the configurational power (Weir, 2020) to mobilize these narratives and in what ways. I am thus interested in the promises that HIV biomedicine and its technologies make to PLWH and the resulting changes in subjectivity and identity that hopeful scientific advancements bring about (Race, 2001; Persson, 2004, 2013; Squire, 2010, 2013; Lloyd, 2018; Walker, 2019, 2020). In the post-AIDS narratives and TasP public health strategies undetectability becomes a central feature at both the community level, where it is propagated as that which will end the epidemic, and the individual level, where it is mobilized to promote health and avoid sexual transmission to potential partners (Gagliolo, 2021; Lloyd, 2018).

For Rose (2007), an essential dimension of ethopolitics is that our ethics are increasingly organized around the ideals of health and life, producing anxieties, fears, and dread about our

biological futures. These feelings about mortality and morbidity are reframed within an ethos of hope, anticipation, and expectation (Rose, 2007). Indeed, the growing field of positive psychology rose with the discourse of hope in healthcare and efforts to produce and quantify levels of happiness, optimism, and resilience in society (Petersen, 2015). As Petersen (2015) argues, "the ideas of positive psychology have been applied far beyond the clinic, as part of a general process of neoliberal 'responsibilisation', orientated to making individuals more motivated, self-sufficient, and enterprising in all areas of their life" (p. 45). Hope, therefore, emerges as a necessary component of healthy citizenship (Petersen, 2015) and is a dynamic and relational emotion that materializes within individuals and from the spaces and institutions in which people move about (Cook & Cuervo, 2019). Hope is experienced individually and collectively; "it ties together personal biographies, collective hopes for a better future, and broader social, economic and political processes" (Novas, 2006, p. 291). As such, I align with Mattingly's (2010) description of hope as not just an emotion but a practice in that it is not something that is "primarily located within biotechnical practices or dominant discourses that engender optimism or tragic pessimism (depending on one's view) but rather, first and foremost, in highly situated practices of people struggling to live with chronic medical conditions" (p. 6). In other words, I explore how the personal hopes and everyday practices of PLWH are infused with hopeful biomedical narratives and how these practices may reproduce and sustain hopeful attachments to science and medicine.

Hope is a future-orientated emotion that evokes a sense of possibility for a better tomorrow in the present (Ahmed, 2010; Mattingly, 2010; Novas, 2006; Petersen, 2015; Wettergren, 2024). As Ahmed (2010) argues, "hope is a feeling that is present (a pleasure in the mind) but is directed toward an object that is not yet present" (p. 181). However, hope does not

always have a specific imagining of what the future can or should look like; it does not need a particular object. For example, Cook and Cuervo (2019) contend that there are two modes of hope: non-representational hope, which has no specific view of the future and is characterized by the affect of hope or the feelings and sensations of hopefulness, and representational hope, which entails forms of hope orientated towards a specific, hoped-for future. They emphasize that these two forms of hope are not separable in either theory or praxis, writing, "modes of hope are subject to change, shifting along with the contours of the events or circumstances that individuals experience, with the specific ways in which they understand or experience them, and with the social positions that they occupy" (Cook & Cuervo, 2019, p. 1113). In other words, hope is determined from the top down *and* actively encouraged by individuals and communities (Cook & Cuervo, 2019). Becoming undetectable brings about both modes of hope, in that this medical status is promised to bring about the dream of a world free of HIV cultivated by the individual health practices of PLWH.

Hope is intimately tied to fear and trust (Petersen, 2015; Wettergren, 2024). Being hopeful requires some suspension of disbelief or doubt about the uncertainties attached to biomedical interventions that are said to restore, enhance, and optimise health; it entails having a profound sense of trust that these innovations will work (Petersen, 2015). Yet, hoping can never completely shut down all suspicion, no matter how much we try not to think about the things that give us anxiety or fear. Speaking to hope's non-representational capacity, Wettergren (2024) writes, "under extremely uncertain circumstances, for instance, the short-term object [of hope] may be non-representational because even tomorrow cannot be trusted" (p. 8). In other words, we may feel hopeful but not quite know what we are hopeful about for fear of what the future may bring. As Bloch (1959/1996) once argued, "the future dimension contains what is feared or

what is hoped for," but if we can thwart those fears through the imagination of a better future, then we are only left with what is hoped for (p. 4). Fear is thus a motivator of hope; indeed, we need fear to recognize hope, and if we can identify a source of hope, we can manage our fears (Wettergren, 2024).

Hope and its companion emotion fear are part of what Adams et al. (2009) call *regimes of anticipation,* which "are distributed and extensive formations that interpolate, situate, attract and mobilize subjects individually *and* collectively" (p. 249). Ernst Bloch (1959/1996) described hope as an "anticipatory consciousness" in that we recognize the "not-yet" in the evolving present (pp. 12-13). Bloch (1959/1996) articulates that hope is not just an emotion that is the opposite of fear but a "*directing act of a cognitive kind*" (p. 12). For Ahmed (2010), hope directs us toward the future in that it "anticipates a happiness to come" – we imagine we *could* be happy if things go the right way rather than thinking we *will* be happy (Ahmed, 2010, pp. 181-182).

Contemporary life is thus organized around hopeful anticipation, an affective state characterized by an "excited forward looking subjective condition" that entails nervous anxiety and a "continual refreshing of yearning, of 'needing to know'" (Adams et al., 2009, p. 247). Being hopeful also means being anxious about what could be lost (Ahmed, 2010), in that "hope involves wanting something that might or might not happen. Hope is about desiring the 'might,' which is only 'might' if it keeps open the possibility of the 'might not" (p. 183). Hopeful anticipation is more than a wager on what lies ahead; it is a moral economy in which the future shapes the possibilities for action in the present, making the future experienced in the here and now (Adams et al., 2009). This process is affective, in that anticipatory regimes foreground the unknown and uncertain within the inevitability of the future in the present, provoking feelings of fear and hope that mobilize us into *some* kind of action (Adams et al., 2009).

Based on the interviews I conducted, the identity of "person living with HIV" enshrined in the Denver Principles and constructed in the early days of the epidemic by HIV/AIDS activists in protest to the medicalized narratives of AIDS that were hyper focused on death (Ariss, 1997) has shifted to the technoscientific identity of undetectable – what I am calling the undetectable self.[121] I contend that the undetectable self is not just a technoscientific identity but an affective narrative self, configured through the affective practices of maintaining a suppressed viral load and the prefigured cultural field of hopeful and dominant biomedical discourses within which PLWH come to understand and relate to their sense of self. Importantly, the undetectable self is a survivor, someone who has overcome the traumas that make up life with HIV and stands in opposition to the weak and passive victim. The undetectable self, in the era of HIV normalization, hearkens back to the Denver Principle's (1983) first declaration, that PLWH are not victims because that would imply defeat. The undetectable self also comes to eclipse and stand in for the intricacies of the self, making these complexities themselves undetectable.

In what follows, I set the scene in section 6.1 by describing Brianna's lifeline, which depicts her journey from diagnosis to undetectability and living with HIV. I then break down the undetectable self into two hopeful affective narratives (the undetectable self as healthy, and the undetectable self as moral and safe) in 6.2. Section 6.3 presents a counter-narrative that discusses the detectable Other and the skeptics, who I describe as hope aliens, who are unsure about the hopeful messaging around undetectability.

[121] The irony in this sentence is not lost on me. HIV/AIDS activists fought in the beginning of the epidemic to construct HIV subjectivities away from medical and scientific discourses such as 'patient' (this is the whole point of using language like 'people living with HIV'), and yet undetectability, a scientific term, has become one of the central ways through which PLWH have come to understand themselves today.

## 7.1. Setting the Scene

The art of narrative configuration, according to Ricoeur (1983/1990), consists of "making […] discordance appear concordant" such that "the discordant overthrows the concordant in life, but not in tragic art" (p. 43). Understanding living with HIV as a collection of discordant events, actions, and circumstances, the narrative configuration of one's life with HIV as an undetectable self is an attempt to bring about the *appearance* of concordance. Narrative configuration also imposes meaning by "grasping together" events into a comprehensible narrative structure that elicits a particular point (Ricoeur, 1983/1990). Of course, lived experiences are not *always* storied, but transforming our experiences into narratives comes from a "desire to have real events display the coherence, integrity, fullness, and closure of an image of life that is and can only be imaginary" (White, 1980, p. 27). This desire, I would argue, is akin to hope because it involves "imagination [and] a wishfulness that teaches us about what we strive for in the present" (Ahmed, 2010, p. 182). Ricoeur (1983/1990) recognized that "emplotment is never the simple triumph of 'order'" (p. 73), and thus, no matter how much we want to give order to our lives, they are inherently messy. As Brianna's (Black heterosexual woman, recently diagnosed) lifeline (figure 7) and the stories from other participants show, efforts to create narrative concordance out of one's lived experiences is complex. Participants jumped back and forth between speaking about the positive effects of being undetectable, such as living a normal life and 'moving on', and the difficulties of living with HIV, including dealing with stigma and the moral burden of responsibility to comply with treatment plans.

Nonetheless, each telling of one's story is an attempt at making sense or meaning out of the events that have unfolded in one's life. These narratives might change over time as new

insights are gleaned, new moments occur, and others' interpretations of those stories are realized. As Frank (2002) argued,

> Stories give legibility; when shaped as narratives, lives come from somewhere and are going somewhere. Narratability provides for legibility and out of both comes a sense of morality—practical if tacit answer to how we should live. This morality is not fixed but is constantly being revised in subsequent stories, including retellings that put different emphases on old stories. (p. 111)

I use Brianna's lifeline to exemplify how she attempts to create a sense of concordance through the configuration of the undetectable self. Demonstrating the "discordant concordance" of narrative configuration (Ricoeur, 1983/1990, p. 42), her narrative is also fraught with several moments of discordance as she comes up against the realities of living with HIV as a Black woman.

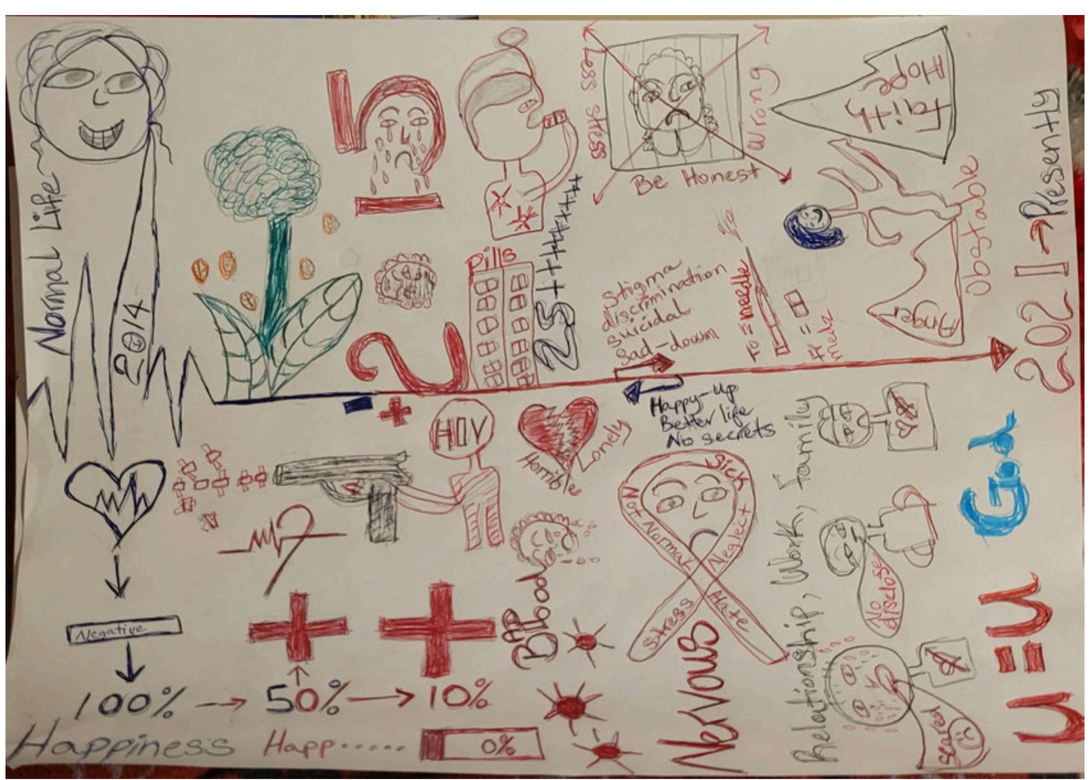


Figure 7. Brianna's Lifeline

Brianna starts by explaining the left side of her lifeline. This section is coloured in blue, her favourite colour, representing her life before being diagnosed with HIV. She writes,

> So the first part it says normal life. Me, being a female, and the line that goes up and down, you know, when you're in a hospital and you see the, I don't remember what you call it, but life/[EKG] machine that goes up and down that's still in living the life. You feel, healthy, you feel normal, you're breathin and everything. And that's why I put it in blue, and it's also my favourite colour. And [below] I put […] the heart that show's still living, [there's a] pulse, a normal [heart] rate and no HIV, and [below] it says HIV negative, which includes the normal life and which is also a result of 100% and that's happiness, right? I've nothing to worry about.

Several times, she mentions that this part of her lifeline is about her 'normal' life when she is happy and has nothing to worry about. She goes on to describe her diagnosis and the emotions she felt at the time in detail,

> And then beside is the flowers […] which include 2015. And the leaf that's falling down, showing [me] being diagnosed and [when] I heard about it and, you know, like that's where emotions start to interfere in your life. The leaf signifies being broken down. So when yeah, it's like, it's like fall when everything is just, you know, like fallin. And because I was growing right, but then, you know, everything falling down and then 2015 beside it, that's the year of being diagnosed, and the five-- I tried to put an emoji there to show that it's sad, crying. And the ['0' in] 2015 […] has like dark because it's showing that I'm in darkness. Below it, […] like when it happened it was like a bullet going towards your heart. And below it, it says broken heart or lifeline. So it's like, for instance, you are living and everything and then now it's like you die. Not literally, but you know.

Brianna uses several metaphors to talk about being diagnosed, including falling leaves during Autumn and a 'bullet moving towards your heart.' As Sontag's (1977) analysis of HIV/AIDS, cancer, and tuberculosis reveals, illness stories are infused with metaphors. The metaphors Brianna uses to represent her diagnosis intimate a sense of death, an end to who she once was. She describes this time as feeling as though she is "in the dark," signalling the uncertainty of what it means to be HIV-positive, which can be amplified for members of Black communities should they be unaccepting of PLWH. This is a moment of narrative discordance or, as described in chapter 5, a biographical rupture.

The rest of her line is coloured in red, representing her life with HIV. The colour red has long been the signifier of HIV/AIDS, historically used by artists to create the now well-known

Red Ribbon to commemorate and support PLWH and their caregivers (Visual AIDS, 2017). The artists chose red for its vibrancy, "attention-getting," and the connection to blood, passion and anger, and love (Sadao, 2011; Visual AIDS, 2017, n.p.). The ribbon is called "the red ribbon of hope" (Sadao, 2011), a hope attached to activism and the power of grassroots organizing to bring attention to a disease that was killing people but was largely ignored by the powers to be because of its association with 'undesirable' groups of people. Today, this hope is increasingly attached to biomedical technologies that make people undetectable. For example, AIDS Vancouver's undetectable campaign, aptly titled "Undetectable: The New Face of HIV," shows images of the red ribbon being drained of the red or HIV in a person's blood (Cole, 2014). The red is replaced by a white ribbon signals a kind of purity that comes with being undetectable, with only a few pixels of red left on the tip of the ribbon (Cole, 2014; Lloyd, 2018). This shift in how the ribbon is portrayed represents an effort to reimagine, reinterpret, and rebrand the Red Ribbon as a symbol of HIV awareness and HIV in the TasP era (Lloyd, 2018). It also rebrands what it means to be living with HIV; viral suppression requires "new technoscientific possibilities for virological work upon the self [and] a new ethical imperative to contain the virus circulating within one's blood and minimize one's risk to others" (Lloyd, 2018, p. 485).

Brianna uses the Red Ribbon and the colour red to depict her life with HIV, which suggests that she does not understand herself as free from HIV, and 50% to depict how she remains uncomfortable with the diagnosis. She described feeling as if she occupies a kind of liminal space in which she is living both with and without HIV. She explains,

> And below it, the plus sign is an HIV sign, positive to show positive and then 50%. The reason why I used 50% is because even though you've been diagnosed, at the same time, you're still living the same way. And I start to write H-A-P-P- and not the full word, because you're still happy because you're living and it's not […] a risk anymore. […] but [at] the same time, you're still not comfortable, but, you know, there's nothing you can do about it.

While undetectable, she faces the challenge of taking pills for the rest of her life.

> And, so above the line, […] that's where it has pills. And that's the new challenge that I have to take pills the rest of my life. That's actually new for me. And so I have a picture there of me taking pills and have two [HIV] cells to show that undetectable, so there's not much [HIV] cells there. And 25+++++, that shows that, OK, [I'm] going to be 25 soon, so I just put 25 and the plus plus are showing that the rest of my life [I have to] continuously [manage HIV].

Brianna explicitly described needing to have hope to cope with negative feelings about being diagnosed. In the meantime, she will continue to pursue the same goals she had before diagnosis, hopeful that she will be cured when science prevails as the hero who saves the day (Haraway, 1989).

> And then over the line, that's where I have, well I try to put, that's me running up the hill in faith and hope, you know, still having faith, same way, still having hope and running from anger and running over the obstacle, which is I have negativity about the diagnosed, you know, even though the diagnosis is not, you know, it's not good, but at the same time, I still have to make positivity out of the bad same way because life goes on and things, changes, you know. For instance, hopefully, they can even find a cure or something, right? And that's where you have to just have hope and faith in what you do, and you still can live your life same way and goals that you still want to have. You still can have them same way because our diagnosis is not going to stop or pause anything that you want to, you know, you want to achieve in life, right? Because you're not wearing it out, it just in the blood and it can't come out and do anything, right. So you have to just like push through in life.

Despite her hopeful positivity, Brianna's story reveals the contradictions inherent in post-AIDS discourses. She grapples with wanting to live life normally, defined as the same way she lived before her diagnosis, wanting to have children and get married, while also experiencing mental health challenges and physical illness because of HIV.

> I would say [p] my lifeline [p] it looks […] like moving from […] a normal life going into so many obstacles [to] not […] normal anymore. […] like irregular and so many down time[s] and being emotional. And having some side effects of stuff, it's like in many situations you have to think of how you're going to deal with it […]. I don't [allow] that to hold me down, but I still manage to push through, [past] each obstacle and continue living life with [HIV], even on a day-to-day activity. Even though I still have to […] take medications and so on and still do appointments and I still [view living with HIV as] something normal. So I turn the

> abnormal into normal. Yeah. So, yeah, I would just say from normal to not normal, but at the same time, it's [p] […] [a]new normal. […] [I used to take no] medications and now, I have to take medications, to go to appointments, and I have to […] look out for [interactions] with other pills […] and you have to ensure that you always check your CD4, […] do blood work. […] […] you have to still be responsible too— like to remember oh yeah, take your meds because you want to continue that way of living and feeling healthy […] while being on treatment. In order to even [do] your goals, you have to, you know, feed yourself and just be happy and do what you're doing every day. It's like a pattern.

These quotes reveal that Brianna struggles with the imperative to be hopeful and optimistic about living with HIV, actively turning "the abnormal into the normal" through having faith in the possibility of a cure and just 'moving on with life,' while also acknowledging that her life with HIV is now a "new normal" as she manages side effects, mental health issues, taking medications, checking CD4 counts, and making sure other drugs do not interact negatively with her HIV medications.[122] Her description signals the constant vigilance needed to live as a respectable HIV citizen in a regime of anticipation and hope that characterizes our modern epoch (Adams et al., 2009; Rose, 2007). She ends her lifeline by writing out "presently" in blue, representing what she feels is a return to normal or at least an imagined new normal as the undetectable self.

## 7.2. Configuring the Undetectable Self

In this section I discuss the two ways PLWH configure their undetectable self. First, the undetectable self is constituted through the affective practices that PLWH engage in to maintain this hopeful status, such as strictly adhering to their treatment plans by taking their medications, going to doctors' appointments, regularly monitoring their viral loads through blood tests, obtaining their medications, and interacting with ASOs, social service agencies, and public

[122] My interjection here is to show how narratives can be co-constructed (Frank, 2010; Riessman, 2008).

health. These coalesce into what Mykhalovskiy, McCoy, and Bresalier (2004) called healthwork or the "broad terrain of everyday/every night activities through which people look after their health" (p. 323). These practices contribute to the production and sedimentation of a hopeful atmosphere around biomedical interventions and technoscientific discovery. Here I am thinking about Wetherell's (2012) argument that "affective practice is something that can be encountered as a pre-existing given—and at that point it may feel as though we are entering a 'zone' or an 'atmosphere' – but it is also something that is actively created and needs work to sustain" (p. 142). Hope is thus located within and (re)produced through the everyday practices of PLWH negotiating what it means to be healthy and undetectable – making decisions about medications and treatment plans; evaluating when and to whom to disclose; communicating with doctors, pharmacists, social workers, and other service providers; and actively working to spread messages about the science of undetectability.

Second, the undetectable self is constructed through the configuration of PLWH's lived experiences by a prefigured cultural field of hopeful and dominant biomedical discourses of HIV health care. According to Ricoeur's (1983/1990) notion of prefiguration, our lived experiences are symbolically mediated by a cultural field articulated by signs, rules, and norms that give meaning, interpretability, or "readability" to action (p. 58). Ricoeur defines culture as a symbolic system that provides the necessary context for interpreting human action (Dowling, 2011/2015). I suggest that affect helps people to interpret and make meaning of their experiences, select which moments of their HIV story to tell, make decisions about who to tell these stories to and under what circumstances, and to understand their sense of self. Living with HIV is thus configured within a cultural field symbolically mediated by the norms, rules, laws, and affects constituted through the biomedical and scientific knowledge about HIV. Therefore, how PLWH

configure their lived experiences inherently draws upon the hopeful symbols of medicine and science to understand their new sense of self.

The hopeful affective narratives that biomedical interventions produce by way of promises of a post-AIDS world and the normalisation of HIV, become essential elements in how people configure their undetectable selves. These hopeful narratives promise not only a return to health defined as being without illness, but also a future where they are perceived as responsible and morally worthy citizens who do not need to disclose and who should be free of legal liability and stigma. Yet, hope can be cruel in a similar way that Berlant (2007) describes cruel optimism as “a relation of attachment to compromised conditions of possibility” (p. 33). Participants spoke to the cruelty of hope by explaining the disjuncture between its promises and their everyday experiences living with HIV.

### 7.2.1. The Undetectable Self as Healthy

Hopefulness about an undetectable status comes about because PLWH have a profound sense of “fear of illness, the predicament of being potentially ill, is the motivation for undertaking HIV testing and an intensified regimen of self care” (Ariss, 1997, p. 48). Fear of illness, logically, brings about a hopeful attachment to biomedical intervention as that which will return one to ‘normal’ and ‘healthy’ state. I am interested in how “health becomes an individual goal, a social and moral responsibility, and a site for routine biomedical intervention” (Clarke et al., 2010, p. 63). For example, advertisements for HAART that evoke death “operate as the unspoken Other that is mobilized in the constant imagining of the future” (Race, 2001, p. 181). These advertisements become techniques of responsibilization whereby PLWH are commanded to take the necessary steps to extend their life and help their immune system (Race, 2001). Health is thus depicted as a “prudent self-management exercise,” and pharmaceuticals are naturalized as a

necessary substance that will bring about a "longer, healthier, and more glamourous life" (Race, 2001, p. 181).

For Cara, an Indigenous heterosexual woman diagnosed mid-epidemic, the hope is not just that medications will bring about a better life, but that biomedical interventions will one day find the cure for HIV. Undetectability is just a stepping stone to one day being completely free of HIV:

> I'm actually U=U now, undetectable [equals] untransmittable, you know. And I'm very happy for that. And so is my family because the next step is the cure. And if we can get some research, we're hoping to have the cure. You know that would be my next step. I'll be cured from this disease. But I don't know if it's going to happen in my lifetime, but I hope for the future […] And with Hep C, I heard they came out with a cure for it. So I'm hoping there's going to be a cure for HIV and AIDS.

Cara recognizes that being undetectable does not mean she is cured of HIV, but her undetectability brings hope while she waits for scientific heroes to save the day sometime in the future.

Research shows that PLWH define health in relation to medical and technological discourses as well as other markers of health such as feelings of well-being, energy, and happiness (Persson, Race, Wakeford, 2003; Wong & Usher, 2008). The undetectable self as healthy, thus emerges as a "composite phenomenon operating within several domains of meaning" (Persson, Race, Wakeford, 2003, p. 402). For example, Victoria talks about how she scrupulously takes her medications and follows her treatment plan so that she can stay as healthy as possible. She uses a military metaphor to describe her immunity-producing cells as her soldiers and army, intimating that HIV feels like a corporeal invasion and the medications she takes are the medics healing her soldiers on the battlefield that is her body.

> I try to stay as healthy as I can. I take my medication. I follow my regimen. I mean, I do the best I can, and I've been undetectable since the moment I got on meds. Undetectable, undetectable, undetectable and like my CD4 count is over 1200.

> Like, hell, I'm doing really good. You know, like those are my soldiers, you know, that's my army and I need every one of them! So don't die on me! [laughs] They're my soldiers! [laughs]. (Victoria, diagnosed early in epidemic, white heterosexual woman)

Victoria described a similar sense of pride at remaining undetectable in her lifeline (shown on page xi of this manuscript) debrief.

> There's a few cells in the painting, on the edges and that represents the body of a person living with HIV is their cells. And that identifies CD4. CD4 to me are cells that-- those are my soldiers! Those are the ones that keep me alive and strong and keep me going. And I need all those cells because I can't lose any. Because when your CD4 is down, you're prone to get infections. So they always say CD4 high, viral load low, in regards to [being] undetectable. I've always been undetectable. Within six months of my diagnosis, I was undetectable and have been ever since. So those cells are my soldiers. (Victoria, diagnosed early in epidemic, white heterosexual woman)

Victoria's narrative describes how her body becomes the site or field on which the battle takes place and the medicine she takes, the heroic figure who saves the day. Her compliance with a treatment regimen is necessary to attack the virus that is destroying her immune cells and making her sick. Surrendering to the 'enemy' is not seen to be an option because doing so might result in being blamed (by others and/or oneself) for a failure to 'fight'. This description exemplifies the narrative of "healing as a battle" in which "the patient […] is reconceived as having his own heroic or at least compliant qualities and responsibilities that can be mobilized to help win the battle against the invading pathogens" (p. 62-65). Hope lingers on the battleground where biomedicine and virus go head-to-head and undetectability, read as a return to health, is the desired ending.

Jamie mentioned the word undetectable 28 times in our interview, signalling that this status has a profound meaning in her life. Being undetectable for her meant that she was healthy to the point where she did not feel like she was living with illness. She stays active, resisting the stereotypical image of PLWH we often saw in movies as emaciated bodies lying in hospital beds.

For Jamie, the only thing holding her back from some semblance of normality is the law that says she has to disclose her status to her sexual partners. She explains,

> I've been undetectable since 2010-2019, and I'm healthy— it's like, I don't have it. The only thing that tells me that I'm not healthy or that I'm not me, is that damn piece of paper that I have to disclose. […] Nobody would ever know that I have [HIV] because I'm still running, I'm still jogging, I'm still doing everything, and I feel great most of the time. But it's when I meet that person, I think I may have an opportunity [to] share my life with, [that is] when that big cloud comes back over my head […] how do I say [I have HIV] and how do I even bring this subject up to somebody? […] It's still the fear. Doesn't matter how it's going to come out. It's still the fear of disclosing something like this to somebody that you're hoping to have a lifetime with.

Jamie recognizes the contradictions between a hopeful, undetectable self and the reality that HIV stigma is still relevant today in the context of the criminalization of HIV nondisclosure (as we see in the quote below). While she has come to accept living with HIV, she expresses frustration with the persistence of stigma. Indeed, Jamie challenges us to educate ourselves about undetectability so that we can be more understanding, suggesting that knowledge about biomedical advances have not reached HIV-negative people:

> A part of me is like even though [I've] accepted what I have, like I've adjusted, and I've accepted it. I'm okay with it now. Only because of the stigma and the fear that society still has about it, even after all the decades of people that are still living happy and healthy like myself— I've seen [p] articles in the paper of people that are front page that have had HIV for a long time. […] Even with all [these] people living happy and healthy undetectable [lives] [inaudible] there's still stigma out there and it drives people [p] like myself crazy. Why can't you guys get educated and realise that it's not like it was back when it first came out where there was nothing, there was no antivirals, there was no medication to help the person. (Indigenous heterosexual woman, diagnosed mid epidemic)

For Jamie, an Indigenous woman who already feels stigmatized because of her Indigeneity,[123] being perceived as healthy is important. As Squire (2010) argues, "'health' itself is framed differently by the popular discourses within which the normalised HIV citizen lives, which may

[123] See chapter 6 section 6.4.

present it not medically, but as a personally felt and judged entity" (Squire, 2010, p. 409). Jamie's narrative of feeling healthy and being self-regulating resists the moralizing colonial narratives that depict Indigenous people as unhealthy and irresponsible (Monchalin, 2016; Razack, 2000). Jamie fought to configure her sense of self (Ricoeur, 1983/1990) by telling narratives about being a 'good Indian' who was now sober and taking care of her health. She stated several times that she was always "health-conscious", regularly getting tested for sexually transmitted infections (STIs), including HIV, even before she was diagnosed. Jamie's insistence that she was always-already taking care of her well-being signals how health has become a "matter of ongoing moral self-transformation" (Clarke et al., 2003, p. 63).

Pieter likewise discussed healthy living; not only taking his medications regularly but also investing in dietary supplements and practicing mindfulness. Pieter defines health as more than not having symptoms of HIV, but as a kind of "non-reductive composite notion" (Persson, Race, Wakeford, 2003, p. 409) in which he can exercise control over his body by eating a specific diet and taking vitamins.

> I'm more conscious of my health than ever before. I do take my vitamins and supplements and B12. And […] I don't want to boast about myself. But for a guy who is like 60-69, I have a body that's like a 40 [year-old] […]. I think that is a plus side to being diagnosed. […] I also have anxiety and depression. So I'm managing that. But I also realise how important diet is as part of my own well-being as well. So I'm very conscious of that and I'm managing. […] I have taken what appears to be sounding like a death sentence to now being more mindful of myself, my health, and to make the most of what seemed like a setback. And it still is because […] [I] need to take medicine every day for the rest of my life [...] [which has] become an added responsibility to help maintain a certain quality of life. And that means taking my medication regularly. But I also learned, and I don't know if this is true, but often we may use HIV as an excuse, but— I guess that's what I think for myself, […] if we're taking our medication [...] we are just as healthy as we were before. [...] even though we have a suppressed immune system in a sense— if you're adhering to taking your medications properly, you can have a very healthy immune system. (Pieter, white gay man, diagnosed mid epidemic)

Pieter's strict discipline to healthy living evidences how HIV normalisation is one facet of HIV's naturalisation, where PLWH are constituted as self-regulating, healthy citizens (Squire, 2010). Squire (2010) contends that the "discourses and practices operating around HIV constitute its citizens as biomedicine's partners in a normalised enterprise of survival and, as far as possible, healthy living" (Squire, 2010, p. 408). Healthy living with regards to the undetectable self means not just freedom from illness but a general sense of not being burdened by the knowledge of having a disease (Tan, Lim, and Chan, 2020), as seen in Jamie's description above and Pieter's assertion that PLWH are "just as healthy as we were before." That Pieter also engages in other health practices shows how being a self-regulating HIV citizen means not only engaging in medicalized practices but also "a constellation of similar health consumption practices" (Squire, 2010, p. 412).

Yet, being healthy for participants did not mean that they were free from the complexities of disclosure (as we saw in the narrative by Jamie above), signalling the disjuncture between the hopeful narratives of biomedical sciences with the complexity of living with HIV (Moyer & Hardon, 2014; Squire, 2010, 2013; Walker, 2019, 2020). For example, Jeffrey, a gay white male diagnosed mid-epidemic, explains "I was undetectable. I was healthy" while later in the interview he describes that regardless of feeling healthy, he keeps his diagnosis secret amongst colleagues outside of the HIV/AIDS sector out of fear of how they would react. Not being open about his status caused Jeffrey to feel like he was not able to express his true self which makes him feel frustrated that he cannot be as open about his status as others and, at the same time, hopeful, happy, and grateful because he is healthy. Jeffrey explains,

> I felt like I was holding something back, of who I was […] I couldn't express my whole [self], right? Where people are [like] okay […] "I'm gay." You know, "I have this in my life." […] But just to spit out, "Oh, I'm also HIV positive." It just kind of stays in the back of my brain and […] it bothers me that I can't express that as freely

> as some people […] that are out in the community. But you know, I'm trying every day to take a look at it where I don't have to do that and especially with U=U. Again, that should make me feel more comfortable being okay with my status. […] my life is better […] after dealing with the disease for so long. I've come to terms with it a lot more. And that's something I've noticed [redacted] […] people certainly have more resilience the longer they've lived with the disease. I don't know if it's because they're fed up or if it's […] different reasons, but certainly the longer that we live with it, the more tolerable it gets, I guess. I mean, because I'm healthy […] I'm just as healthy as the person next to me, and I'm super grateful for that. I take one pill a day. So it's a minimal effect on my life. Except for the stigma, except for that, those words, "I'm HIV positive," they're still there.

Jeffrey recognizes that with U=U, he *should* feel more comfortable coming out as HIV positive but there is a disjuncture in his feeling healthy and normal while also experiencing HIV stigma, intimating a sense of disempowerment when hopeful scientific narratives suggest he should feel empowered to disclose. Jeffrey articulates his frustration with how easy it seems for others to disclose their status, to be out and proud about this aspect of their identity. Jeffrey's narrative here signals what Squire (1999) argued long ago, "with HIV too, you are never entirely out; you carry the closet around with you" (pp. 126).

By describing their undetectable selves as healthy, Victoria, Jamie, Pieter, and Jeffrey inevitably set themselves apart from those who do not attain undetectability. Here I am reminded of Metzl's (2010) argument that health encompasses "value judgements, hierarchies and blind assumptions that speak as much about power and privilege as they do about well-being" (pp. 1-2). While health is a sought-after condition, it is a socially dictated standard and a reflection of ideological beliefs (Metzl, 2010). In other words, health can be a physical state, in this case, the absence of illness, but it is also a moral judgement about oneself and others. As Crawford (1994) argued, the HIV epidemic exemplified the ways in which moral boundaries are drawn between the healthy self and the unhealthy other, the 'AIDS patient'. Today, in the 'treatment as prevention' era, new moral boundaries are crafted this time between those who can make

themselves up as the undetectable self and those who become the detectable Other (Lloyd, 2018). This process has important implications for how HIV citizens should conduct themselves and which lives are rendered in need of discipline and control, particularly when this process is taking place within the context of the criminalization of HIV nondisclosure.

The undetectable self is not just someone who understands themselves as healthy, but also as someone who has moral worth as they fashion their day-to-day lives within a strict medical regime to care for the self.

### 7.2.2. The Undetectable Self as Moral and Safe

Regimes of anticipation are composed of hope, fear, and anxiety and are becoming "manifest and palpable through the potentials, promises and *payoffs* of molecularized technoscientific biomedicine" (Adams et al., 2009, p. 250). Medicine today is being reshaped from the "inside out" by new socio-technical arrangements that administer biomedical technological interventions that foster the development of emergent forms of life (Clarke et al., 2010, p. 22). We are increasingly required to work on our selves by optimizing our health and anticipating what might happen to our future selves (Rose, 2007). By doing so, we are under a "moral injunction" to anticipate future possibilities and to avoid them by acting in the present (Adams et al., 2009). Staying informed about possible futures has become a necessary component of good citizenship and morality, "engendering alertness and vigilance as normative affective states" (Adams et al., 2009, p. 254). In this new regime, "social inclusion is increasingly based on autonomous self-mastery and self-discipline, characteristics of the new biomedical moral order" (McSwiggin, 2017, p. 717). In this way, PLWH are downloaded with the moral imperative to "care for the social" (Colvin et al., 2010, p. 1180) by caring for the self.

Hope attached to the promises that are offered by biomedicine is most evident in Aran's statement. He describes having a feeling or a sense that undetectability was a valuable medical status before U=U was publicly known. As a result, he would tell people he was undetectable rather than saying he was HIV positive, suggesting that there is something not only hopeful, optimistic, and happy about being virally suppressed but also something morally worthy in reaching this status:

> I remember when I seroconverted to be HIV positive. I knew that there was some value […] to being undetectable. And I know another organization approached me and asked me, "what are your thoughts about detectability?" And I said, you know what? […] I felt that [it was] another level of medical status, and that was the time that everybody was thinking—they weren't even thinking [about] undetectable equals untransmittable—the U=U campaign wasn't even discussed yet. But I knew there was something significantly different or there was some value […] to becoming undetectable. So I think that time, like in [2010-2019], I was active in engaging with the people who were HIV positive. […] I was informing people around me that I'm undetectable. I wouldn't really say yes, I'm positive. I reached undetectability and I would promote the status of being undetectable with the people around me. And I think I swayed towards that direction. And then I was very excited when the U=U campaign was starting to move forward. (Aran, gay Southeast Asian man, diagnosed late epidemic)

Here Aran attempts to breakdown the natural and neutral sense that the binary categories of "HIV-positive" and "HIV-negative" allude to; notably, that these are socio-technical concepts imbued with meanings of which the former is often stigmatized. Yet, by framing his sense of self as undetectable Aran simultaneously reinforces this binary as undetectability is deemed an approximation of someone who is HIV negative (the virus is literally not visible in someone's blood like those who are undiagnosed). By not using the language 'HIV positive' in telling others about his serostatus, Aran disappears the frightening historical narratives about the deadliness of HIV that have become sedimented in our collective conscious (Crimp, 1991; Patton, 1990; Treichler, 1987/1991; Watney, 1987). The undetectable self is instead felt to

induce a different, more hopeful characterization of PLWH in the narrative of HIV – people that are no longer on the cusp of death, but rather who are moral and responsible citizens.

John described the constant vigilance required to remain undetectable and thus moral as a “hassle,” a “struggle,” and as having to “endure” life with HIV. At the beginning of our debrief he stated:

> When I was reflecting on [the lifeline], what struck me […] in the moment that I was creating it was that I wanted to get across the sort of monotony and the hassle and the struggle and the endurance of being diagnosed and then living with HIV. (John, white gay male, diagnosed mid-epidemic)

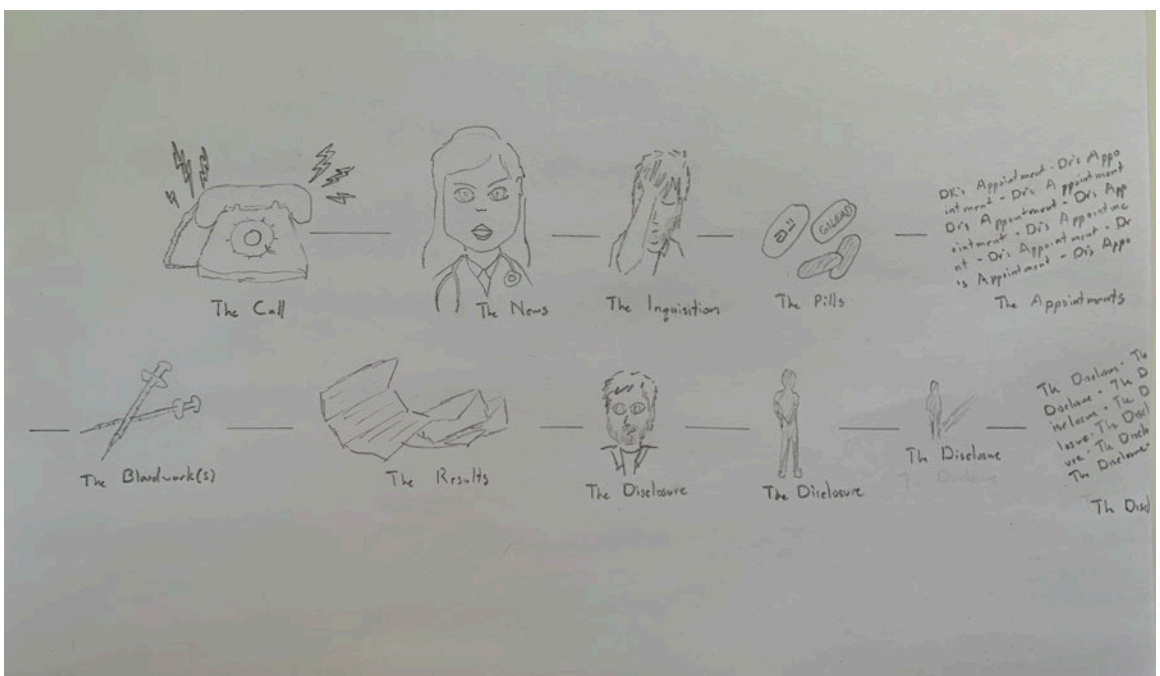


Figure 8. John's Lifeline

When I asked him why he placed such an emphasis on disclosure, he responded by explaining the work that goes into becoming undetectable:

> […] it starts with getting the phone call, getting and hearing the news from the doctor. I call it the Inquisition, which is, you know, 20 questions from the doctor about your sexual history and your past and present and then getting on medication and then all the doctor's appointments. And […] from here on out, it's doctors appointments, lots of doctors appointments and lots of blood work, you know, at least sometimes once a month and then moving to every three months and so forth

> and so on, getting the results of that blood work constant. Maybe anxiety is too strong a word, but you're constantly waiting to hear back the results of your blood work and making sure that things are still working properly and that you're still responding well to medication and that your numbers, the counts are where they should be or need to be or where you want them to be. And then sort of feeling like once those things start to come together, then you're [in] a better place […] to start disclosing. And then that […] turns [into] like— it just becomes like a continuous circus of [p] …

I saw that he was pausing here, so I interjected to ask if he meant to draw his lifeline as a circle with disclosure and treatment becoming a perpetual cycle. He agreed stating:

> I would love to […] portray the things duplicating throughout instead of just […] one off. I was trying to […] portray that a little bit. […] We put the pills in frequently, and not just once, and blood work frequently and not just once, because those are things that are reoccurring all the time. […] it felt like that was sort of the course of my diagnosis to the point [when] disclosure kind of took [over]. [I] […] very much waited until I sort of had […] an understanding of the disease so that I could then be in a position where I could talk about it with other people who didn't. And so when I got to that point—that's when disclosure started to occur and then I started to grapple with that.

John's lifeline shows that undetectability is not a static identity or state; it must be produced daily and thus involves constant effort (Bryant et al., 2023; Gagliolo, 2021). As Race (2001) argued, remaining undetectable means being hyperaware of the always-present possibility of detecting HIV. This induces a process of relentless self-surveillance, whereby PLWH monitor "…the presence of the Other (the virus) *at the level of the individual*", which involves changes in how people live their lives (p. 178). Such individualization of HIV, coupled with the criminalization of HIV nondisclosure, situates PLWH as having the primary responsibility for preventing transmission and absolves HIV-negative people of responsibility (Race, 2012). Dillon and Victoria both spoke to this one-sided burden of responsibility. Dillon expressed frustration at the illogical nature of disclosure laws for undetectable people, especially when disclosure might put him at risk of violence or another negative reaction (Krüsi et al., 2018).

Dillon also claims that the law has the opposite of its desired effect in that it may make some PLWH retreat and not disclose.

> The idea that it's our personal obligation to ask versus our personal obligation to disclose. Now, not only am I responsible for my health, I'm suddenly responsible for another person's health in a way that, they may be an absolute stranger to me, for instance, and suddenly there's an onus and obligation on me to be putting their health first. Even at risk of my personal safety. […] And what it causes is withdrawal and unwillingness to engage with the community […] people go away because that's the message that we're getting is go away, you're dirty, you're corrupted. And there's risk associated for you because you deserve that risk kind of a deal. You deserve to have to carry that weight of being more responsible for other people's health than they are to you. Frequently, I'll be in disclosure situations where I'll disclose my HIV status and the other person may have gonorrhea [and] not disclose it [chuckles], and there's not a big deal there. […] So standardized reporting for stuff like syphilis […] and things like that, that have mandated reporting, no one has to disclose that in person to them [laughs] like, that's not obligated, whereas that's not the case with HIV. […] you can't sue me because I gave you syphilis, but you can sue me because I didn't give you HIV [chuckles]? I can be charged for that, so again, the obligation and the onus, we're putting the whole burden of that social responsibility on the one individual versus spreading it out in a way that makes sense and that is effective. And what that does is it makes people not disclose or not engage. (Dillon, white gay male, diagnosed recently)

Victoria emphasized the same narrative about disclosure responsibility:

> I'm undetectable, so I really don't have to disclose! Because I know that I can't infect you. I just know that because I've had unprotected sex with guys who were negative and I've never infected anyone to this day! I have never infected anyone. So to me, it's just like, where does the responsibility lie, like [p] it takes two people, right? You both are consenting adults. Where does responsibility lie in regards to practising safe sex? Does it always rely on the person that's living with HIV? Shouldn't it also be the responsibility of the other person as well? Like the other person can have herpes, gonorrhea, any STI. You don't know! Why does it lie on the person that's living with HIV all the time? And we are criminalised for it! We're not here to hurt anyone. (Victoria, white heterosexual woman, diagnosed early in epidemic)

Undetectability brings about a desire for PLWH to be absolved of the need to disclose and the surveillant gaze of the law. Yet, Dillon's and Victoria's descriptions of the difficulties with disclosure signal how being undetectable and the moral worth that it affords is configured through an anxious hope (Ahmed, 2010) precisely because there is a lingering threat of

criminalization, regardless of achieving viral suppression, and a pressure to disclose, even when doing so might put one in danger.

Risk becomes an "internal state of vulnerability", highly individualized, and under "self-control" (Sangaramoorthy, 2012, p. 303) such that PLWH become perpetual risk managers (Race, 2001). That risk is internalized in such a way means that it becomes easier to ascribe blame to PLWH who do not achieve undetectability as failing to be self-governing or to take the necessary steps to reduce and/or eliminate risk. Ava explains that being undetectable should release PLWH of the need to disclose their serostatus because they are 'doing the right things' to prevent transmission and insists that people who are not 'caring for the self' and are "infecting others" must be held accountable.

> I'm faithfully taking my meds, so I'm not fearful of transmitting it to anybody because I'm healthy. [...] If you're undetectable, I'm glad that you don't have to disclose. Well, I mean, I don't see why you would have to disclose because […] you can't transmit it to anybody anyway. So that's fair, that you don't disclose, that's fair, but a person who is not taking care of their health and they know that they have HIV and they know that they're not taking their medication and they're full blown out there, you know, infecting others, that's just wrong and they need to be […] held accountable for that. (Ava, white heterosexual woman, diagnosed mid epidemic)

Similar sentiments were given by Jamie, who emphasized that people who are undetectable take care of themselves and are health conscious, which is evidence that they do not want to transmit the virus. She explains,

> I am very healthy and […] I know I'm undetectable. In my mind [I] feel like I don't […] need to tell you. And I know the courts say, you need to tell them, even though you're undetectable—which I think is full of crap. Because if we're undetectable, obviously we're taking care of ourself and we're being respectful. [...] If it wasn't this law, I probably wouldn't— I most likely wouldn't [disclose] because I know that I would never put him in harm's way. Anybody that is undetectable would never put anybody in harm's way. Because that's-- we're obviously self-conscious […] of our health. […] we want to take care of ourselves. (Jamie, Indigenous heterosexual woman, diagnosed mid-epidemic)

Ava's and Jamie's points show the ways in which risk management has changed in the TasP era to be a more individualized and self-driven responsibility rather than a community practice, as it was at the beginning of the epidemic (Race, 2001; Sangaramoorthy, 2012). To be an undetectable self, or "a normalised HIV citizen" means taking "on certain responsibilities towards truth and life. Who we are in relation to HIV, like other socially contentious conditions, is also who, as normalised citizens, we ought to be. Social normalisation is also moral normalisation" (Squire, 2013, p. 98). Their descriptions also show how regimes of anticipation make up the undetectable self as someone who imagines their future by acting in the present. Being prudent about health and adhering to treatment plans means protecting the self and the broader body politic.

While PLWH are responsibilized to take care of their health, their medical decisions are increasingly controlled by the law on HIV nondisclosure. Undetectability, achieved only by taking medications, becomes one of the primary pieces of evidence that a person is being responsible and, thus, that they should not be criminalized. The 2012 decision in *Mabior* stated that a "realistic possibility of transmission" is negated in situations where the person living with HIV wears a condom and has a low viral load. Ontario's prosecutorial guidelines now also say that a person living with HIV in Ontario should not be criminalized if they have a suppressed viral load or undetectable viral load for a minimum period, between four to six months (HIV/AIDS Legal Network, 2024).[124] This point was made clear by John who talks about "non-progressors", people who acquire HIV but whose immune systems prevent the virus from advancing to AIDS.

> The sort of consensus amongst HIV specialists is that you go on medication immediately upon receiving a diagnosis. In the past, […] when I was diagnosed, you used to wait about a year, give or take. They would monitor you and they would

[124] While this is not the law, Crown prosecutors are mandated to follow these guidelines.

> see how your viral load and your CD4 would fluctuate. They would figure out […] what your normal is. Some people are what they call non-progressors. And so they would have very low viral loads and doctors wouldn't feel the need to give them medication because their viral load was very low. That was ideal, that's what you wanted as an HIV-positive person who'd been diagnosed because you didn't want to go on medication because medication has side effects. So you were always hoping that you're in that minority of folks who may not need to go on medication, you'd be a non-progressor. Now they're like, "go on it right away, […] because this may be what keeps you out of jail." And so now […] it's even impacting your medical choices and decisions that you're making. […] We knew that [taking medications] decreased risk of transmission. So, this was something that they could do to show that they were being responsible and trying to not potentially infect others. And I mean, it's hard too because […] how do you judge that, that right to privacy with like the interests of public health. (John, white gay male, diagnosed mid-epidemic)

John's statement and the fact that there is not a clear understanding of the threshold at which one's viral load is low enough not to bring about prosecution speaks to what Sangaramoorthy (2012) terms "numerical subjectivity" whereby statistics and other numerical data like CD4 count or viral load, are more than just social data, they are "numerical considerations [that] play a crucial role in how life is both imagined and lived" (p. 293). In other words, through numbers, categories, and disease status, we come to know ourselves and others, including who is and is not risky (Clarke et al., 2010; Sangaramoorthy, 2012) and who has the capacity to be responsible (McSwiggins, 2017). Viral loads and CD4 counts then become the defining feature of being a responsibilized HIV citizen, whereby the only way to achieve a low or undetectable viral load is through strict adherence to treatment (McSwiggins, 2017; Colvin, Robins, & Leavens, 2011). That the law uses undetectability as evidence of whether to prosecute someone for exposing another person to HIV shows how law and biomedicine work in tandem to regulate risky subjects by way of inducing a moral imperative to be responsible

Of course, the U=U campaign has been incredibly positive for PLWH who can now safely engage in sexual relations without the worry of transmission. Several participants talked

about how being undetectable meant that they were safe and could not hurt anyone else, which brought about a sense of happiness and relief. For example, Samantha, who engages in sex work, explained, "seriously once I hit undetectable, I was so happy, right? Because I felt safe. I felt like I couldn't hurt anybody" (white bisexual trans woman, diagnosed recently). Karam similarly explained, "legally, I don't have to disclose if I'm on consistent medication. I'm undetectable, which [means] I'm no risk. Like sleeping with someone who doesn't know his status, that's more risk than me" (Middle Eastern gay man, diagnosis date unclear). Charlotte talked about how she could finally have sex with her partner without a condom, a physical barrier that reduced their sense of connection.

> I was really glad when the studies came out showing that if you were undetectable, you were untransmissible. At that point my husband and I had an appointment […] with my doctor, and we talked to him about not using condoms. And he basically said, you know, "yes, this is true, this is what the evidence is showing, it's scientific. There is still a wee tiny chance that your husband could get it, but I can guarantee you that if he does get it, we can get him treatment and he can live a long, healthy, normal life." So we both decided to take the risk because up until then, we felt like we were always having barriers, actual physical, literal barriers [chuckle] put between us in our sex life. And it was like less spontaneous, less, I guess, romantic than it was for me, like he would never have used condoms at all, but for me, I could never relax without them […] it was nice to have one barrier lifted instead of another one added at that point in our lives. And so that's, I think, improved our relationship and our sex life. (Charlotte, white heterosexual woman, diagnosed early in epidemic)

For Charlotte, science's promises regarding undetectability generated a sense of happiness in that she can have a better and more intimate sex life. There is a sense of trust in science in her recounting of the doctor's answers to her question about having sex without a condom and that even if her husband were to test positive, treatment exists that promises to make him feel as if nothing has changed.

PLWH configure their undetectable self through these anxious hopes where being undetectable means having some promises fulfilled and others left unfulfilled. An anxiousness

was felt by participants precisely because decisions to prosecute cases of HIV nondisclosure now rest on whether a PLWH is undetectable and for how long. Being undetectable means not being liable to criminalization, but it also means that if one were to ever become detectable, one would be susceptible to criminal prosecution. Even if one is undetectable, PLWH are still under threat from criminalization because not every province has explicit prosecutorial guidelines that make it clear that there is no "realistic possibility of transmission" if an undetectable person does not use a condom (HIV/AIDS Legal Network, 2024). Through these medico-moral-legal forms of regulation, PLWH are encouraged, taught, and disciplined to be self-governing citizens and the primary managers of sexual risk (Race, 2001).

## 7.3. Hope Aliens: The Detectable Other and the Skeptics

This section mobilizes Ahmed's (2008) concept affect aliens, which she describes as people who "do not experience pleasure from proximity to objects that are attributed as being good" (p. 5). Later she describes affect aliens as those who do not desire in the right way; they do not want what is culturally, politically, and/or socially desired, but rather something different (Ahmed, 2010). I use hope aliens to describe those participants who were skeptical about the promises made about undetectability and who chose not to take their medications.

I contend that hope, its anticipatory nature and its relation to fear and anxiety, has become an important mechanism through which medico-moral-legal modes of regulation operate to configure PLWH into the undetectable self and the detectable Other. Those who can reach undetectability are those who are the vision of hope, proper HIV citizens adhering to notions of 'healthy' and responsible living by taking their medications and reducing their threat to the body politic. People who are unable to reach undetectable status, the detectable Other, are relegated to the category of irresponsible and therefore dangerous HIV citizens. The detectable Other

represents an anxious hope for PLWH; even though they might be undetectable now, there is always the possibility that this status can be lost. The cruelty of hope is also shown in how fear of losing the promised object "will defeat the capacity to have hope about anything" (Berlant, 2007, p. 33). The undetectable self is, therefore, tethered to the detectable Other; one does not exist without the other, with the latter working to ensure that the former never falls out of line. This point signals the ways in which the undetectable self is "a self only among other selves" (Taylor, 1989, p. 35), always already in a process of refiguration (Ricoeur, 1983/1990) as we exist in a world where we have the "capacity to affect and be affected" (Seigworth & Gregg, 2010, p. 2) by other selves that are also in a state of continual refiguration.

### 7.3.1. "I don't know about this U=U business": The Skeptics

While this section outlines the more hopeful attachments to an undetectable identity, I caution that participants did not express awareness of the pitfalls of having such hopeful attachments to biomedical technologies. Participants resisted being understood through technoscientific narratives and crafted different meanings out of their experiences. For example, Roxy warned against messaging that HIV is a chronic and manageable illness because it is so lifechanging, so disruptive to one's identity (Alexias, Savvakis, & Stratopoulou, 2016; Carricaburu & Pierret, 1995; Ciambrone, 2001; Ezzy, 2000; Wells et al., 2023; Wouters & de Wet, 2016).

> I would say that there's a danger […] in presenting this as a one-a-day pill that's nothing. It's like you just take a pill, [one] a day now and […] it's like taking, I don't know, a birth control pill or a vitamin. I think the meds are really toxic and I don't know whether it's the virus or the meds itself, but […] so many people have also said, "Oh, I don't have a problem with the HIV, it's the other 20 diagnoses that I have", like high blood pressure, cholesterol, […] all of that. And I think that's caused from the meds and the virus itself. And […] I do take the one a day. […] it has […]physically, it has taken its toll. And so I'm not of the firm belief that this is a one day thing and we're all going to live happily ever after. I think that could be a dangerous message, too. I mean, I know why we do that, because we want to minimise the scare and the stigma and everything else. But some people may

> actually believe that and think, "Oh, this is no problem." (Roxy interview, white heterosexual woman, diagnosed early in epidemic)

Although Roxy understands the importance of the messaging around the manageability of HIV, she fears that making it seem akin to other chronic illnesses like diabetes or high cholesterol negates the harm that it causes (physical, mental, and social). For Roxy, this messaging signals a cruel relation to hope, and she does not buy into the idea that taking one pill a day means "living happily ever after." She refuses to buy into the fantasy that HIV medications make life happy. Caron (2014) states that while there is some truth to thinking about HIV as similar to other chronic illnesses, and that these views come from a place of not wanting to mark PLWH as radically different, the "mere fact of implying as much confirms that it does" (p. 31). This leaves Caron (2014) to question, "if it isn't a catastrophe and it isn't nothing, then *what the hell is it and how can I talk about it*? I don't know, really, but I don't think it's like cholesterol. No one feels nervous in your company because you have high cholesterol. Right?" (p. 31). Both Caron (2014) and Roxy point to the difficulties of trying to normalize HIV. It is not something to be taken lightly, but also not something that should be made exceptional. HIV must be managed and that involves a continuous (re)configuration of one's sense of self, that before being diagnosed, PLWH did not have to think about or do.

Jenny is similarly skeptical about the promises offered by U=U as her serostatus oscillates between detectable and undetectable. Unlike Aran, who above noted that he refuses to say he is HIV-positive, Jenny insists on saying she has AIDS because her CD4 count is so low.

> And even so, […] when people talk about this undetectable business, U=U, I'm like, well I don't get that at all. Mine would go up and down. […] My viral load, they say, if it's, you know, 200 and above it's supposed to be, if it's below that, you have AIDS. Well, technically I have AIDS, but nobody wants to say that. They like to say HIV. So I'm like, ok, well, I'll just say AIDS because if you're going by the numbers. But I don't care about the numbers, the CD4. Now I only have to go for blood work instead of every three months, I went from monthly to three months

> and now six months because they know that it's just going to fluctuate a little bit up and down. But my CD4, [the doctor] says he's not going to worry about checking it anymore. Numbers. Numbers are for the doctors. I go by how I feel. […] You know, when you talk about being with other people with HIV, I still wouldn't be interested, our strains are all different. And with the undetectable business, how do you know you can be undetectable? And then when I was doing blood work every three months, then all of a sudden it could be detectable. It doesn't stay consistent. (Jenny, white heterosexual woman, diagnosis date unclear).

Jenny is an example of someone who dared to question conventional knowledge and understanding of what it means to be undetectable. As Ahmed (2010) writes, "to question is to be affectively an alien" (p. 189). Jenny's point that "numbers are for doctors, I go by how I feel" belies public health messaging that one must engage in self technoscientific HIV surveillance. In this way, Jenny refuses to buy into the promises that are packaged by biomedical narratives because her own experiences reveal viral loads to be inconsistent.

Next, I describe the complexity involved in striving for health and undetectability, while also managing other aspects of one's life and the side effects of medications.

### 7.3.2. "I can't do this every day": The Detectable Others

Hope operates as a governing tool by "managing the present through its temporal projection of a possible future" (Herz & Lalander, 2022, p. 223) free from illness, but also in opposition to the 'real enemy' upon whom the stigmatizing and criminalizing gaze should focus. Hope can act as a technology of control (Ahmed, 2010) to maintain harmful dichotomies between the 'good pozzies' and the 'bad pozzies', which may then be used to justify the continued criminalization of the most marginalized. Indeed, that most of the participants I cited in this chapter are white shows how hope can be whitewashed and is often a privileged emotion. Ahmed (2010) makes this point by arguing that,

> […] hope itself is unevenly distributed, where some not only have more hope than others but acquire their hope by taking away from others, which is, at the same

> time, about making other ‘be’ in order that some can ‘have’ what they hoped for (p. 188).

For example, Black participants in Odhiambo et al.’s (2023) study refused to attach hopeful feelings to undetectability because there was nothing to be hopeful about if reaching undetectability was complicated by structural inequities and the possibility of criminalization and/or deportation still existed. The excerpts below contrast the difficulties in negotiating the complexities of living with HIV and ‘doing what is right’ with ‘doing what is required’.

Ethan’s experience shows how the ability to adhere to a treatment plan is connected to one’s sense of self, marking those who can or do not adhere as failures, or as he states, “a loser” for going “back into [his] addiction” and not using medications.

> At first [HIV] didn't [affect my mental health] at all. […] I just kind of ignored it, pretended like it didn't even happen […]. I just went about my business not taking meds. And […] I ended up staying off drugs, once I got diagnosed, I stopped using drugs, like completely. I just didn't take my medications. So I managed, I stayed clean for 10 years. And then 10 years, I ended up falling off the wagon […]. I went back into my addiction and I was […] losing weight and stuff. And […] I guess [not] being clean and not taking the meds I was doing, OK. I wasn't getting super sick, but my counts obviously weren't very good. But […] I didn't feel any effects from it. It wasn't until getting clean this time that it really […] started to hit me. I just felt like a loser. And I felt like I had to do something and get back on track and start taking my meds and I'm doing good. I'm 220 pounds now. And it's the most I've ever weighed and I'm healthy. But when I first got here, I was pretty depressed and hating life and just getting back on the meds to get healthy and knowing that I am undetectable is like huge for my mindset […] I'm not depressed anymore […] knowing that I've got it under control. And yeah, I feel a hell of a lot better mentally […] (Ethan, white heterosexual male, diagnosis date unclear)

That going back on medication and “getting clean” made Ethan feel a sense of accomplishment is evidence of how “healthwork [is] continuous with a practice of the self that encourages individual [people living with HIV] to actively transform their lives and selves as part of responding to the compliance demands of a new biomedical regimen” (Mykhalovskiy, McCoy, & Bresalier, 2004, p. 331). Working on oneself can bring about feelings of happiness, as it did

for Ethan, if one is able to obtain what is promised. In this way, being hopeful that using medication will bring about happiness sustains the modes of regulation that biomedical regimes require. As Ahmed (2010) writes, "[…] the promise of happiness keeps things in place: happy and hopeful subjects are well adjusted because they have adjusted to a demand they do not know has been made" (p. 189). Despite achieving undetectability, Ethan stated that he still does not know how to disclose his serostatus and is not sexually active because "every time it comes down to doing anything with anyone, [HIV] pops into my head and […] nothing functions […] it's hard to deal with. I don't know how people are going to react."

Others, like Pup, actively made decisions to take medication breaks because the side effects from medications were too burdensome. Pup initially had to take 18 pills a day, something he felt he could not manage. He felt resigned about his diagnosis, describing how the medications would kill him anyway given the kinds of side effects he experienced and which pushed him to decide to stop taking them. He explains,

> When I first got diagnosed, when I was taking the 18 pills, I'm like [inhales loudly] Yeah, I really don't want to [says with a grumbled voice]. And there's a few times like I'll admit, I missed doses like I can't do this every day. There's no way. And then I'm like the chemicals alone, are probably going to kill me anyway. I had nausea, weight loss, I was pale, pale, pale. And with the six twice a day, it wasn't as bad, like I still had the diarrhea and the nausea. When I went to three, […] I got the growth hump. But that's gone now. Didn't get the Kaposi's sarcoma or anything, which is good. [...] Honestly, I wanted to stop, I'm like, I can't do it […] after a while, I couldn't, I said I couldn't do this, and then I stopped. Took a medication break and then […] I got my bloodwork tested and everything, they're like, well you're still undetectable and everything, but your numbers are kind of low, so [inaudible] back on [the medication] I did take medication breaks in between though with the new ones today, I've missed maybe three times. (Pup, Indigenous two-spirit and gay, diagnosed mid-epidemic)

Pup's story describes how PLWH grapple with the moral obligation to achieve health and to take responsibility for it when there are very real consequences to their health brought about by such obligations. Persson and Newman (2006) drew similar conclusions when a participant was

“obliged to choose between two undesirable alternatives: between a vulnerable self and vulnerable health, between madness and jeopardizing the containment of his HIV” (p. 1592). This point intimates how self-governance is not always practiced under conditions of freedom (Mykhalovskiy, McCoy, & Bresalier, 2004). Hope, therefore, gives the illusion that choices made towards the promotion of health, emphasizing individual responsibility and strict adherence to treatment plans, will bring about happiness. For Pup, however, it was not taking his meds or doing what others require of him that brought a sense of relief.

## 7.4. Final Thoughts

In this chapter, I examined how PLWH configure their undetectable self within the biomedical and technoscientific cultural field. They did this through narratives of healthy living, responsibility, and safety, which makes becoming undetectable a moral obligation imposed upon the self. I then discussed counter-narratives to the undetectable self, the hope aliens, who do not buy into the fantasies offered by biomedical interventions and must negotiate the side effects of medications with the “good feelings” of being undetectable. I showed that hope operates not only through the narratives of biomedicine that people take up in the configuration of their undetectable self, but also that people’s everyday practices of negotiating life with HIV sustain the happy and hopeful feeling around biomedical narratives of undetectability. Lastly, I showed how some PLWH are hope aliens, people who do not always take up the hopes offered by biomedical narratives that position undetectability as the *only* way to be an HIV citizen in the TasP era. Instead, the PLWH I cited are skeptical about biomedical promises and dare to question the science. Others refused to take medications because of harmful side effects that negatively impacted their quality of life or their ability to do their jobs. Not taking their

medications is a way to resist biomedical narratives that import a moral imperative to adhere to treatment by doing what they feel is right for their bodies.

I want to emphasize that this interpretation of people's stories as the undetectable self, is but one understanding. In telling one's story, multiple selves can be constructed depending on the time, context, and audience (Bernays et al., 2014). As Bernays et al., (2014) argue, "what he or she chooses to show at a particular time through different remembrances and articulations is dependent on the setting, listener, and motivation, and is thus inevitably co-constructed between the interviewer and listener" (p. 630). The people I interviewed may have talked more about undetectability in their HIV stories precisely because the project is about the criminalization of HIV nondisclosure, where being undetectable means not being susceptible to prosecution (at least in some provinces and under certain conditions). Indeed, I reject the notion that stories have some kind of *mimetic* quality or the understanding that "stories merely imitate a reality independent of stories, that they are merely surrogate versions…" (Frank, 2010, p. 88) of what I would have seen and experienced had I been in the participant's shoes. Instead, I was more interested in understanding "the storyteller's intended or unintended creativity in sketching windows on reality, and the contexts that make particular kinds of creativity seem necessary" (Frank, 2010, p. 89). In other words, this chapter explored how PLWH configure their various experiences, under what circumstances, and why these configurations become necessary.

In the next chapter, I tie together the components of this dissertation to propose an affective victimology. I also discuss some of the limitations and contributions of this project and propose the need for an affective victimology which takes seriously the role of emotions in who get ascribed victim status, who gets to feel the complex feelings of victimhood, and how emotions are implicated in punitive criminal justice policies.

# Chapter 8.

# Conclusion: Re-framing Anti-Victim Narratives Towards an Affective Victimology

> *I don't believe in the victim philosophy because if you want to sit there and be a victim, you are a victim. That's self-fulfilling. I don't buy that. […] you got a problem? How do I fix it? I don't think that most people understand that […] during the early 80s, we were all sitting like sheep in a pan waiting to be slaughtered [pause] and suddenly AIDS is there and everybody's already got it in the gay community […]. No, no, I don't believe in the victim thing.*
>
> *- Buttercup, white gay male, diagnosed early in epidemic*

> *[I] definitely [feel like] a survivor, but I don't think victim, no, but definitely a survivor […] I was watching people drop like flies around me […] the early years of HIV […] people were just dropping. You were going to funerals weekly almost back then. […] [so] a survivor is somebody who doesn't allow themselves to be victimised by a situation and who overcomes the challenges of those to some extent.*
>
> *- James, white gay male, diagnosed early in epidemic*

PLWH have a complex relationship to notions of victimhood. Both James and Buttercup refuse to take on a victim mentality. Instead, they prefer not to linger in one's sadness and/or grief, and to move on. They describe being a victim as an unproductive subject position yet, being victimized by the government's refusal to respond to the deaths caused by HIV in the 80s is exactly what mobilized the anger that fuelled much of the activism during that time. As Cole (2016) aptly articulates, "the opposition of passive victims versus active-vulnerable subjects relies on a construction of agency and victimhood as an either/or proposition abstracted from the social and political contexts that generate victimization" (p. 270). This kind of anti-victim talk is one of the inspirations for this project.

I started this dissertation thinking about HIV nondisclosure and victimhood because, as the law stands, if someone living with HIV does not disclose to their sexual partner in a situation

where they do not use a condom *and* have a low viral load, the law *makes* the person not disclosed to a victim and the PLWH an offender regardless of how someone may identify. I use the word 'make' in reference to Alexander McClelland's (2024) argument that people's experiences come to be known through "official ways of knowing" such as press releases, police reports, safety warnings, media reports, and the law (p. 90). In other words, the law calls into being people who experienced nondisclosure *as* victims while PLWH who do not disclose are called into being as perpetrators regardless of their reasonings for not disclosing.

Given this context, I was curious about how people make sense of not being disclosed to, whether they think of themselves as victims, and where this aspect of their HIV story fits within the broader narrative of their lives. To answer this question, I set out to interview both PLWH and HIV-negative people who were not disclosed to. Recruiting HIV-negative people who were not disclosed to turned out to be more difficult than anticipated (I was only able to recruit one person in this situation). Which organizations do I send recruitment posters to that would target this group of individuals? If I send recruitment material to sexual assault resource centres, will I be encouraging people to report nondisclosure to police and thus reproduce official ways of knowing (McClelland, 2024)? When the pandemic struck, recruitment became even more challenging. I sent my recruitment documents to ASOs across BC and Ontario which enabled me to interview PLWH of different ages, race, sexual orientation, and gender (N=43). The questions I asked participants living with HIV became broader, encompassing more than nondisclosure, to better understand people's HIV stories. These stories included reflections on their emotions and feelings regarding their diagnosis, disclosing to other people, treatment, criminalization, and victimhood (see Appendix A for more detailed questions). To complement the interviews, I also included a drawing component in which individuals drew their HIV story as a lifeline (N=25).

Once participants completed their lifelines, we met on Zoom once more to debrief their drawing. In this secondary, mini-interview, I asked participants to describe their lifelines, to provide further explanation about the significance of the symbols, colours, and/or line variations they used, and whether drawing these life events unlocked new insight into the emotions they felt during that moment in their life.

The interviews and lifelines opened-up “worlds of feeling” (Plummer, 1995, p. 155) or an array of complex emotions and feelings that make up the stories told by PLWH. This notion identifies how “much of storytelling deals with the worlds of emotions” but also how much is left out “including ways of feeling not even recognised as feeling” (Plummer, 1995, p. 154). The “worlds of feeling” (Plummer, 1995, p. 155) that emerged from participant’s stories goes beyond the moment of nondisclosure or how one acquired HIV but towards broader understandings of what it means to live with HIV within and across the different eras of the HIV/AIDS epidemic – from crisis to normalization and criminalization.

Using a theoretical framework based in theories on affect, narrative, and identity, I developed the notion of the *affective narrative self* to articulate these feelings. The affective narrative self describes the ways in which humans come to define themselves and others through narratives (historical, mythological, fictional, biographical, cultural, familial, traditional, modern, political, medical, legal, etc.) that become affectively charged, what I called affective narratives. Affective narratives become charged as they circulate through and within time as they are used to configure the story of one’s sense of self and our senses of others, and as they are refigured through the reception of that telling.

To define affect, I mobilized the work of Margaret Wetherell (2012), who develops the concept of “affective practices” to recognise the ways in which affects impinge and shape the

psychosocial field, and Sara Ahmed's (2004) articulations about what emotions 'do' as they stick to certain objects, events, people, and narratives. To understand how the affective narrative self is formed, I employed Ricoeur's (1983/1990), notion of narrative identity made through the "hermeneutic circle of mimesis" which he describes more aptly as "an endless spiral that would carry the mediation past the same point a number of times, but at different altitudes" (p.72). This interpretative spiral comprises the prefigured (pre-narrative) field of action and experience, the act of configuring these experiences into a plot that "mediates between the individual events or incidents and the story" (Ricoeur, 1983/1990, p. 65), and the refiguration or interpretation of that narrative by the listener/reader such that the practice of emplotting events into a narrative, transforms them "into experience that has meaning" (Frank, 2010, p. 136). The affective narratives that emerge from this interpretative spiral, are socially, cultural, and historically situated and thus provide the stock of knowledge by which people understand the affective practices (Wetherell, 2012) of their daily lives and define their sense of self. In other words, this theoretical concept allows for an examination of how selves are formed, transformed, and shaped by "the narratives produced and available from the point of view of the power relations they inscribe and the worldview they support through their ideological functioning" (Venn, 2006, p. 112).

Across the three analysis chapters, I presented several different affective narratives that emerged from people's stories about nondisclosure, their diagnosis, and treatment experiences; these affective narratives resulted in different conceptualizations of self, including an undetectable self and most prominently, a denial of victimhood (evidenced also by the quotes at the beginning of this chapter). Although, in a few cases people felt like victims of their partner's

nondisclosure while others felt like victims of the law on HIV nondisclosure, public health, disclosure, circumstances, sexual assault, or other acts of interpersonal violence.

Chapter 5 is dedicated to exploring how people make sense of victimhood in the context of nondisclosure. While I initially thought that every analysis chapter would explore participant feelings about victimhood, people rarely spoke about this without direct prompts to do so. Instead, they emphasized the grief of living with HIV (chapter 6) and what it means to be undetectable (chapter 7). In chapter 5, I suggested that this was most likely because the term 'victim' in the HIV/AIDS community reflects a prickly identity with negative historical connotations and because PLWH rarely discuss how they acquired HIV as this is generally considered to be a stigmatizing question – similar to asking what someone did to end up in prison. These sentiments were evident in the first major theme of chapter 5, in which several participants shifted the blame for their partner's nondisclosure onto themselves and denied a personal sense of victimhood. Yet, some participants (see section 5.2.) vehemently expressed that they felt like victims of nondisclosure and were angry about not being given a choice whether to engage in sex with someone living with HIV. This suggests that nondisclosure is an affective practice configured through the prefigured narratives about 'victims', safe/unsafe sex, innocence, blame, culpability, and responsibility such that some read the practice of nondisclosure as a victimizing event through their anger while others read it as a moment of shame for their failure to engage in safe sex. Shame and anger are thus *some* of the emotions that structure whether people configure their affective narrative selves as victims of nondisclosure or not.

Parallels can be drawn between people's feelings of grief around their diagnosis, the loss of their old self, and the challenges of living with HIV that might register as grief such as

experiences of stigma (see chapter 6) and victimization. Victimization is understood as "an ontological assault on our sense of self" (Pemberton et al., 2018, p. 5), an "event" that "impinges upon the possibilities of those victimized and various elements of their embodied existence" (Spencer, 2011, p. 40), and reflects "being acted upon" (Cole, 2016, p. 271). PLWH may not identify *as* victims of HIV or that they are victimized (for reasons mentioned above and in chapter 5), but their stories of grief intimate the victimizing *effects* of policies, laws, and historical narratives that act upon PLWH to regulate their lives and in the case of the HIV/AIDS crisis, allow them to die. The victimizing effects are what Squire (2013) describes as the "particularities" of HIV that continue to be felt regardless of the hopeful messages proffered by biomedicine that aim to normalize HIV. These include the ongoing difficulties of disclosure, stigma, criminalization, rejection, violence, and ideas about how PLWH 'should' conduct themselves (Squire, 2013). In chapter 7, I showed how this is most readily seen through the convergence of biomedicine and law to responsibilize PLWH to prevent onward transmission by diligently taking their medications, achieving a low or undetectable viral load, and always practicing disclosure to a new sexual partner.

I am certainly not arguing that PLWH *need* to or *should* define their experiences through the language of victimization. Indeed, as Cvetkovich (2003) argues, public cultures that acknowledge trauma in ways that are "politically powerful without being based in claims of victimization" (p. 284) can and do form. This kind of public culture is exactly what the HIV community created in the early years of the epidemic, and which I argue, continues today. Despite feelings of victimization articulated by some participants and the configuration of a victim identity by those who felt betrayed and angry at their partner for not disclosing, a general denial of HIV or nondisclosure victimhood was apparent throughout the interviews. I contend

that the participants' disavowal of victimhood occurred through the coupling of who 'victims' are thought to be with ideas about defeat or passivity (Christie, 2018; Cole, 2016, 2006; Dunn, 2010; Gavey, 1999; Holstein & Miller, 1990; Lamb, 1999) which also does the work of further entrenching modes of governance that responsibilize individuals regarding their own sexual health and safety, the effects of which I explore in chapter 7.

In the final analysis chapter, I showed how PLWH configure their affective narrative selves through the affective practices (Wetherell, 2012) of maintaining a suppressed viral load and by mobilizing the prefigured cultural field of hopeful and dominant biomedical narratives. This results in the configuration of a responsible, healthy, moral, and safe undetectable self who stands in opposition to the detectable other who fails to adhere to their treatment plan and is therefore immoral, irresponsible, and risky. This bifurcation along virological lines parallels narratives about survivors who can overcome their traumas thus "[imposing] compulsory hopefulness and optimism in the service of neoliberal capitalist production" (Koyoma, 2011, n.p.) and weak or passive victims who embody the failed neoliberal subject.

I contend that a politics of victimhood is (re)ignited when people who are not disclosed to are *made* into victims and PLWH who do not disclose are *made* into dangerous offenders by the law. This is a contentious and inconsistent politics that insists that people must reject victimhood because it is a weak or helpless identity and thus a shameful subject position to take up, while at

the same time readily ascribing this status to certain groups (e.g., heterosexual, white women)[125] who are constructed as always-already innocent and in need of saving by the law. For example, Walklate (2011) contends that in the hierarchy of victimization people whose lifestyles render them prone to victimization such as the unhoused, people who use drugs, and sex workers, are often deemed vulnerable yet are denied victim status. In other words, while in advanced liberalism (Rose, 1993) people are encouraged to avoid taking on a 'victim-mentality' (Cole, 2006; Stringer, 2014), victimhood is being used to configure affective narratives that situate some people as innocent and good and others as guilty and bad/risky thus producing a "'backlash' [that] categorically denies systemic inequities and delegitimizes collective action" (Cole, 2006, p. 19). As such, victimhood should not be deleted from our "political vocabulary", instead we must reclaim and redeploy it in ways that recognizes everyday injustices and insidious traumas (Cole, 2016, p. 271; Koyama, 2011).

In the current HIV era, we must consider whether it is time to entertain the idea that oppressive forces like the law on nondisclosure and public health policies like TasP, which aim to regulate the behaviours of PLWH, are *victimizing*. What might an affective narrative of victimization do in the fight against systems of oppression and marginalization that

[125] While we do not know the race of the women who came forward with allegations of HIV nondisclosure against PLWH, we know that of the 183 men who faced charges related to HIV nondisclosure since 1989, 63% were involved in heterosexual relationships. We also know that in the "hierarchy of victimization" (Carrabine et al., 2004, p. 116) white women are more readily given the label victim, especially in the context of a racist and colonial history in which white women are constructed as 'damsels in distress' in need of protection by white men from Black men and because they are able to perform victimhood in socially acceptable ways (Phipps, 2021; lemieux, 2017). For example, lemieux (2017) writes in relation to the #MeToo movement, "white women know how to be victims. They know just how to bleed and weep in the public square, they fundamentally understand that they are entitled to sympathy. Conversely, Black women, when victimized, know that we need to tuck that shit in and keep it moving, that few people will care what we've endured or even believe that it happened—and a lot of us seem to struggle with the idea that we can be victimized in the first place" (n.p.). Of course, not all white women may be afforded this status; working-class white women, for instance, are more often represented as figures of disgust rather than sympathy (Tyler, 2008; Lawler, 2005).

vulnerabilize[126] and exclude PLWH, particularly those who are racialized and poor, from protection and care? I pose this question because I am not sure what a narrative of victimization might do politically. Maybe it does nothing and there is no point in using this language. Maybe there are other narrative configurations that are more suitable. I am, however, critical of the outright denial of victimization and of the conflation of victimhood with weakness, as if one cannot be a victim and still be strong and act with agency. This logic flows from my own experiences of victimization. I see great strength in being a victim because of the pain that experiencing or witnessing a victimizing event brings into one's consciousness, which Massumi (2002, p. 16) describes as "the felt reality of relation" that can potentially motivate us into action, provide the basis for collective acts of resistance, and enable the politicization of certain spaces and issues. Afterall, it was a collective feeling of victimization by state agencies that failed to take action during the height of the HIV/AIDS crisis that motivated the anger that galvanized groups such as ACT UP to fight back (Gould, 2009). My claims here are also supported by those participants who spoke about feeling *victimized*:

> I feel victimized, but do I feel like a victim? And then I'm like, what's the difference? Is it semantics? I do feel victimized, but not so much by my community, but by the police and by health care practitioners, specifically public health (John, white gay male, diagnosed mid epidemic).

My analysis shows that while PLWH do not readily configure their affective narrative selves as victims in light of the nondisclosure they experienced, they recognize and *feel* the ways in which they are *victimized* by laws and policies that harm them in the name of 'protecting' the broader

[126] I am referring to the body of literature that has criticized the notion of 'vulnerability' arguing that it is not a natural, taken-for-granted phenomenon or subject position, but rather that people are *made* vulnerable through harmful policies that then seek to regulate, discipline, and control. See for example: Brown, K & Wincup, E. (2020). Producing the vulnerable subject in English drug policy. *International Journal of Drug Policy*, 80, 102525; Cole, A. (2016). All of Us Are Vulnerable, But Some Are More Vulnerable than Others: The Political Ambiguity of Vulnerability Studies, an Ambivalent Critique. *Critical Horizons*, 17(2), 260-277; Larios & Paterson (2021) Fear of the other: vulnerabilization, social empathy, and the COVID-19 pandemic in Canada. *Critical Policy Studies*, 15(2), 137-145.

HIV-negative public. This is a public from which they are actively excluded by way of laws and public health policies that configure PLWH as inherently risky (Kinsman, 2024). Participants expressed these feelings through melancholic narratives about the biographical disruption they experienced following diagnosis and the subsequent loss(es) they felt in terms of their sense of self, as well as through narratives of loss in relation to friends, partners, and social networks as discussed in chapter 6, which stands in contrast to the hopeful narratives they offered about the undetectable self in chapter 7.

It is my hope that the complexity with which the politics of victimhood continues to be played out amidst the HIV/AIDS epidemic and criminalization of HIV nondisclosure provides a starting point for commencing a broader dialogue about an *affective victimology*. This is a victimology that is embedded within the critical victimology tradition but that goes beyond examining who is a victim and the power structures that determine who gets ascribed this label, to consider the role that emotions play in contouring the politics of victimhood. This developing field would entail examining the affective labour, or the ways in which our emotions, affective states, and feelings are put to work *upon* us by politicians, policy makers, mass culture, and/or social movements, to shape how we configure our contact with others, or per Ahmed (2004), the boundaries and borders between bodies. For example, an affective victimology could interrogate: the ways in which sympathy becomes politicized as a result of the affective labour of victim's rights groups and/or carceral feminists who construct a discourse of victimhood that situates 'the victim' as always-already innocent and therefore worthy of our collective sympathy and the 'offender' as someone to be feared and who is deserving of harsher forms of punishment; how narratives of empowerment and hope within the HIV/AIDS community work to subdue or delegitimize the material inequalities and social divisions embedded in public health policies

such as TasP; or how anger and shame operate within the context of criminalizing HIV nondisclosure to mark some as victims while others are relegated to "live in a negative relation to the law, facing criminal or public health sanctions and [who] must live a life under constant threat" (McClelland, 2024, p. 22).

An affective victimology would also answer the challenge put forward by Spencer (2011), who called on victimologists to be more attentive to the corporeal and thus to bring into focus the "complex bodily experiences of victimization" including our emotions (p. 32). A victimology that is more attentive to the bodymind considers the relations that victims engage in following experiences of trauma (e.g., with criminal justice agencies, other victims, family members, and people who harm), how each individual gives meaning to these relations (Spencer, 2011), and how these different moments of contact are shaped by affects. Developing an affective victimology therefore heeds Rock's (2002) call to be more attentive to what it means to suffer and experience a harmful or traumatic event. As such, emotions can serve as a liberating force for victims rather than being a hinderance to recovery or a symptom of pathology, for if victimhood is a felt experience it is not a fixed state, but rather a "dynamic process in which an individual's capacity to survive may be subject to change over the course of their life" (Walklate, 2011, p. 188).

Lastly (although, certainly, there is more to this dialogue than what I can consider here), developing an affective victimology would enable us to address victimization, or how people are harmed, in ways that extend beyond the interpersonal. It does so without resorting to narratives about one's character, innocence, resilience, or agency because it "questions and resists the impulse to delete the term 'victim' from our political vocabulary" and instead, insists on reclaiming and redeploying it (Cole, 2016, p. 271). Projects within an affective victimology

could interrogate how to do the work of taking back and/or (re)mobilizing the term and identity of 'victim' in the way that affect theorists have problematized dichotomizing emotions and affects into seemingly mutually exclusive positive and negative camps, as emotions that are frequently "described as negative or even destructive can also be enabling or creative, often in their very refusal of the promise of the social bond" (Ahmed, 2004, p. 201). Could the (re)configuration of 'victimhood' be enabling or productive in its capacity to reject the push to always be a resilient self-governing subject? What might this refusal do in the larger project of social justice?

## 8.1. Limitations of the Research

As a result of pandemic restrictions, I could only speak to people who had access to technology (e.g., a phone, computer, or tablet) since I conducted interviews over Zoom, Microsoft Teams, or by phone call. This limited the people I could talk to in terms of socioeconomic status and areas/spaces where there is limited access to an internet connection. Given that the interviews were conducted online, usually in people's homes and sometimes from their cars, some participants did not partake in the interview in a completely private setting, which may have limited what they felt comfortable to freely discuss with me. It thus posed limits to the confidentiality I could offer participants as it was up to them to ensure they conducted the interview in a private space, which, given the lack of childcare options during the pandemic, was not always possible. The online nature of the interviews also posed limitations on the accuracy of transcripts as some participant's devices made it difficult to understand what they were saying or there would be connection issues that interrupted the flow of interviews and rendered portions of the recordings inaudible that I might have picked up on had we conducted the interview in person.

Methodologically (and theoretically), studying the sociality of emotions is a difficult endeavour. Studies based in psychology and neuroscience use experiments and brain mapping techniques not only to locate where emotions take place in the brain (Adolphs & Anderson, 2018), but also to identify typologies of emotions (Izard et al., 2011), and the psychophysiological nature of emotions (Jones, 2016). These mechanisms of researching emotions yield interesting results, but do not 'get at' the ways in which emotions are felt and experienced, socially constructed, nor the relationships between emotions, people, and society. Studies in the sociology of emotions have theorized the sociality of emotions (see for example Hochschild, 1979 and Kemper, 1978), but specific methodological insights into how researchers can *see* emotions while conducting interviews, focus groups, or analysing documents, and how to elicit emotions while working with human participants are relatively new. For example, Flam and Kleres (2015) edited a book exploring some of the different methods used to research emotions in the sociological tradition.

Interpreting the emotions that people display or talk about is a difficult project since what we express or say in relation to how we feel might not reflect the "right" emotion. Stated another way, the language we use to talk about emotions might not represent how we truly *feel* (Gould, 2009). Second, while journalling about the important emotional moments that occurred during the interviews is useful for analyzing emotional responses to the re-telling of experiences, there is still the problem of affect, which is not spoken or even visibly displayed since it occurs at a nonconscious level (Gould, 2009; Massumi, 2002). Moreover, the ways in which we communicate emotions is culturally delineated and thus poses problems to interpreting emotions and defining the parameters of specific emotions (Ahmed, 2004). For example, what does anger look and feel like, and is it experienced the same across cultures and individuals?

To overcome these challenges, and as Wettergren (2015) contends, I used different theories of affect and emotion to articulate my interpretations about how participants felt about the events they were describing. Each analysis chapter starts with a description of the emotion I am investigating, and which informed my interpretations of participant narratives. However, I recognize that my own positioning might impact the kinds of emotions I am 'seeing'. Perhaps I chose to focus on grief because participant's stories made me sad. Certainly, their stories made me recollect my own past traumas which made writing this dissertation more challenging. Maybe I am negative about hope because I feel pessimistic about the power of medicine and its associated institutions, having been failed by the medical establishment on numerous occasions when doctors dismissed my health concerns because of my weight.

There were also limitations brought on by the very questions I was asking. As a white, middle class, heterosexual, HIV-negative cisgendered woman, there are certainly questions and analyses that I was blind to. For instance, I did not thoroughly explore issues related to class throughout this dissertation while I did engage in discussions about race, gender, and sexual orientation. I find that my own middle-class positionality often makes me not see class in my analysis. Recognizing this, I plan to write a paper that focuses on class, capital, and affect involved in the complex practices of HIV disclosure and nondisclosure.

As someone who was sexually assaulted in the past, my emphasis on victimization and victimhood might have been (and probably is) borne from these experiences and therefore possibly not the questions I *need* to be asking in the context of the criminalization of HIV nondisclosure. I write 'need' in the previous sentence to signal that my project was not embedded within the HIV/AIDS community and thus critical insight into the issues I explore in

this dissertation are missing. To fill this gap, I ground my analysis not only in the stories of participants but in the stories of HIV/AIDS activists, scholars, writers, and PLWH.

## 8.2. Future Research Directions

As with any research, finishing one project often leads to several different and/or new lines of inquiry. In this section, I address a few of these that came up for me. I also discuss, in hindsight, what I would do if I could start my PhD all over again.

First, future research could examine how, when, and why certain narratives become or do not become affectively charged and how are they mobilized in the telling of people's experiences. This research could return to the questions I posed in chapter 3 section 3.2.1. How are emotions involved in the configuration of narratives? What kinds of memories, histories, and impressions do we draw upon as we create these narratives? What kind of affective practices are deployed and suppressed when we configure our life experiences into a narrative? How are emotions implicated in the refiguration of a plot or the kinds of interpretations we make when we hear others' stories? Who has the "configurational power" (Weir, 2020) to tell certain narratives about themselves? Given that narratives are also temporally structured (Ricoeur, 1983/1990, 1984/1985, 1985/1990), this project could expand on the lifeline component of this dissertation to examine more closely how time is experienced by people who are living with HIV or people who have been harmed by sexual assault and/or other harms. Combing the two, a future project could explore affective narratives as they move through time/different eras, how they shift, evolve, or stay stagnant, how they get mobilized in the telling life stories or the construction of other narratives, and the reverberations of these configurations.

Second, future research can expand upon the first analysis chapter to examine more broadly the affective practices of heterosexual safe/unsafe sex and how heterosexual men and

women define their responsibilities in sexual encounters. Given that heterosexual women report instances of HIV nondisclosure to police more often than gay men (Hastings et al., 2022) and that the use of HIV prevention strategies like PrEP and PEP by heterosexual women is low compared to gay men (O'Byrne et al., 2023) it would be fruitful to understand how heterosexual men and women, of different ethnicities and ages, negotiate safe sex and their responsibilities to each other in the context of U=U and the criminalization of HIV nondisclosure. A comparative project could also include individuals within the LGBTQ2S+ community and a genealogy of safe sex messaging in Canada that would explore safe sex messaging marketed towards people of different sexual orientations, ethnicities, genders, and ages. Similarly, a project expanding on the first analysis chapter could examine how ASOs and the broader HIV community understand and think about victimization/victimhood today – both in terms of experiencing nondisclosure (interpersonal feelings of victimization) and criminalization (structural conditions that victimize).

Third, given that I was unable to recruit enough HIV negative people who experienced nondisclosure and went to the police[127], it would be fruitful to speak to those who came forward with allegations of HIV nondisclosure to understand their motivations and experiences. It would also be worthwhile to obtain any victim impact statements made or submitted during nondisclosure trials and to explore the configuration of victims and accused persons by legal actors via criminal trial transcripts and judicial decisions. I had attempted to gain access to victim impact statements for this project but with pandemic limitations, time constraints, and publication bans in cases of HIV nondisclosure, I was not successful in this endeavour. Perhaps, future research needs to expand beyond HIV nondisclosure cases to gain access to victim impact statements that are not limited to publication bans to glean the ways in which victims configure

[127] Recall from the methodology chapter that I was only able to recruit one person who was HIV negative but who experienced nondisclosure from a sexual partner.

their stories within this narrative structure and the effect of these stories within the criminal justice process. This research would speak to ongoing scholarship in law and emotions that examines the role of emotions in legal structures including arguments made by lawyers and judicial decision making (Bergman Blix & Wettergren, 2016; Bergman Blix, 2019). In particular, it would add to Susan Bandes' (1996) critiques of victim impact statements within the U.S. context as evoking emotions that are inappropriate in the legal context. It would thus add a more nuanced discussion about victim impact statements within Canadian (Manikis, 2015; Ruparelia, 2012; Smith, 2011) that takes into consideration the emotions generated by victim impact statement and their effects.

Lastly, and this is my in hindsight moment, future research should engage with the Canadian Coalition to Reform HIV Criminalization and other organizations working to end the criminalization of HIV in Canada to aid in any advocacy efforts, including research that explores the harmful effects of being on the sex offender registry list and the impacts of criminalization on vulnerabilized groups such as the African, Caribbean, and Black communities impacted by HIV in Canada. This project would start with the intention of working collaboratively to make sure that PLWH are meaningfully involved in the study and that the goals of the project are aligned with the objectives of the coalition in order to advance policy.

## 8.3. Contributions of the Research

> *One of the things that I talked to in the room, which is always a room filled full of sero-discordant folks is, "what are you doing to make someone comfortable, to feel like they can disclose to you?" [I'm] sort of flipping the script a little bit and saying, "Well, what's your role in disclosure? How are you phrasing the question? How are you approaching it? Are you asking them in such a way that [is] shutting down the conversation? Are you communicating to them that you're actually an ally or that you're educated [about HIV]?" […] even with your listing for this study, you were very plainly, […] "I do not support..." [laughs] Because I'm reading it going, "OK, well, what direction is she taking this in?" Because*

*I'm not going to participate in something that is nebulous? And then, you were like, "this is clearly my stance, and this is what I want to have happen." And I was like, "Okay, […] she's a safer space for me to […] have this conversation" […]. I feel like that's important. And poz-people are […] looking for those cues or for that knowledge to identify where [and when] it's safe for them to have these conversations.*

- *John, white gay male, diagnosed mid epidemic*

In this dissertation, I proposed the theoretical concept of affective narratives to understand how people configure their sense of self in relation to others and the narratives that circulate about HIV, victimhood, responsibility, safe/unsafe sex, treatment, etc. With this concept, I attempt to answer Rock's (2002) call for a broader "phenomenology of the victim" which examines "when and with what consequences does a person understand himself or herself to have *become* some existential entity called a victim" (p. 22, emphasis in original). I suggest the need to develop and turn to an *affective victimology,* which would aid us in answering Rock's question by interrogating the role of emotions in the politics of victimhood, experiences of victimization beyond psychology, and people's motivations and actions following an event of victimization. An affective victimology would expand the more recent narrative turn in criminology (Presser, 2009, 2016; Presser & Sandberg, 2019, 2015; Sandberg & Ugelvik, 2016) which emphasizes "how narratives inspire and motivate harmful action, and how they are used to make sense of harm" (Presser and Sandberg, 2015, p. 1) and victimology which focuses on, among other questions, how people experience wrongdoing and the influence of victimization on the harmed person's life story (Hearty, 2021; Pemberton, Aarten, Mulder, 2018; Pemberton, Mulder, Aarten, 2018). An affective dimension to these questions urges an examination of how emotions are implicated in the kinds of narratives that are told, how they are configured, and how they are mobilized in different contexts, for different purposes.

Conceptualizing the affective narrative self also brings into conversation theories of affect, identity, and narrative to understand what emotions and narratives do in the project of the self, both in terms of how we come to know our personal identities and how others 'read' us. Alongside narrative scholars that have articulated the relationship between narrative and identity (Eakin, 2008; Ezzy, 1998; Holstein & Gubrium, 2000; Klepper, 2013; Lawler 2014; Meuter, 2013; Polkinghorne, 1988; Ricoeur, 1984/1985, 1991a, 1991b; 1992; Somers & Gibson, 1994; Venn, 2006, 2020; Williams, 1984) and affect and emotions scholars that consider the function of emotions in the formation/performance of the self (personal and/or social) (Ahmed, 2004; Burkitt, 2018; Hoschschild, 1983; Lupton, 1988; Wetherell, 2012), I have honed in on the connection between affect and narrative to situate people and their experiences within particular contexts. I have taken the articulations of affect advanced by cultural theorists who explore the work of affect in literary, political, national, and other narratives to understand how these wider narratives are mobilized and/or rejected by people as they negotiate and make sense of their experiences. In other words, I am pushing for a theory of affect that does not reify only the political machinations of affect but also how these impinge upon our everyday lives, or the psychosocial field, as we make judgements about ourselves and others and decisions about how to (re)act.

I also make an important methodological contribution to the sociological and cultural study of affects, feelings, and emotions by using thematic narrative analysis, interviews, and visual lifelines to observe, investigate, and elicit affects, feelings, and emotions. Aside from psychological and bio-neuroscientific methods which use brain imaging and experiments to understand our emotions, sociological and cultural studies have yet to form a comprehensive methodology around extracting "emotion data" (Flam & Kleres, 2015, p. 3). As such, this

dissertation provides a way of obtaining and engaging in an analysis of emotion data, most notably using the visual lifeline to provide a different mechanism of 'seeing' emotions through drawings, colours, and symbols.

My dissertation provides a unique understanding of the ways in which the politics of victimhood operates in the context of criminalizing HIV nondisclosure, and within the HIV/AIDS community more broadly, by exploring how PLWH configure their affective narrative selves throughout the eras of the epidemic. I showed how victimhood continues to be a contentious identity and subject position in the way that PLWH rarely use this language to describe their experiences without prompt. I provide an important distinction between 'victim' as a label, 'victimhood' as an identity, and 'victimization' as an event or something that is done to someone, which can inform further analyses of how someone can be victimized without taking on victimhood as a personal identity. I hope that this differentiation between concepts will complicate policymaker demands to consider the 'victim' in cases of HIV nondisclosure by showcasing the messiness inherent in how people understand victimizing events. Most importantly, I hope that it emphasizes to policymakers the need for thinking beyond the binary of victims and perpetrators and towards a more humane understanding of the decisions regarding disclosure and nondisclosure that people make and the everyday challenges that PLWH face as they navigate stigma and criminalization. As such, there is an urgent need to imagine ways of repairing both the interpersonal harm that nondisclosure represents for some and the systemic harm inflicted upon PLWH because of the law on nondisclosure, punitive public health policies, and HIV-related stigma. These mechanisms must shift us away from resorting to the law as the primary response to nondisclosure, what some people identify as, a victimizing event.

One such avenue, as I have suggested in a previous publication (Bogosavljević & Kilty, 2023), is transformative justice (TJ) which stands opposite the hostile environment that is created by the criminal legal system. This approach is rooted in the principles of penal abolition, Black Liberation, Indigenous justice, and queer/trans resistance. TJ offers a framework for addressing harm without perpetuating further harm. Unlike restorative justice (RJ), which focuses on returning to pre-existing conditions that often uphold violent structures, TJ emphasizes challenging and transforming the very structures that contribute to harm in the first place (Brown, 2020; Kim 2018; Smith 2010). These ideas are being taken up by a coalition of survivors of sexual assault, domestic violence, and human trafficking who are rejecting the use of the law, which they argue is dehumanizing and re-victimizing, instead advocating for TJ and RJ (see: Survivors 4 Justice Reform). They refuse to have their stories be used for justifying violence towards harm-doers and instead want to see policies implemented which allow the use of TJ and RJ in violent cases like sexual assault (Gallant, 2023). I contend that in this era, when there is a strong desire to move towards less punitive approaches to repairing harm, we need more than reforms to the law on HIV nondisclosure as the CCRHC has worked hard to accomplish, but for alternative justice processes that do not rely on the law.

Lastly, as the quote from the beginning of this section states, the dissertation, I hope, encourages a conversation about everyone's role in disclosure, which disrupts law's responsibilization of PLWH. Taking John's message seriously, I wish to impart in the reader a sense of agency in your everyday interactions, wherever possible, by questioning whether you are creating a space that is safe enough for people to disclose personal information, like being HIV positive. We do not need a law to force people to disclose personal information but rather, collectively, we must work to create the conditions in which violence, rejection, hatred, and

ostracization no longer characterize life with HIV thus making it possible for PLWH to disclose their status without fear.

# Chapter 9.

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# Appendix A.

# Interview Guide – HIV Positive Participants

<u>Introductions</u>

**Press Record:** Before we begin, I want to confirm that we have gone over the consent form? That you consent to participate in this aspect of the project? And that you consent to be video and audio recorded/ audio recorded/ that you don't consent to be recorded and that the researcher will take detailed notes instead?

I also want to let you know that at the end of the interview you will be asked if you want to participate in a creative activity and debrief session.

One last thing before we begin, I want to ask how you would like to be identified throughout the interview and in publications in terms of your pronouns, ethnicity or race, sexuality and class (rich, poor, lower middle-class, upper middle-class)?

<u>Open Invitation to Speak:</u>

Just to review the objectives of the project once more, we are interested in exploring the emotions and feelings about being diagnosed and living with HIV, about being or not being disclosed to, and about disclosing your status to sexual partners in the context of the criminalization of HIV nondisclosure in Canada. We are specifically interested in the identity or identities you make take up in response to these events. These identities can include being a victim, survivor, or something else that you have identified based on your own experiences. Perhaps you don't see your diagnosis as creating an identity, but rather as having led you to have certain feelings, which we would like you to describe.

I would like to start by having you tell me your HIV story. You can start from wherever you want. This is your opportunity to speak.

*Prompt:* I want you to think about your life before your diagnosis, when you were diagnosed, and living with HIV including your experiences with disclosure.

<u>Life before HIV</u>

Since I am trying to understand your HIV story, I would like you to tell me about your life before you were diagnosed with HIV.

*Prompts*

1. How did you spend your time?
2. What were your future plans and goals?
3. How did you feel about disclosure of HIV prior to being diagnosed?
4. Have you ever faced any challenges in your social or emotional life before your diagnosis?
    a. What kinds of difficulties/challenges were these? (e.g. gender-based discrimination, racism, exclusion from services, housing, or employment)
    b. How did these feel?

<u>Diagnosis</u>

I would like to talk more specifically about the time you were diagnosed with HIV.

1. When were you diagnosed?
2. Where were you?
3. What did the space look and smell like?
4. What did the space feel like?
5. How did you find out?

6. How did you feel when you were diagnosed?
7. What kinds of bodily reactions did you have when you found out?
    a. Did you cry? Did your stomach hurt? Did you shake?

Living with HIV/AIDS and Disclosure

1. How did your diagnosis impact your life?
    a. Did you tell people your status?
        i. If so, who did you tell?
            1. How did that feel?
            2. How did they react?
            3. How did their reaction make you feel?
    b. How did your diagnosis impact your relationships – sexual, family, and friends?
    c. How was your mental health impacted?
    d. How has your diagnosis impacted or not your future plans and goals?
    e. How has HIV stigma impacted your life?
        i. How does HIV stigma make you feel?
2. How does living with HIV make you feel today?
    a. Did you go through any bodily changes and if so how do you feel about these changes?
    b. How do you feel about your treatment plan?
3. How has your experience been with the medical community?
    a. Please describe a positive and a negative experience.

As you probably are aware, Canada criminalizes people living with HIV for not disclosing their status to their sexual partners unless they wear a condom *and* have a low viral load. So, for this part of the interview, I would like to focus on disclosure and criminalization.

1. How do you feel about having to disclose your status to sexual partners?
    a. Did this feeling change after you were diagnosed? If so, how?
    b. Have you ever disclosed to a partner?
        i. If you did, how did they react to your disclosure?
            1. In terms of their body language, their facial expression, the volume of their voice, and any other markers of emotion?
        ii. How did you respond to their reaction?
            1. In terms of your own bodily reactions including your body language, facial expression, the volume of your voice?
    c. If you have a method of documenting that you disclosed, how do you do this?
2. How does the criminalization of HIV nondisclosure make you feel?
    a. How has criminalization impacted your life and relationships?
3. Did your partner disclose to you?
    - o If they did, how did that moment feel?
        - ▪ Where were you?
        - ▪ What kind of bodily reactions did you have?
    - o If they didn't, how did you feel when you found out that your partner did not disclose to you?
        - ▪ Where were you when you found out?
        - ▪ What bodily reactions did you have when you found out?
        - ▪ What did you do?
            - Did you go to the police?

        - If you did, how did the police treat you?
      - Did you feel like a victim?
4. What did staff at any organizations or doctors you went to for support tell you about disclosure and the law?
   a. What organizations did you go to?
   b. Did they provide you with written information about the law and your responsibilities?

<u>Concluding Questions</u>

1. Is there anything that I didn't discuss or address that you feel should be addressed or is there anything that you want to ask me about?
2. If you know someone else who you think would like to participate, please pass along my contact information.
3. If you feel that you have something else to add or would like to change your mind about being part of the study, please feel free to contact me.
4. Lastly, I will leave you with this list of phone numbers for people and organizations you can contact if this interview has brought up any sensitive issues that you are feeling distressed about.

<u>Lifeline Activity</u>

Would you like to participate in this aspect of the project? ____ Yes ______No

If so, when would it be an appropriate time to meet for a debriefing session?

I am going to email you the consent form and lifeline instruction sheet. What is the best email address to send this information to you (*if no contact through email*)?
If after reading the consent form and instructions you no longer wish to participate in this aspect of the project please email me at [email address] or call me at [phone number].
*<u>If participant asks for more information about the lifeline say this:</u>*

*As part of this research project, we are going to use lifelines as a visual depiction and extension of the interview to explore your HIV story. You are going to be provided with detailed instructions on how to draw your lifeline but as an introduction I am going to briefly go over the activity right now. Once I have explained the activity you can let me know if you would like to participate in the second part of this project.*

*Very briefly, if you agree to participate in this aspect of the project, you are going to draw a lifeline about your HIV story. You can use whatever materials you wish (crayons, felt pens, magazine cut outs, etc) or computer/tablet software. The aim of this activity is to draw significant events related to your HIV story onto a traveling line – this "line" doesn't have to be straight and doesn't have to be a line at all if that is how you wish to represent your HIV story.*

*Each event or milestone should be labelled as a picture, image, symbol, or sign – you should avoid long sentences if possible. You are however free to write down words if you believe they add meaning. Feel free to use clippings from magazines or to copy and paste images from the internet if you choose to draw your lifeline on the computer. Your drawing can be as extensive or as minimalistic as you wish.*

*You are also going to draw a legend that provides the person viewing your lifeline with more details as well as a short paragraph that discusses your lifeline and what it means to you. We will then discuss your lifeline and your experiences drawing it at a debriefing session.*

*This is meant to be a fun, creative and possibly therapeutic activity. As such, you do not need to be afraid of doing this 'artistic' work. I am here to help in any way you need. The most important thing is that you enjoy the process!*
Thanks again for talking with me.

# Appendix B.

# Interview Guide – HIV Negative Participants

Introductions

**Press Record:** Before we begin, I want to confirm that we have gone over the consent form? That you consent to participate in this aspect of the project? And that you consent to be video and audio recorded/ audio recorded/ that you don't consent to be recorded and that the researcher will take detailed notes instead?

I also want to let you know that at the end of the interview you will be asked if you want to participate in a creative activity and debrief session.

One last thing before we begin, I want to ask how you would like to be identified throughout the interview and in publications in terms of your pronouns, ethnicity or race, sexuality and class (rich, poor, lower middle-class, upper middle-class)?

Open Invitation to Speak:

Just to review the objectives of the project once more, we are interested in exploring the emotions and feelings related to your experiences of a sexual partner not disclosing their HIV positive status to you before engaging in sex. We are specifically interested in the identity or identities you might have taken up in response to this event. These identities can include being a victim, survivor, or something else that you have identified based on your own experiences. Perhaps you don't see your experience as creating an identity, but rather as having led you to have certain feelings, which we would like you to describe.

I would like to start by having you tell me your nondisclosure story. You can start from wherever you want. This is your opportunity to speak.

*Prompt:* I want you to think about your life before the nondisclosure event, the nondisclosure event itself and your life after the event.

Life before experiencing nondisclosure

Since I am trying to understand your nondisclosure story, I would like you to tell me about your life before you experienced this event.

*Prompts*

5. Where did you live?
6. What did you do for work?
7. How did you spend your time?
8. What were your future plans and goals?
9. How did you feel about disclosure of HIV prior to your experience of nondisclosure?
10. Have you ever faced any challenges in your social or emotional life before this experience?
    a. What kinds of difficulties/challenges were these? (e.g. gender-based discrimination, racism, exclusion from services, housing, or employment)
    b. How did these feel?

Finding out your partner did not disclose their HIV positive status

I would like to talk more specifically about the time when you found out that your partner didn't disclose.

1. What did you do when you found out?
    a. Did you go to the police?
        i. If so, what happened?

            1. How did they treat you?
            2. How did you feel in the police station? What did it smell and look like?
        ii. If you didn't, why did you choose not to go to the police?
    b. Did you go to the hospital, a community clinic, or your general practitioner?
        i. If so, what happened?
        ii. How did it feel to go to the hospital or your general practitioner?
2. Where were you when you found out?
    a. What did the space look and smell like?
    b. What did the space feel like?
3. How did you find out?
    a. How did you feel when you found out?
    b. Did you or do you still feel like a victim when you found out?
    c. What kinds of bodily reactions did you have when you found out?
        i. Did you cry? Did your stomach hurt? Did you shake?
4. How did this news impact your life?
    a. Did you tell someone that this happened?
        i. If so, who did you tell?
            1. How did that feel?
            2. How did they react?
            3. How did their reaction make you feel?
    b. How was your mental health impacted?
    c. How has this experience impacted or not your future plans and goals?
    d. How did or didn't this experience impact your relationships – sexual, family, and friends?

For this part of the interview, I would like to focus on your feelings about disclosure and nondisclosure and the law.

1. How do you feel about criminalizing HIV nondisclosure?
2. How do you feel about nondisclosure now?
3. What did staff at any organizations (police, hospitals, your GP) you went to for support tell you about disclosure and the law?
    a. What organizations did you go to?
    b. Did they provide you with written information about the law and your rights?

Concluding and Demographic Questions

1. How do you identify in terms of:
    a. Gender
    b. Nationality
    c. Sexuality
    d. Age
2. Is there anything that I didn't discuss or address that you feel should be addressed or is there anything that you want to ask me about?
3. If you know someone else who you think would like to participate, please pass along my contact information.
4. If you feel that you have something else to add or would like to change your mind about being part of the study, please feel free to contact me.

5. Lastly, I will leave you with this list of phone numbers for people and organizations you can contact if this interview has brought up any sensitive issues that you are feeling distressed about.

Lifeline Activity

Would you like to participate in this aspect of the project? ____ Yes _____No

If so, when would it be an appropriate time to meet for a debriefing session?

I am going to email you the consent form and lifeline instruction sheet. What is the best email address to send this information to you (*if no contact through email originally*)?

If after reading the consent form and instructions you no longer wish to participate in this aspect of the project please email me at [email address] or call me at [phone number].
*If participant asks for more information about the lifeline say this:*

*As part of this research project, we are going to use lifelines as a visual depiction and extension of the interview to explore your nondisclosure story. You are going to be provided with detailed instructions on how to draw your lifeline but as an introduction I am going to briefly go over the activity right now. Once I have explained the activity you can let me know if you would like to participate in the second part of this project.*

*Very briefly, if you agree to participate in this aspect of the project, you are going to draw a lifeline about your nondisclosure story. You can use whatever materials you wish (crayons, felt pens, magazine cut outs, etc) or computer/tablet software. The aim of this activity is to draw significant events related to your nondisclosure story onto a traveling line – this "line" doesn't have to be straight and doesn't have to be a line at all if that is how you wish to represent your nondisclosure story.*

*Each event or milestone should be labelled as a picture, image, symbol, or sign – you should avoid long sentences if possible. You are however free to write down words if you believe they add meaning. Feel free to use clippings from magazines or to copy and paste images from the internet if you choose to draw your lifeline on the computer. Your drawing can be as extensive or as minimalistic as you wish.*

*You are also going to draw a legend that provides the person viewing your lifeline with more details as well as a short paragraph that discusses your lifeline and what it means to you. We will then discuss your lifeline and your experiences drawing it at a debriefing session.*

*This is meant to be a fun, creative and possibly therapeutic activity. As such, you do not need to be afraid of doing this 'artistic' work. I am here to help in any way you need. The most important thing is that you enjoy the process!*

# Appendix C.

# Debrief Guide – HIV Positive Participants

Oral Consent Form

Hello ____! Thank you for drawing your lifeline and agreeing to speak with me again. I hope you had fun drawing the lifeline!

We are first going to start with the oral consent form for this session. *(Review form and obtain oral consent)*

**Press Record:** I just want to confirm that we have gone over the consent form?

That you consent to participate in this aspect of the project?

That you consent to be video and audio recorded/ audio recorded/ that you don't consent to be recorded and that the researcher will take detailed notes instead?

And that you consent to taking a screenshot of your lifeline for research and teaching purposes and emailing it to the researcher?

Okay perfect! Now that the administrative component is finished let's begin.

Debrief Session

I would like you to take a few minutes to look at your lifeline and think about what it means overall.

*Prompts:*

1. What does the way you drew your line symbolize?
2. Why did you choose these symbols? What do they represent?
3. What do the colours represent?
    a. Why did you choose one colour?
4. How did you feel when you were drawing your lifeline?
    a. What thoughts came to mind?
    b. What bodily reactions did you have?
        i. Did you cry? Did you shake? Did your stomach hurt?
5. Looking at your lifeline, how would you summarize your story?

Concluding Questions

1. Is there anything that I didn't discuss or address that you feel should be addressed or is there anything that you want to ask me about?
2. If you feel that you have something else to add or would like to change your mind about being part of the study, please feel free to contact me.
3. Lastly, if you still have the contact form from the last time we spoke, please refer back to it if you feel this debrief session has brought up any sensitive issues that you are feeling distressed about. If you don't have it, please let me know and I can email it to you again.

# Appendix D.

## Debrief Guide – HIV Negative Participants

Hello ____! Thank you for drawing your lifeline and agreeing to speak with me again. I hope you had fun drawing the lifeline!
We are first going to start with the oral consent form for this session. *(Review form and obtain oral consent)*
**Press Record:** I just want to confirm that we have gone over the consent form?
That you consent to participate in this aspect of the project?
That you consent to be video and audio recorded/ audio recorded/ that you don't consent to be recorded and that the researcher will take detailed notes instead?
And that you consent to taking a screenshot of your lifeline for research and teaching purposes and emailing it to the researcher?
Okay perfect! Now that the administrative component is finished let's begin.

<u>Debrief Session</u>

Tell me about your drawing.

*Prompts:*

1. What does the way you drew your line symbolize?
2. Why did you choose these symbols? What do they represent?
3. How did you feel when you were drawing your lifeline?
    a. What thoughts came to mind?
    b. What bodily reactions did you have?
        i. Did you cry? Did you shake? Did your stomach hurt?

<u>Concluding Questions</u>

1. Is there anything that I didn't discuss or address that you feel should be addressed or is there anything that you want to ask me about?
2. If you feel that you have something else to add or would like to change your mind about being part of the study, please feel free to contact me.
3. Lastly, if you still have the contact form from the last time we spoke, please refer back to it if you feel this debrief session has brought up any sensitive issues that you are feeling distressed about. If you don't have it, please let me know and I can email it to you again.

# Appendix E.

# Oral Consent Form Interview – HIV Positive Participants

Université d'Ottawa | University of Ottawa

**Oral Consent Form – Interviews (HIV Positive Participants)**

**Title of the study:** The Emotional and Felt Experience of HIV Nondisclosure

**Principal Researcher**: Katarina Bogosavljevic | Doctoral Candidate | Department of Criminology | University of Ottawa |

**Doctoral Supervisor:** Dr. Jennifer M. Kilty, PhD. | Full Professor & Chair | Department of Criminology | University of Ottawa | 120 University Private | Ottawa, ON | K1N 6N5|

**Invitation to Participate:** I am invited to participate in the abovementioned research study conducted by Katarina Bogosavljevic under the supervision of Dr. Jennifer M. Kilty. This project is funded by the Social Sciences and Humanities Research Council.

**Purpose of the Study:** The purpose of the study is to examine how people living with HIV/AIDS feel about experiencing HIV nondisclosure in order to better understand the criminalization of HIV nondisclosure in Canada. Specifically, the researchers are interested in feelings about being diagnosed and living with HIV, feelings related to experiences of a partner not disclosing their HIV status prior to either consensual or non-consensual intercourse, and feelings about nondisclosure and disclosure generally. The researchers aim to understand the identities that people may take up in response to these events and the role of emotions and feelings in shaping these identities.

**Description of Participation:** My participation in this project will include one interview, approximately one hour in length, during which I will be required to respond to questions asked by the researcher. Some questions are structured in nature while others are open-ended so as to encourage me to speak openly about my experiences. The interviews will be scheduled at a time, place, and date most convenient for both me and the researcher. Due to the COVID-19 pandemic, interviews will be conducted over Zoom or by telephone and will be audio and video recorded if on Zoom and audio-recorded if by telephone. I will also be asked whether I want to participate in a creative activity and debrief session that will occur at a later date.

**Risks:** My participation in this study will entail that I volunteer personal information that may bring up memories or moments that feel difficult to recount and may bring about some discomfort or distress. I will never be forced to answer any questions that I do not feel comfortable answering and I may withdraw from the study at any time. I have received assurance from the researcher that every effort will be made to minimize the risks of emotional or psychological discomfort. At the end of the interview I will be provided with a list of names and

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contact phone numbers at local AIDS Service Organizations who I can contact should I continue to feel any distress following the interview.

**Benefits:** My participation in this study will contribute to ongoing efforts by HIV/AIDS activists, organizations, people living with HIV/AIDS, and scholars to study the criminalization of HIV nondisclosure in Canada. My participation in this study will also contribute to an area of knowledge in the field of criminology that has not yet been explored. This is the first known study to explore the role of emotions in structuring identity in the context of HIV criminalization. The hope is to make both an academic and policy contribution.

**Confidentiality and anonymity:** I have received assurance from the researcher that the information I will share will remain strictly confidential and that I, as a participant, will be completely anonymous. I understand that the contents of the interview will be used only for research and publication purposes and that all identifying names or features (including names of cities, dates, specifics of your HIV story etc) will be removed or modified from the transcripts and publications in order to protect confidentiality. The researchers will protect anonymity by allowing participants to choose a pseudonym. Pseudonyms will be used in any publication and in the writing of the dissertation to protect my identity.

For interviews conducted over Zoom, every interview will have a different meeting ID/link and password and will use all security measures available on the platform such as using a waiting room where the host (researcher) has to approve entry and the researcher will lock each meeting so no one else can join. In order to minimize the risk of security breaches and to help ensure my confidentiality, the researchers recommend that I use standard safety measures such as using a secure connection and to not share the meeting ID and password with anyone else. For privacy and confidentiality purposes, I am encouraged to conduct the online interview in a space that is private to limit the chances of being overheard.

**Conservation of data:** The data collected, including the digitally recorded audio and video files, transcripts of the interviews, and notes taken will be kept in a secure manner. Hard copies of transcripts and notes will be stored in a locked box in the researchers home office, audio and video recordings will be stored on a password protected USB key in the researcher's locked box, and all other electronic files including the audio and video recordings will be stored in a password protected folder that is in a separate password protected user account on the researcher's personal computer. This user account is disconnected from any cloud services. Audio and video recordings will be deleted as soon as transcription is complete, and all other data will be stored for a period of five years following the defence and then will be destroyed using secure deletion protocols.

**Compensation:** I will be given a $40 honorarium for generously contributing my time to this research project. I will still be given this $40 even if I decide to withdraw from the study at a later date. The honorarium will be offered via e-

transfer to my personal banking account or through Western Union where I will be able to pick up cash.

**Voluntary Participation**: I understand that I am under no obligation to participate. If I choose to participate, I can terminate the interview at any time, withdraw from the study at any time and/or refuse to answer any questions that I do not feel comfortable answering without suffering any negative consequences. If I choose to withdraw, all data gathered until the time of withdrawal will be securely deleted from the recording device and destroyed. The destroyed data will not be used in the study. If by participating in this interview, I feel that my memories or emotions are hard to handle, I can contact one of the staff at AIDS Service Organizations that the researcher has provided me with.

**REB Contact Information:** If I have any questions regarding the ethical conduct of this study, I may contact the Protocol Officer for Ethics in Research, University of Ottawa, Tabaret Hall, 550 Cumberland Street, Room 154, Ottawa, ON K1N 6N5, Tel.: (613) 562-5387, Email: ethics@uottawa.ca

**Consent to participate:** I agree that in consenting to participate in this project I do not give up any rights. I have been informed about the different requirements of the research and that I agree to take part in the interview portion of the research project. The reason I am not providing my signature and that I am providing oral consent is to protect my anonymity and maintain confidentiality in the research. I agree to participate in the above research study conducted by Katarina Bogosavljevic, a PhD Candidate in the Department of Criminology, University of Ottawa, whose research is under the supervision of Dr. Jennifer Kilty.

___ Yes  ___ No  ____________ Signature of Researcher  ______ Date

With my permission only, this interview will be audio and video recorded using the record feature on Zoom or by a digital recording device if interview done over the phone. Only the researcher will have access to the recording. If I do not wish to be video recorded, the researcher may audio record the conversation and if I do not wish to be audio or video recorded the researcher will take detailed notes.

I agree to the audio recording of this interview:

___ Yes  ___ No

I agree to the video recording of this interview:

___ Yes  ___ No

If I have any questions about the study, I may ask them now and/or contact the researcher or her supervisor using the contact information given. Participants should save or print a copy of this consent form for their personal records.

# Appendix F.

# Oral Consent Form Interview – HIV Negative Participants

Université d'Ottawa | University of Ottawa

**Oral Consent Form – Interviews (HIV Negative Participants)**

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Canada

**Title of the study:** The Emotional and Felt Experience of HIV Nondisclosure

**Principal Researcher**: Katarina Bogosavljevic | Doctoral Candidate | Department of Criminology | University of Ottawa |

**Doctoral Supervisor:** Dr. Jennifer M. Kilty, PhD. | Full Professor & Chair | Department of Criminology | University of Ottawa | 120 University Private | Ottawa, ON | K1N 6N5|

**Invitation to Participate:** I am invited to participate in the abovementioned research study conducted by Katarina Bogosavljevic under the supervision of Dr. Jennifer M. Kilty. This project is funded by the Social Sciences and Humanities Research Council.

**Purpose of the Study:** The purpose of the study is to examine how people who are HIV negative feel about experiencing HIV nondisclosure in order to better understand the criminalization of HIV nondisclosure in Canada. Specifically, the researchers are interested in feelings related to experiences of a partner not disclosing their HIV status prior to either consensual or non-consensual intercourse, and feelings about nondisclosure and disclosure generally including the law. The researchers aim to understand how people respond to HIV nondisclosure including the identities they may take up and the role of emotions and feelings in shaping these identities, and the actions they take in response to nondisclosure including going or not going to the police.

**Description of Participation:** My participation in this project will include one interview, approximately one hour in length, during which I will be required to respond to questions asked by the researcher. Some questions are structured in nature while others are open-ended so as to encourage me to speak openly about my experiences. The interviews will be scheduled at a time, place, and date most convenient for both me and the researcher. Due to the COVID-19 pandemic, interviews will be conducted over Zoom or by telephone and will be audio and video recorded if on Zoom and audio-recorded if by telephone. I will also be asked whether I want to participate in a creative activity and debrief session that will occur at a later date.

**Risks:** My participation in this study will entail that I volunteer personal information that may bring up memories or moments that feel difficult to recount and may bring about some discomfort or distress. I will never be forced to answer any questions that I do not feel comfortable answering and I may withdraw from the study at any time. I have received assurance from the researcher that every effort will be made to minimize the risks of emotional or psychological discomfort. At the end of the interview I will be provided with a list contact phone

numbers at local crisis centres that I can contact should I continue to feel any distress following the interview.

**Benefits:** My participation in this study will contribute to ongoing efforts by HIV/AIDS activists, organizations, people living with HIV/AIDS, and scholars to study the criminalization of HIV nondisclosure in Canada. My participation in this study will also contribute to an area of knowledge in the field of criminology that has not yet been explored. This is the first known study to explore the role of emotions in structuring identity in the context of HIV criminalization. The hope is to make both an academic and policy contribution.

**Confidentiality and anonymity:** I have received assurance from the researcher that the information I will share will remain strictly confidential and that I, as a participant, will be completely anonymous. I understand that the contents of the interview will be used only for research and publication purposes and that all identifying names or features (including names of cities, dates, specifics of your nondisclosure story etc) will be removed or modified from the transcripts and publications in order to protect confidentiality. The researchers will protect anonymity by allowing participants to choose a pseudonym. Pseudonyms will be used in any publication and in the writing of the dissertation to protect my identity.

For interviews conducted over Zoom, every interview will have a different meeting ID/link and password and will use all security measures available on the platform such as using a waiting room where the host (researcher) has to approve entry and the researcher will lock each meeting so no one else can join. In order to minimize the risk of security breaches and to help ensure my confidentiality, the researchers recommend that I use standard safety measures such as using a secure connection and to not share the meeting ID and password with anyone else. For privacy and confidentiality purposes, I am encouraged to conduct the online interview in a space that is private, to limit the chances of being overheard.

**Conservation of data:** The data collected, including the digitally recorded audio and video files, transcripts of the interviews, and notes taken will be kept in a secure manner. Hard copies of transcripts and notes will be stored in a locked box in the researchers home office, audio and video recordings will be stored on a password protected USB key in the researcher's locked box, and all other electronic files including the audio and video recordings will be stored in a password protected folder that is in a separate password protected user account on the researcher's personal computer. This user account is disconnected from any cloud services. Audio and video recordings will be deleted as soon as transcription is complete, and all other data will be stored for a period of five years following the defence and then will be destroyed using secure deletion protocols.

**Compensation:** I will be given a $40 honorarium for generously contributing my time to this research project. I will still be given this $40 even if I decide to withdraw from the study at a later date. Compensation will be offered via e-

transfer to my personal banking account or through Western Union where I will be able to pick up cash.

**Voluntary Participation**: I understand that I am under no obligation to participate. If I choose to participate, I can terminate the interview at any time, withdraw from the study at any time and/or refuse to answer any questions that I do not feel comfortable answering without suffering any negative consequences. If I choose to withdraw, all data gathered until the time of withdrawal will be securely deleted from the recording device and destroyed. The destroyed data will not be used in the study. If by participating in this interview, I feel that my memories or emotions are hard to handle, I can contact one of the counsellors from the list provided to me by the researcher.

**REB Contact Information:** If I have any questions regarding the ethical conduct of this study, I may contact the Protocol Officer for Ethics in Research, University of Ottawa, Tabaret Hall, 550 Cumberland Street, Room 154, Ottawa, ON K1N 6N5, Tel.: (613) 562-5387, Email: ethics@uottawa.ca

**Consent to participate:** I agree that in consenting to participate in this project I do not give up any rights. I have been informed about the different requirements of the research and that I agree to take part in the interview. The reason I am not providing my signature and that I am providing oral consent is to protect my anonymity and maintain confidentiality in the research. I agree to participate in the above research study conducted by Katarina Bogosavljevic, a PhD Candidate in the Department of Criminology, University of Ottawa, whose research is under the supervision of Dr. Jennifer Kilty.

___ Yes ___ No ________________ Signature of Researcher ________ Date

With my permission only, this interview will be audio and/or video recorded using the recording feature on Zoom or by using a digital recording device if interview done over the phone. Only the researcher will have access to the recordings. If I do not wish to be video recorded, the researcher may audio record the conversation and if I do not wish to be audio or video recorded the researcher will take detailed notes.

I agree to the audio recording of this interview:

___ Yes ___ No

I agree to the video recording of this interview:

___ Yes ___ No

If I have any questions about the study, I may ask them now and/or contact the researcher or her supervisor using the contact information given. Participants should save or print a copy of this consent form for their personal records.

# Appendix G.

# Oral Consent Form Debrief and Lifeline Activity– HIV Positive Participants

Université d'Ottawa | University of Ottawa

**Oral Consent Form – Lifeline Activity and Debrief Session – HIV Positive Participants**

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Canada

**Title of the study:** The Emotional and Felt Experience of HIV Nondisclosure

**Principal Researcher**: Katarina Bogosavljevic | Doctoral Candidate | Department of Criminology | University of Ottawa |

**Doctoral Supervisor:** Dr. Jennifer M. Kilty, PhD. | Full Professor & Chair | Department of Criminology | University of Ottawa | 120 University Private | Ottawa, ON | K1N 6N5|

**Invitation to Participate:** I am invited to participate in the abovementioned research study conducted by Katarina Bogosavljevic under the supervision of Dr. Jennifer M. Kilty. This project is funded by the Social Sciences and Humanities Research Council.

**Purpose of the Study:** The purpose of the study is to examine how people living with HIV/AIDS feel about experiencing HIV nondisclosure in order to better understand the criminalization of HIV nondisclosure in Canada. Specifically, the researchers are interested in feelings about being diagnosed and living with HIV, feelings related to experiences of a partner not disclosing their HIV status prior to consensual intercourse, and feelings about nondisclosure and disclosure generally. The researchers aim to understand the identities that people may take up in response to these events and the role of emotions and feelings in shaping these identities.

**Description of Participation:** My participation in this part of the project will include drawing a lifeline either by hand or using computer software I have available to me, in my own time, followed by a debrief session that is scheduled at a time and date most convenient to me. The creative part and debrief session will last approximately one hour and one hour in length respectively.

I am required to draw a lifeline or a visual depiction of my life events as they relate to my HIV diagnosis and the context within which I became HIV positive. Once I have completed my drawing, I will send the researcher my lifeline either by taking a screenshot or picture of my lifeline and emailing it to her or by mailing a physical copy of my lifeline by self-addressed and stamped return envelope that the researcher will mail me. I give permission for the researcher to exhibit and publish my anonymized lifeline in her dissertation, in conference presentations and in publications.

I also consent to participate in a debriefing session. During the session, I will be asked to describe my lifeline and the feelings and emotions I had while drawing my lifeline. I consent to the audio and video recording of the debrief session for transcription purposes.

**Risks:** My participation in this study will entail that I volunteer personal information that may bring up memories or moments that feel difficult to recount and may bring about some discomfort or distress. I will never be forced to answer any questions that I do not feel comfortable answering and I may withdraw from the study at any time. I have received assurance from the researcher that every effort will be made to minimize the risks of emotional or psychological discomfort. At the end of the debrief session I will be provided with a list of names and contact phone numbers at local AIDS Service Organizations who I can contact should I continue to feel any distress following the creative activity and debrief session.

**Benefits:** My participation in this study will contribute to ongoing efforts by HIV/AIDS activists, organizations, people living with HIV/AIDS, and scholars to study the criminalization of HIV nondisclosure in Canada. My participation in this study will also contribute to an area of knowledge in the field of criminology that has not yet been explored. This is the first known study to explore the role of emotions in structuring identity in the context of HIV criminalization. The hope is to make both an academic and policy contribution.

**Confidentiality and anonymity:** I have received assurance from the researcher that the information I will share will remain strictly confidential and that I, as a participant, will be completely anonymous. I understand that the contents of the debriefing session and lifeline will be used only for research and publication purposes and that all identifying names or features (including names of cities, dates, specifics of your HIV story etc) will be removed or modified from the transcripts and publications in order to protect confidentiality. I understand that the anonymized lifeline might be published in another form (e.g. a publication, a report, website, or in print or electronic format). I also understand that the lifeline might be used for educational/ teaching purposes, presentations, and secondary analysis after the study is complete. The researchers will protect anonymity by allowing participants to choose a pseudonym. Pseudonyms will be used in any publication and in the writing of the dissertation to protect my identity. I understand that I should avoid putting any identifying information on the lifeline.

Given that debriefing sessions will be held via Zoom, every session will have a different meeting ID/link and password and will use all security measures available on the platform such as using a waiting room where the host (researcher) has to approve entry and the researcher will lock each meeting so no one else can join. In order to minimize the risk of security breaches and to help ensure my confidentiality, the researchers recommend that I use standard safety measures such as using a secure connection and to not share the meeting ID, link and password with anyone else. For privacy and confidentiality purposes, I am encouraged to conduct the online debriefing session in a space that is private to limit the chances of being overheard.

**Conservation of data:** The lifelines will be kept in a secure manner. Hard copies of the lifelines will be stored in a large art portfolio in the researcher's locked home office and electronic copies of lifelines including screenshots and photos taken by me will be stored in a password protected folder that is in a separate password protected user account on the researcher's personal computer. This user account is disconnected from any cloud services. The lifelines (both electronic and hard copies) will be stored for a period of five years following the defence and then will be destroyed using secure deletion protocols.

The data collected, including the digitally recorded audio and video files and transcripts of the debriefing session will be kept in a secure manner. Hard copies of the transcripts and notes will be stored in a locked box in the researchers home office and audio and video recordings will be stored on a password protected USB key in the researcher's locked box. All other electronic files will be stored in a password protected folder that is in a separate password protected user account on the researcher's personal computer. This user account is disconnected from any cloud services. Audio and video recordings will be deleted as soon as transcription is complete and all other data will be stored for a period of five years following the defence and then will be destroyed using secure deletion protocols.

**Compensation:** I will be given a $40 honorarium for generously contributing my time to the creative lifeline activity and $40 for participating in the debriefing session. I will still be given this $40 even if I decide to withdraw from the creative activity and/or debrief session at a later time. Compensation will be offered via e-transfer to my personal banking account or through Western Union where I will be able to pick up cash.

**Voluntary Participation**: I understand that I am under no obligation to participate. If I choose to participate, I can withdraw from the study at any time and/or refuse to answer any questions that I do not feel comfortable answering without suffering any negative consequences. If I choose to withdraw, all data gathered until the time of withdrawal will be securely deleted from the recording device and destroyed. The destroyed data will not be used in the study. If I choose to withdraw from one or two aspects of the project, the data collected from the task(s) I did not withdraw from can and will still be used in the researcher's dissertation, publications, and conference presentations.

If by participating in this debriefing session, I feel that my memories or emotions are hard to handle, I can contact one of the staff at AIDS Service Organizations that the researcher has provided me with.

**REB Contact Information:** If I have any questions regarding the ethical conduct of this study, I may contact the Protocol Officer for Ethics in Research, University of Ottawa, Tabaret Hall, 550 Cumberland Street, Room 154, Ottawa, ON K1N 6N5
Tel.: (613) 562-5387
Email: ethics@uottawa.ca

**Consent to participate:** I agree that in consenting to participate in this project I do not give up any rights. I have been informed about the different requirements of the research and I agree to take part in the debriefing session. The reason I am not providing my signature and that I am providing oral consent is to protect my anonymity and maintain confidentiality in the research. I agree to participate in the above research study conducted by Katarina Bogosavljevic, a PhD Candidate in the Department of Criminology, University of Ottawa, whose research is under the supervision of Dr. Jennifer Kilty.

Yes No Signature of Researcher Date

With my permission only, photos or screenshots of my lifeline will be taken by me, to be shared for research and teaching purposes including in presentations and publications. I agree to take a photo or screenshot of my lifeline and email it to the researcher or to mail a physical copy of my lifeline to the researcher:

Yes No

With my permission only, the debrief session will be audio and/or video recorded using the recording feature on Zoom or by using a digital recording device if debrief session is held over the phone. Only the researcher will have access to the recordings. If I do not wish to be video recorded, the researcher may audio record the conversation and if I do not wish to be audio or video recorded the researcher will take detailed notes.

I agree to the audio recording of this debrief session:

Yes No

I agree to the video recording of this debrief session:

Yes No

If I have any questions about the study, I may ask them now and/or contact the researcher or her supervisor using the contact information given.

You should save or print a copy of this consent form for your personal records.

# Appendix H.

# Oral Consent Form Debrief and Lifeline Activity – HIV Negative Participants

Université d'Ottawa | University of Ottawa

**Oral Consent Form – Lifeline Activity and Debrief Session – HIV Negative Participants**

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Ottawa ON K1N 6N5
Canada

**Title of the study:** The Emotional and Felt Experience of HIV Nondisclosure

**Principal Researcher**: Katarina Bogosavljevic | Doctoral Candidate | Department of Criminology | University of Ottawa |

**Doctoral Supervisor:** Dr. Jennifer M. Kilty, PhD. | Full Professor & Chair | Department of Criminology | University of Ottawa | 120 University Private | Ottawa, ON | K1N 6N5|

**Invitation to Participate:** I am invited to participate in the abovementioned research study conducted by Katarina Bogosavljevic under the supervision of Dr. Jennifer M. Kilty. This project is funded by the Social Sciences and Humanities Research Council.

**Purpose of the Study:** The purpose of the study is to examine how people who are HIV negative feel about experiencing HIV nondisclosure in order to better understand the criminalization of HIV nondisclosure in Canada. Specifically, the researchers are interested in feelings related to experiences of a partner not disclosing their HIV status prior to either consensual or non-consensual intercourse, and feelings about nondisclosure and disclosure generally including the law. The researchers aim to understand how people respond to HIV nondisclosure including the identities they may take up and the role of emotions and feelings in shaping these identities, and the actions they take in response to nondisclosure including going or not going to the police.

**Description of Participation:** My participation in this part of the project will include drawing a lifeline either by hand or using computer software I have available to me, in my own time, followed by a debrief session that is scheduled at a time and date most convenient to me. The creative part and debrief session will last approximately one hour and one hour in length respectively.

For the creative activity, I am required to draw a lifeline or a visual depiction of my nondisclosure story and how it has or hasn't affected me and my sense of self. Once I have completed my drawing, I will send the researcher my lifeline either by taking a screenshot or picture of my lifeline and emailing it to her or by mailing a physical copy of my lifeline by self-addressed and stamped return envelope that the researcher will mail me. I give permission for the researcher to exhibit and publish my anonymized lifeline in her dissertation, in conference presentations and in publications.

I also consent to participate in a debriefing session. During the session, I will be asked to describe my lifeline and the feelings and emotions I had while drawing

my lifeline. I consent to the audio and video recording of the debrief session for transcription purposes.

**Risks:** My participation in this study will entail that I volunteer personal information that may bring up memories or moments that feel difficult to recount and may bring about some discomfort or distress. I will never be forced to answer any questions that I do not feel comfortable answering and I may withdraw from the study at any time. I have received assurance from the researcher that every effort will be made to minimize the risks of emotional or psychological discomfort. At the end of the debrief session I will be provided with a list of contact phone numbers at local crisis centres that I can contact should I continue to feel any distress following the creative activity and debrief session.

**Benefits:** My participation in this study will contribute to ongoing efforts by HIV/AIDS activists, organizations, people living with HIV/AIDS, and scholars to study the criminalization of HIV nondisclosure in Canada. My participation in this study will also contribute to an area of knowledge in the field of criminology that has not yet been explored. This is the first known study to explore the role of emotions in structuring identity in the context of HIV criminalization. The hope is to make both an academic and policy contribution.

**Confidentiality and anonymity:** I have received assurance from the researcher that the information I will share will remain strictly confidential and that I, as a participant, will be completely anonymous. I understand that the contents of the debriefing session and lifeline will be used only for research and publication purposes and that all identifying names or features (including names of cities, dates, specifics of your nondisclosure story etc) will be removed or modified from the transcripts and publications in order to protect confidentiality. I understand that the anonymized lifeline might be published in another form (e.g. a publication, a report, website, or in print or electronic format). I also understand that the lifeline might be used for educational/teaching purposes, presentations, and secondary analysis after the study is complete. The researchers will protect anonymity by allowing participants to choose a pseudonym. Pseudonyms will be used in any publication and in the writing of the dissertation to protect my identity. I understand that I should avoid putting any identifying information on the lifeline.

Given that debriefing sessions will be held via Zoom, every session will have a different meeting ID/link and password and will use all security measures available on the platform such as using a waiting room where the host (researcher) has to approve entry and the researcher will lock each meeting so no one else can join. In order to minimize the risk of security breaches and to help ensure my confidentiality, the researchers recommend that I use standard safety measures such as using a secure connection and to not share the meeting ID, link and password with anyone else. For privacy and confidentiality purposes, I am encouraged to conduct the online debriefing session in a space that is private to limit the chances of being overheard.

**Conservation of data:** The lifelines will be kept in a secure manner. Hard copies of the lifelines will be stored in a large art portfolio in the researcher's locked home office and electronic copies of lifelines including screenshots and photos taken by me will be stored in a password protected folder that is in a separate password protected user account on the researcher's personal computer. This user account is disconnected from any cloud services. The lifelines both electronic and hard copies will be stored for a period of five years following the defence and then will be destroyed using secure deletion protocols.

The digitally recorded audio and video files and transcripts of the debriefing session will be kept in a secure manner. Hard copies of the transcripts and notes will be stored in a locked box in the researcher's home office and audio and video recordings will be stored on a password protected USB key in the researcher's locked box. All other electronic files will be stored in a password protected folder that is in a separate password protected user account on the researcher's personal computer. This user account is disconnected from any cloud services. Audio and video recordings will be deleted as soon as transcription is complete and all other data will be stored for a period of five years following the defence and then will be destroyed using secure deletion protocols.

**Compensation:** I will be given a $40 honorarium for generously contributing my time to the creative lifeline activity and $40 for participating in the debriefing session. I will still be given this $40 even if I decide to withdraw from the creative activity and/or debrief session at a later time. Compensation will be offered via e-transfer to my personal banking account or through Western Union where I will be able to pick up cash.

**Voluntary Participation**: I understand that I am under no obligation to participate. If I choose to participate, I can withdraw from the study at any time and/or refuse to answer any questions that I do not feel comfortable answering without suffering any negative consequences. If I choose to withdraw from all components of the study, all data gathered until the time of withdrawal will be securely deleted from the recording device and destroyed. The destroyed data will not be used in the study. If I choose to withdraw from one or two aspects of the project, the data collected from the task(s) I did not withdraw from can and will still be used in the researcher's dissertation, publications, and conference presentations. If by participating in the creative activity and debrief session, I feel that my memories or emotions are hard to handle, I can contact one of the counselors from the list provided to me by the researcher.

**REB Contact Information:** If I have any questions regarding the ethical conduct of this study, I may contact the Protocol Officer for Ethics in Research, University of Ottawa, Tabaret Hall, 550 Cumberland Street, Room 154, Ottawa, ON K1N 6N5
Tel.: (613) 562-5387
Email: ethics@uottawa.ca

**Consent to participate:** I agree that in consenting to participate in this project I do not give up any rights. I have been informed about the different requirements of the research and I agree to take part in the creative activity and debriefing session. The reason I am not providing my signature and that I am providing oral consent is to protect my anonymity and maintain confidentiality in the research. I agree to participate in the above research study conducted by Katarina Bogosavljevic, a PhD Candidate in the Department of Criminology, University of Ottawa, whose research is under the supervision of Dr. Jennifer Kilty.

___ Yes ___ No ________________ Signature of Researcher ________ Date

With my permission only, photos or screenshots of my lifeline can be taken and shared for research and teaching purposes including in presentations and publications. I agree to take a photo or screenshot of my lifeline and send it to the researcher:

___ Yes ___ No

With my permission only, the debrief session will be audio and/or video recorded using the recording feature on Zoom or by using a digital recording device if debrief session is held over the phone. Only the researcher will have access to the recordings. If I do not wish to be video recorded, the researcher may audio record the conversation and if I do not wish to be audio or video recorded the researcher will take detailed notes.

I agree to the audio recording of this debrief session:

___ Yes ___ No

I agree to the video recording of this debrief session:

___ Yes ___ No

If I have any questions about the study, I may ask them now and/or contact the researcher or her supervisor using the contact information given.

You should save or print a copy of this consent form for your personal records.

# Appendix I.

## Lifeline Activity Instructions HIV Positive Participants

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Canada

**Lifeline Instructions: HIV Positive Participants**

***Please have your lifeline ready for a debriefing session on:***

Introduction

As part of this research project, we are going to use the lifelines as a visual depiction and extension of the interview to explore your nondisclosure story. This involves exploring your emotions and feelings related to your experiences of nondisclosure in the context of the criminalization of HIV nondisclosure in Canada. We are specifically interested in the identity or identities you make take up in response to these events. These identities can include being a victim, survivor, or something else that you have identified with your own experiences. Perhaps you don't see your diagnosis as creating an identity, but rather as having led you to have certain feelings, which we would like you to describe. We are also interested in the actions you may or may not have taken as a result of finding out your partner didn't disclose their HIV positive status prior to sex.

Activity Description

You are asked to draw your significant life events onto a "traveling line" or some other shape that you believe represents your feelings about your experiences. You can do this by using various materials such as magazine clippings, pencil crayons, markers, glue, scissors, scrap paper, coloured paper, and sticky notes – anything that you have on hand. It can be as minimal or as extensive as you want it to be. Please use either 8 X 11in or 11 X 16in paper.

Alternatively, you can draw your lifeline using any software that you prefer and have at your disposal such as Microsoft Word.

Each event or milestone should be labelled as a picture, image, symbol, or sign – you should avoid sentences if possible. You are however free to write down words if you believe they add meaning. If you are using Microsoft word or another software, feel free to copy and past pictures from the internet that you feel best symbolize certain events in your life – this will be similar to using cutouts from magazines.

In addition, you are to create a legend (like those found on a map) to describe these visual depictions and to help viewers of your lifeline to better understand your experiences. The legend should include what the different line variations mean (e.g. what do the ascending and descending parts of your line symbolize) and what the symbols you have drawn or pasted signify etc.

Lastly, you should think about how you are going to present your HIV story during the debriefing session. You can write this down on the back of your lifeline to help you discuss your drawings during the debriefing session. Think of this part as the

short description you see under paintings at a museum or any other gallery – you are the artist and this is what you want to share with whoever will see your work.

Once you have completed your lifeline drawing, please take a picture (if you drew it by hand) or screenshot (if you drew it on your computer) of your drawing and email it to [redacted] Alternatively, if you drew your lifeline by hand and wish to mail it to the researcher, please email Katarina at the email provided above and she will send you a self-addressed and stampedenvelope so you can mail it to her.

Remember, you do not need to be afraid of doing this 'artistic' work. This activity is meant to be fun and creative and I am here to help in any way you need. The most important thing is that you enjoy the process!

Step 1: Drawing your line (10 minutes)

The first step in creating your lifeline is to draw the line. Please draw a line or some other shape that best represents your HIV story. For example, it could be a squiggly line, ascending and descending parts, jagged lines, right to left etc. While drawing the line, please consider the following questions:

- How would you describe yourself as a person before your diagnosis? Are you different now? How?
- What has been the biggest change since your diagnosis?
- How do you feel about your HIV story?
- What shape represents your HIV story?
  - Is it a line or is it a circle?
- What colour(s) would represent how you felt in different moments in your life?
  - Ex: black for 'low' moments or red for when you were diagnosed with HIV or yellow to represent 'high' moments
  - Why did you choose these colours? What do they signify?
- What kind of line variations symbolize events in your life before and after your diagnosis and at the time of your diagnosis?
- What kind of line variations symbolize different emotions related to events in your life before and after your diagnosis and at the time of your diagnosis?
- Where do you want to start drawing your line? Why have you chosen this direction? What does this direction symbolize?
  - Left to right?
  - Right to left?

Step 2: Drawing your HIV Story (50 min)

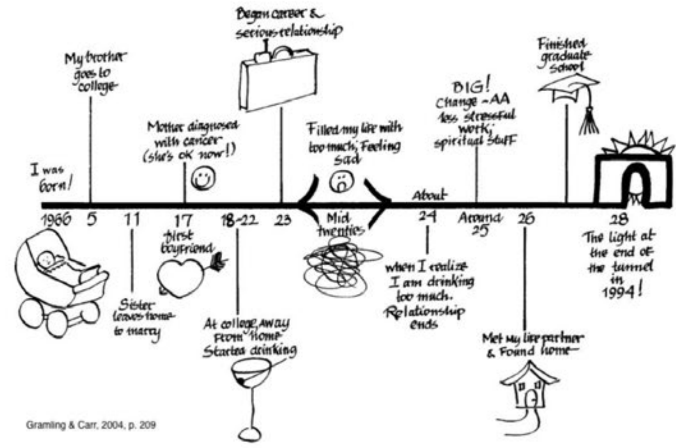
Now we are going to summarize key moments in your HIV story. Through this exercise we want to visually capture significant events in your HIV story and how they impact your sense of self. This can include important events before being diagnosed with HIV and after your diagnosis, your feelings and emotions when you were told about your positive status and after your diagnosis, and how disclosure and criminalization impact your HIV story and sense of self more

generally. Remember that these should be represented as images, symbols, shapes, signs, or pictures and that words are allowed but sentences should be avoided.

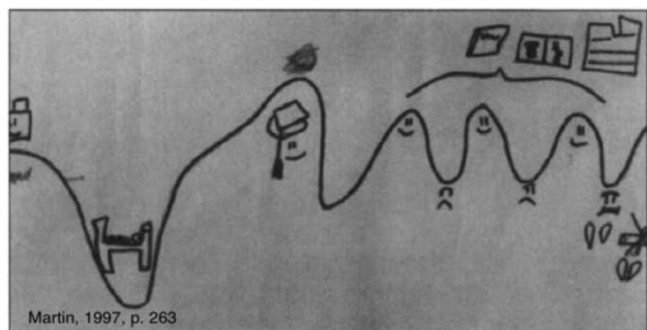
While drawing these life events, consider the following questions:

- What symbols come to mind when you think about your emotions and feelings in relation to your diagnosis?
- What symbols come to mind when you think about your feelings related to having to disclose your status to a sexual partner or of not being disclosed to?
- What symbols come to mind when you think about your emotions and feelings related to criminalization?
- What symbols come to mind when you think about other significant life events before and after your diagnosis? Your relationships? Work? Family?
- Have you ever faced any challenges in your social or emotional life before and after your diagnosis?
    - What kinds of difficulties/challenges were these? (e.g. gender-based discrimination, racism, exclusion from services, housing, or employment).
    - What kinds of images or symbols represent these challenges?
    - Did some of these change after your diagnosis?
    - How do these challenges make you feel?
- How did you overcome these challenges?
    - What symbols or images represent your resiliency and coping strategies?
    - If you haven't overcome these challenges, what symbols or images represent this?
    - How did overcoming or not these challenges make you feel?

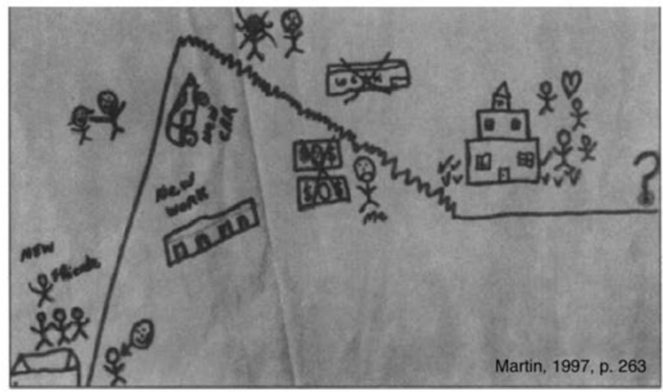
**Examples of Lifelines**



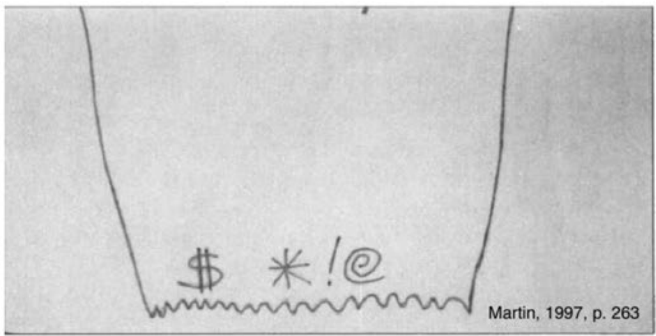

Gramling & Carr, 2004, p. 209



Martin, 1997, p. 263



Martin, 1997, p. 263



Martin, 1997, p. 263

# Appendix J.

## Lifeline Activity Instructions HIV Negative Participants

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Canada


**Lifeline Instructions: HIV Negative Participants**

***Please have your lifeline ready for a debriefing session on:***

Introduction

As part of this research project, we are going to use the lifelines as a visual depiction and extension of the interview to explore your nondisclosure story. This involves exploring your emotions and feelings related to your experiences of nondisclosure in the context of the criminalization of HIV nondisclosure in Canada. We are specifically interested in the identity or identities you take up in response to these events. These identities can include being a victim, survivor, or something else that you have identified with your own experiences. Perhaps you don't see your experience as creating an identity, but rather as having led you to have certain feelings, which we would like you to describe. We are also interested in the actions you may or may not have taken as a result of finding out your partner didn't disclose their HIV positive status prior to sex.

Activity Description

You are asked to draw your significant life events onto a "traveling line" or some other shape that you believe represents your feelings about your experiences. You can do this by using various materials such as magazine clippings, pencil crayons, markers, glue, scissors, scrap paper, coloured paper, and sticky notes – anything that you have on hand. It can be as minimal or as extensive as you want it to be. Please use either 8 X 11in or 11 X 16in paper.

Alternatively, you can draw your lifeline using any software that you prefer and have at your disposal such as Microsoft Word.

Each event or milestone should be labelled as a picture, image, symbol, or sign – you should avoid sentences if possible. You are however free to write down words if you believe they add meaning. If you are using Microsoft word or another software, feel free to copy and past pictures from the internet that you feel best symbolize certain events in your life – this will be similar to using cutouts from magazines.

In addition, you are to create a legend (like those found on a map) to describe these visual depictions and to help viewers of your lifeline to better understand your experiences. The legend should include what the different line variations mean (e.g. what do the ascending and descending parts of your line symbolize) and what the symbols you have drawn or pasted signify etc.

Lastly, you should think about how you are going to present your HIV nondisclosure story during the debriefing session. You can write this down on the back of your lifeline to help you discuss your drawings during the debriefing

session. Think of this part as the short description you see under paintings at a museum or any other gallery – you are the artist and this is what you want to share with whoever will see your work.

Once you have completed your lifeline drawing, please take a picture (if you drew it by hand) or screenshot (if you drew it on your computer) of your drawing and email it to [redacted] Alternatively, if you drew your lifeline by hand and wish to mail it to the researcher, please email Katarina at the email provided above and she will send you a self-addressed and stamped envelope so you can mail it to her.

Remember, you do not need to be afraid of doing this 'artistic' work. This activity is meant to be fun and creative and I am here to help in any way you need. The most important thing is that you enjoy the process!

Step 1: Drawing your line (10 minutes)

The first step in creating your lifeline is to draw the line. Please draw a line or some other shape that best represents your HIV nondisclosure story. For example, it could be a squiggly line, ascending and descending parts, jagged lines, right to left etc. While drawing the line, please consider the following questions:

- How would you describe yourself as a person before you found out that your partner did not disclose their HIV positive status?
- Are you different now? How?
- What has been the biggest change since you found out?
- How do you feel about your HIV nondisclosure story?
- What shape represents your HIV nondisclosure story?
    - Is it a line or is it a circle? Some other shape? Why that shape?
- What kind of line variations symbolize events in your life before, after, and at the time of the nondisclosure experience?
- What kind of line variations symbolize different emotions related to events in your life before, after, and at the time of the nondisclosure experience?
    - How are you going to represent nondisclosure on your line? Squigly line? Sharp ascending or descendnig line?
- Where do you want to start drawing your line? Why have you chosen this direction? What does this direction symbolize?
    - Left to right?
    - Right to left?

Step 2: Drawing your Nondisclosure Story (50 min)

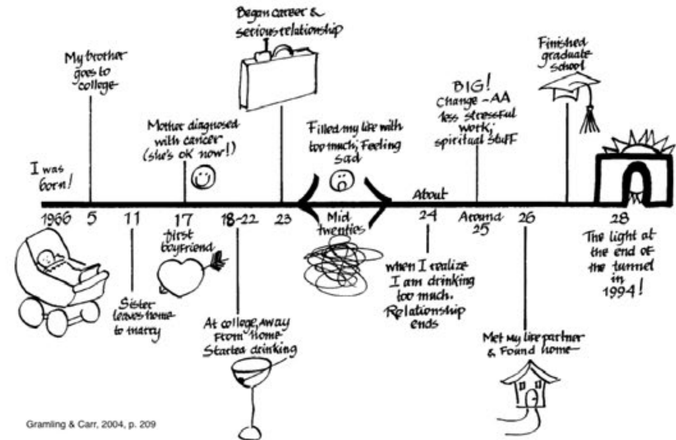
Now please summarize key moments in your HIV nondisclosure story. Through this exercise I want you to visually capture significant events in your HIV

nondisclosure story and how they impact your sense of self. This can include important events before finding out that you weren't disclosed to and after you found out, your feelings and emotions when you found out that you were not disclosed to, how disclosure and criminalization impact your sense of self, and the actions you took in response to nondisclosure such as going or not going to the police. Remember that these should be represented as images, symbols, shapes, signs, or pictures and that words are allowed but sentences should be avoided.

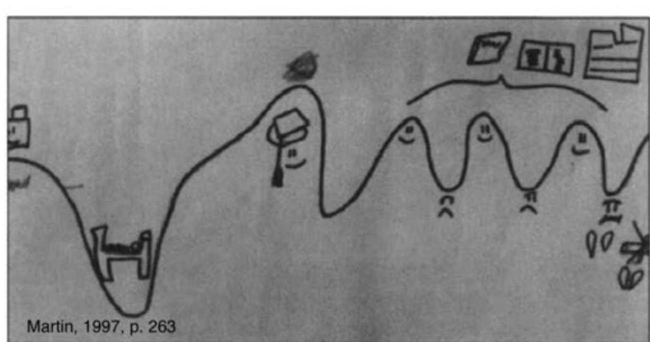
While drawing these life events, consider the following questions:

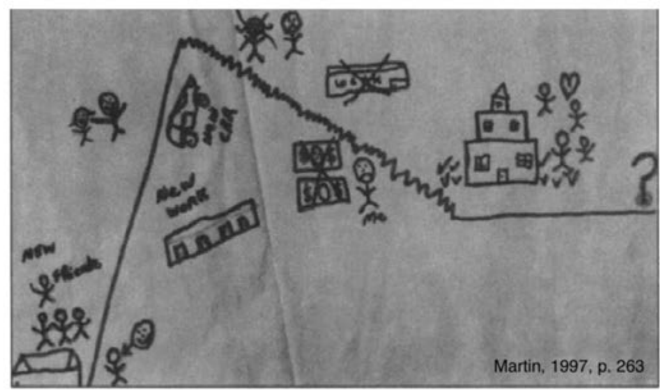
- What symbols come to mind when you think about your emotions and feelings in relation to your nondisclosure experience?
  - How do you identify after this experience?
  - How has it impacted or not the way you understand and/or see yourself and your body?
  - How has it impacted (or not) your relationships?
- What symbols come to mind when you think about your emotions and feelings related to the actions you took in response to your nondisclosure experience?
  - Did you go to the police?
    - If you did, what kinds of symbols or images come to mind that would reference your emotions and feelings related to this experience?
      - How were you treated? What did the room smell like? What did the room feel like?
    - If you didn't, what symbols or images come to mind that would reference your reasons for not going to the police?
- What symbols come to mind when you think about other significant life events before and after your experience of nondisclosure? Your relationships? Work? Family?
- Have you ever faced any challenges in your social or emotional life before and after your nondisclosure experience?
  - What kinds of difficulties/challenges were these? (e.g. gender-based discrimination, racism, exclusion from services, housing, or employment).
  - What kinds of images or symbols represent these challenges?
  - Did some of these change after your experience of nondisclosure?
  - How do these challenges make you feel?
- How did you overcome these challenges?
  - What symbols or images represent your resiliency and coping strategies?
  - If you haven't overcome these challenges, what symbols or images represent this?
  - How did overcoming or not these challenges make you feel?

**Examples of Lifelines**

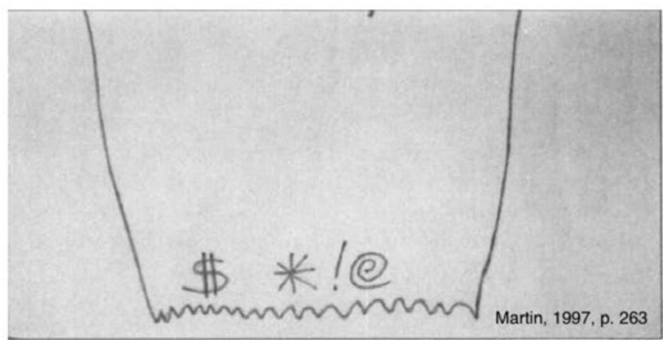


Gramling & Carr, 2004, p. 209


Martin, 1997, p. 263



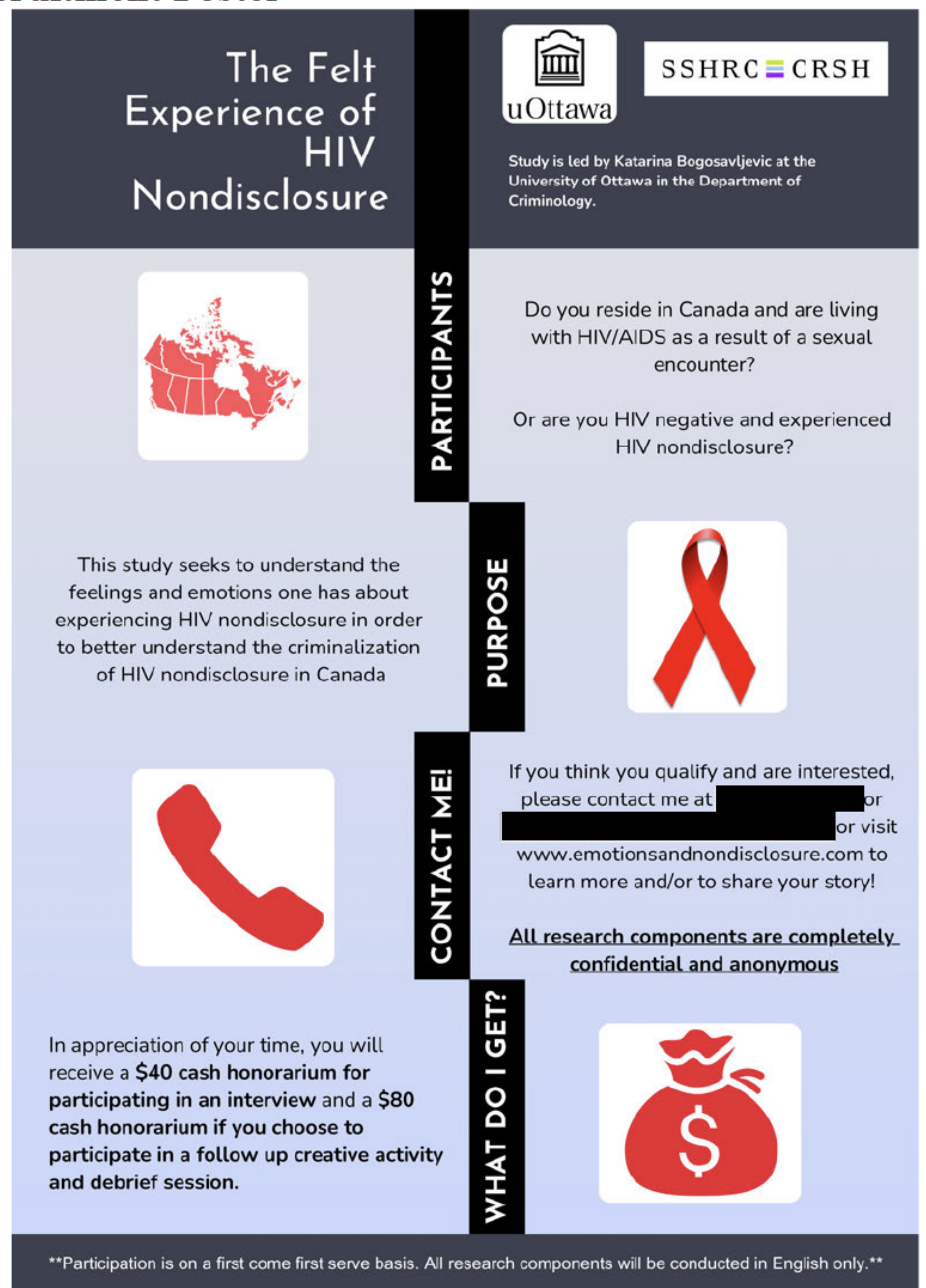

Martin, 1997, p. 263




Martin, 1997, p. 263

# Appendix K.

## Recruitment Poster



## Appendix L.

## Recruitment Social Media Post

# The Felt Experience of HIV Nondisclosure

Do you reside in **Canada** and are **living with HIV/AIDS** as a result of a **sexual encounter**?

Or are you **HIV negative** and **experienced HIV nondisclosure**?

This study seeks to understand the **feelings and emotions** one has about **experiencing HIV nondisclosure** in order to better understand the criminalization of HIV nondisclosure in Canada

Please contact me at [redacted] or [redacted] or visit **www.emotionsandnondisclosure.com** to learn more and/or to share your story!

You will receive a **$40 cash honorarium** for participating in an **interview** and a **$80 cash honorarium** if you choose to participate in a follow up **creative activity and debrief session**

All research components are completely **confidential** and **anonymous**

SSHRC CRSH

Study is led by Katarina Bogosavljevic at the University of Ottawa in the Department of Criminology.

# Appendix M. Ethics

13/10/2020

Université d'Ottawa
Bureau d'éthique et d'intégrité de la recherche

University of Ottawa
Office of Research Ethics and Integrity

**CERTIFICAT D'APPROBATION ÉTHIQUE I CERTIFICATE OF ETHICS APPROVAL**

| | |
|---|---|
| **Numéro du dossier / Ethics File Number** | S-08-20-5931 |
| **Titre du projet / Project Title** | "Victim and Vector": Challenging Notions of Victimhood in HIV Nondisclosure |
| **Type de projet / Project Type** | Thèse de doctorat / Doctoral thesis |
| **Statut du projet / Project Status** | Approuvé / Approved |
| **Date d'approbation (jj/mm/aaaa) / Approval Date (dd/mm/yyyy)** | 13/10/2020 |
| **Date d'expiration (jj/mm/aaaa) / Expiry Date (dd/mm/yyyy)** | 12/10/2021 |

## Équipe de recherche / Research Team

| Chercheur / Researcher | Affiliation | Role |
|---|---|---|
| Katarina BOGOSAVLJEVIC | Département de criminologie / Department of Criminology | Chercheur Principal / Principal Investigator |
| Jennifer KILTY | Département de criminologie / Department of Criminology | Superviseur / Supervisor |

**Conditions spéciales ou commentaires / Special conditions or comments**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