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## HIV Stalks Bodies Like Mine: An Autoethnography of Self-Disclosure, Stigmatized Identity, and (In)Visibility in Queer Lived Experience

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HIV Stalks Bodies Like Mine: An Autoethnography of Self-Disclosure, Stigmatized Identity,  
and (In)Visibility in Queer Lived Experience

by

Steven Ryder

A dissertation submitted in partial fulfillment  
of the requirements for the degree of  
Doctor of Philosophy  
Department of Communication  
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## **DEDICATION**

I write to honour the lives and legacies of my queer family  
who are too often rendered invisible and “less than”  
because of HIV.

## ACKNOWLEDGMENTS

I completed my dissertation mostly in isolation but not without the assistance of a great many others, near and far, living and dead. For and to them, I am deeply indebted and feel intimately connected through and because of this project. My story on the pages ahead would not have been possible without their stories. I tell this story, in part, so that you may know them through our shared bonds and to keep their stories alive. These stories have always been important.

I acknowledge my partner, Andrew, for these last thirty-four years of laughter, tears, love, and growth. We have built and maintain our connection through friendship and trust. During light days and darkness, I have never been disappointed. You are the staunchest and most stoic of supporters. You have made me fall in love so many times, always with you. Thank you for letting me follow this PhD dream and for walking with me as I did so. I hope that we remain together always for no one complements, challenges, or completes me as wholly as you do. *Je t'aime beaucoup.*

I thank my parents, Stella and Thomas, for *being* there for me. I grew up in an atmosphere of permission and curiosity that you diligently nurtured and sustained in and out of our home. Even when I doubted, in the darkest moments of personal struggles with sexual orientation, you caught me when I leaped. You both truly walk your talk. It wasn't until I spread my own wings when moving out into the world that I began to appreciate the simplicity and expansiveness of your parentage and your love. You catalyzed my thirst for understanding, *sine qua non*. With no children to call my own, I can only hope that the classrooms and surrounding circumstances in which I may

find myself from time to time will allow me to share your gifts with others. My love for you is fathomless, Mum and Dad.

I would not have become so acutely devoted to Ethnography nor believed that I could ever be ready to attempt the PhD without those awkward first sparks fanned by Dr. Diana Denton who has, over the last decade, also become the dearest of friends. I rely heavily upon your spirit and worldview, Diana, and relish our many conversations and your gentle insights. Few have touched me so lightly yet deeply. May good health grant us collaborations and enduring friendship well into our winter years.

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To Dr. Nancy Romero-Daza, my thanks for international and interdisciplinary perspectives as well as the passion you maintain for marginal groups deserving of representation. I shall also be forever mindful, when crossing international borders, to carefully choose my words when describing the contents of a second bag as “for my work.” I felt your passion for this project. I’m thankful for your insights through the lens of Anthropology and for the marginal with whom you so tirelessly work.

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To Ariane Anderson, I miss you. Repeatedly, I want to sit down over breakfast and chat about all of the things. Your physical absence punctuates just how much you meant and shall always mean. Thank you for modeling the kind of person I strive to be in the world. Your illness brought “living” into acute focus and helped me to make more sense of my own struggles and my orientation toward illness. I loved that words were often superfluous to our understanding and being. To be in each other’s presence was enough. You were larger than life, and full of sarcasm, sagacity, and an abundance of love. You radiated in every direction and across a multitude of dimensions. You were among the first to welcome me to USF and the one, among many, whose

absence leaves the biggest void in my being. Keep that chic coiffure a healthy distance from the fire as you light up the great beyond, gurl! You'll always be with me.

There have been so many, especially during my early university years, who welcomed my perpetually emergent queer body and all its shit. I am thankful for you all, and especially my long-time gay sisters, Dwight and Walter. Gurls! We've seen and done a lot and I am the richer for it. Thanks for letting my story intersect with yours and for continuing to dance with full hearts and with wild abandon to the music of our queer family.

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## ABSTRACT

This dissertation examines self-disclosure of Human Immunodeficiency Virus (HIV) status within the context of communication between long-standing friends. For the purposes of my study, I define this type of friendship as those who have known me for at least two years and with whom I communicate regularly. These are friends who tend to know a variety of personal details about me, ranging from superficial to private and trivial to essential. I use autoethnography to ground the study in my lived experience. By doing so, I present intimate accounts of my communication with others across my lifespan to function as background for disclosures I make in the present. My aim is to answer two questions: a) what does it mean relationally to disclose one's HIV status to people who are long-standing friends; and, b) what do these conversations demonstrate about self-disclosure amid the tension of stigmatized identity, the perpetuation of silence, unhealthy rituals of relational communication, and diminished visibility for people living with HIV (PLHIV) and illness? These questions underscore the importance, complexity, and dimensions of disclosure as a moral duty, a social responsibility, and the consequences of interactions that entail non-disclosure in everyday life. As I write "through" disclosure, these questions guide but will not limit my inquiry. I remain aware that disclosure remains complex, and that the context of disclosure is organic and subject to change over time and relative to the given writer and story. Finally, I write this dissertation from a place of privilege owed to my body, its geographical location, socio-economic status, and legal standing because others, especially those who live with HIV, too often cannot.

**CHAPTER ONE:**  
**A QUEER, POZ, FAGGOT AND SELF-DISCLOSURE**

This is an autoethnographic study about self-disclosure, which according to Jourard, 1971a) “is the act of making yourself manifest, showing yourself so others can perceive you” (p.19). Yet, everything about a person cannot be revealed in one act, constrained by a specific time or space (see Adams, 2011). Therefore, I propose to treat self-disclosure as a process, like the peeling of an onion, which reveals oneself, layer by layer. I make myself visible to others over time and across contexts through what can be gleaned from an accumulation of discrete disclosure events (see Altman & Taylor, 1973). For example, the revelations in my study use personal experiences which span several decades to situate self-disclosure in the specific context of HIV. By doing so, I hope to circumvent the tales which circulate widely about what this illness (HIV, specifically) is and is not, who it affects and does not affect. These tales are often told as being factual. Indeed, some are that way. Yet, spurious lies and partial truths also run rampant. Therefore, I use this study to craft a “counter narrative,” an alternate story<sup>1</sup> which challenges assumptions and is authored and lived by someone who has experienced HIV firsthand (see Spieldenner, 2014). Specifically, I write about the (non-)disclosure of my own HIV status in everyday life experience to long-standing friends and the forces that constrain “difficult” or “impossible” conversations about HIV. These conversations and their impact are never certain, and the work of self-disclosure is never-ending. I cannot overstate this point. Simultaneously, I attend to the myriad ways that

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<sup>1</sup> I will often use the terms lived experience and story interchangeably. They are synonymous within the context of this project.

identity is implicated in the act of (non-)disclosure and, in turn, how disclosure affects who I am and who I am allowed to be.

Disclosure of HIV is important for many reasons, but two reasons are most prominent throughout my study. First, HIV continues its global spread. In part, omnipresent fear and ignorance fuel this process. I will address how disclosure of an HIV-positive (HIV+) status has tremendous potential to counter that spread. Second, HIV continues to affect the LGBTQ+<sup>2</sup> community disproportionately (e.g., more than is evident in the general population). As such, I feel that I have inherited the social expectation of performing the bulk of the emotional labour that is layered upon my illness. *Pre-disclosure: How is this work still relevant, I mean, isn't there a cure for HIV now? That could never happen here, could it? Those folks must be promiscuous. I would never sleep with a POZ faggot. They're dirty. They deserve it. Post-Disclosure: What does it mean? How did I contract it? Oops! Am I "feeling" ok? It's a chronic yet manageable illness now though, isn't it? You're sure I can't get it? Here, taste this!*

This study calls readers to examine their contributions (e.g., choice of language, attitude, direct and indirect participation, etc.) that permeate and perpetuate both people's understandings of HIV and the social expectations which intersect with this illness. Through the stories and disclosures featured in my study, I attempt to disrupt social exclusion. *On more than one occasion because of this illness, people have stopped talking to me (mid-sentence), have become defensive or abusive, and then foreclosed on our relationship. I have learned to accept these ruptures as gifts. Nevertheless, such interactions continue to be steeped in violence.* In doing so, I hope to

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<sup>2</sup> I use the umbrella term LGBTQ+ throughout this dissertation to refer to the spectrum of identities that make up the queer community. The order or omission of letters (from the fuller abbreviation) should not be construed as inference that some members are hierarchically more significant than others or less visible or representative of this diverse community, my queer family.

stage the importance of disclosure in the process of reclaiming one's authentic<sup>3</sup> identity. *Disclosing feels like a recipe that calls for a hefty pinch of self-talk with a peppering of interpersonal revelation.* As I convey and explore this story, I also draw many parallels between coming out as gay and coming out with respect to HIV. These two processes feel similar and have potentially significant outcomes.

Two research questions drive this dissertation:

(RQ1) What does it mean relationally to disclose one's HIV positive status to people who are long-standing friends?

(RQ2) What do these conversations demonstrate about self-disclosure amid the tension of stigmatized identity, the perpetuation of silence, unhealthy rituals of relational communication, and diminished visibility for PLHIV and illness?

These questions underscore the importance and dimensions of disclosure as a moral duty and a social responsibility, as well as the consequences of (non-)disclosure in everyday life. In doing so, I remain aware that disclosure is complex and the contexts in which disclosure occurs, or does not occur, are organic and subject to change. As I write through disclosure, the above questions guide, but do not limit, my inquiry.

### **The Importance of this Dissertation**

Each of us is likely to have a story to tell about HIV, whether one is directly affected or not. Illness adds to the complexity of everyday communication experiences that involve disclosure.

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<sup>3</sup> I define authentic as a way of living which favours self-disclosure rather than self-concealment. When one lives authentically, they actively reveal themselves in their interactions with others and thereby gain a greater understanding of themselves because of these interactions and the reciprocated disclosures which are likely to occur from others in turn. Authenticity is a contested term. In the web of stories that we tell about ourselves and others, authenticity is implicated in our crisis of representation over who we claim to be and who others assume/claim/expect we are. The gulf between these two prospects seems irreconcilably wide. For this dissertation, I will prevail upon authenticity to describe who I claim to be with the understanding that identity is never static but rather always emergent, negotiated, and fluid without end.

The chronic dilemma for disclosure is that to drop one's guard and make oneself vulnerable, even for just a moment, is to surrender to the "irreversible" nature inherent to communication (Watzlawick, Bavelas, & Jackson, 2011). As hard as we might try, we cannot "take back" what we communicate. In my choice to be vulnerable, I hope to find it safe to draw to the surface what may be hidden. This dissertation is a crucial step toward making the complex simpler and to normalizing an HIV self-disclosure process. I hope that as I share my and others' experiences of disclosure, I make it easier for further disclosure to occur, both for myself and for others because of the example I aim to make.

Silence inhibits the sharing of HIV illness stories. Thus, telling my story refutes a broad societal expectation that people like me should remain silent. *Gurl. You better fasten your seatbelt, because when faced with a choice between decorum and avoiding death, I'll always be choosing the latter.* Storytelling effectively re-positions illness from being only a medical marker to also being about consequential lives. Telling my story is at once a revelation of who I am and an invitation for you to reciprocate (Jourard, 1971a). This reality delineates and saturates a symbolic exchange between bodies as they are lived in their locally-situated, dynamic, and complex cultural contexts in which they occur. Storytelling is a form of activism that disrupts the many rigid and taken-for-granted perceptions which arise through and across a complex network of relationship (Al-Solaylee, 2013, 2016, 2021; Rofes, 1998; Jones, 2016; Kaufman, et al., 2004, 2014; Kramer, 1978, 1983, 1985; Kushner, 1993; Lambert, 2013; Poletta, 2006; Zingaro, 2009). It can serve to counter representational categorizations and impositions of what commonly passes for "good health," which, in turn, negate a broader and more inclusive socially just way of inter-relating through illness. In these ways, readers do not get to passively witness my story unfolding, but rather are called to become an active participant who intersects with my story and its implicit

challenge to think critically about the story you write for yourself. Importantly, scholars use storytelling to mindfully open a generative space in which vulnerable, heretofore untellable stories may begin to voice the subtle yet persistent problems of illness (in)visibility—brought on through the symbolic nature (Burke, 1966) of language—and their affect (see Bochner & Ellis, 2016; Berry, 2013; Berry & Patti, 2015). In these ways, this dissertation aims to break new ground concerning HIV and disclosure.

I am HIV+ and, thus, politically implicated as researcher in this study. Concurrently, I mark that my story is *needed* to challenge the silencing discourse brought about by the routinely exclusionary, heteronormative, and homophobic praxis of the normative social order<sup>4</sup>. My story is not the only story of living with HIV. However, to keep my story hidden means one less voice is present to disrupt the many forces that seek to marginalize or otherwise exclude people like me, and especially those marked by illness, from the narratives of normalization that exist and are drawn on in wider circulation. These narratives actively seek to prevent full participation of queer bodies from illness discourse and further marginalize us. I recognize that my story is no more important than any other story. Yet, it is also no less important. Unfortunately, turning away from stories that express undesirable, uncomfortable, or *dis-quieting* aspects of life, for many people in my lived experience, is easier than putting in the work to engage with each other. I hope that readers will be able to connect to the issues that circulate about HIV at the intersection of their own resonant lived experience (Bochner & Ellis, 2016). Further, I hope that they will (re)consider HIV through what they hopefully learn and my standpoint.

Telling stories from a first-person account about HIV is important because others often talk about HIV on behalf of PLHIV. Second-hand accounts, however well-meaning, often increase the

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<sup>4</sup> I refer to the normative social order as the way in which everyday life is organized, by design, to exclude, downplay, or dismiss unwanted participants (e.g., folks who identify as LGBTQ+, racialized bodies, disability, and so on).



conditions for people's fear, stigma, social exclusion, and harm. One need only look for evidence in the literature written before 1996 when highly active antiretroviral therapy (HAART; see Glossary) when HIV was typically regarded as a fatal illness. For instance, Herek (1996) aptly taps the zeitgeist of that time when he writes:

Imagine a disease that arouses great fear throughout the United States, especially in New York and other large cities where it is rampant. Imagine that the disease has no cure and is fatal to most people who manifest its symptoms. Physicians prescribe a variety of treatments but with little success. Imagine that people who get sick are widely assumed to have engaged in immoral behaviors-probably related to sexual behavior or consumption of drugs. Imagine that the illness strikes disproportionately among Blacks, ethnic minorities, immigrants, and the poor. Many members of these groups even believe the epidemic to be the product of a conspiracy against them by the powerful of society. If someone famous gets sick or dies from the illness, considerable speculation arises about that person's secret life. Imagine that the lack of effective treatments leads society to focus on prevention efforts. Attempts are made to change "immoral" behaviors that are thought to predispose people to the disease. A movement arises to shut down public establishments where such behaviors occur, because they are viewed as breeding grounds for the disease. Imagine that many people explain the disease as a punishment from God for sin, while others claim it is Nature's retribution for maladaptive behavior. Some commentators regard the epidemic as fortunate: It has provided a dramatic opportunity for battling unnatural and unhealthy behaviors. (p. 107)

Herek is not wrong in his depiction of that time period, even if he excludes explicit mention of queer bodies. However, these messages are not all true and few of them, if any, originate from

PLHIV. Personally, I grew up hearing and sometimes believing that these tales were or could be true, especially when they were communicated in the guise of “news.” I did not understand myself well enough, in the ways that I do now, to discount, dismiss, or re-author these messages from my standpoint. I was susceptible. Still, I knew enough to respond rationally to existential propaganda. And, whether it was my young age, my association with university-based gay activism, or a supportive inner circle of queer peers, I chiseled out enough truth to light a path through uncertainty.

I didn’t do it alone. I’m here now because my queer family, my extended queer family, socialized me to be wary. That is, they helped me to translate imagination into practice, somatically testing what being and performing gay might mean. The process of “becoming” myself with others inspires me to look at the qualitative and relational dynamics of making sense, of my queer body, pre- and post-illness.

First-person autoethnographic responses to HIV by PLHIV are particularly useful in addressing the relational aspects of self-disclosure. Yet, exemplars of these first-person accounts told by PLHIV are rare in the extant academic research literature. There is literature that in various ways engages HIV disclosure in the form of essays, plays, film, memoirs, testimonies, and historical fiction (see, for example, Al-Solaylee, 2013; Zezima, 2006; Kramer, 1978, 1983, 1985; Kushner, 1993; Shilts, 1987; Rofes, 1998; France, 2016; Jones, 2016). The living record of HIV is undeniable. Well, almost. The African-American community is especially impacted by the historical and continuing denial of HIV (Harden, 2012; Villarosa, 2017; Foster, 2007), as has been modern-day South Africa under former president Thabo Mbeki (Kalichman, 2014). Nonetheless, many accounts, as evocative and compelling as they may be, continue to speak *on behalf* of PLHIV

(see Serovich, 2001)<sup>5</sup>, rather than allowing us to speak for ourselves. For this project, these accounts give shape to the broad context in which HIV has and continues to emerge, as well as frame and underscore specific issues that still require attention (for example, fear of the unknown, and stigma). Some writing touches upon related issues, but few of them dwell in the everyday experience of HIV in the context of relationship, which is acutely important to this project.

I have come to experience self-disclosure of HIV serostatus as operating within a complex and tension-filled environment. Chief among the influences of a relational understanding of HIV illness are a) the criminalization of PLHIV who fail to disclose their HIV+ status before intimate<sup>6</sup> contact; b) the mechanics and implications of self-disclosure; c) the inherent risk of disclosure, including perceptions attached to sexual practices of MSM (men who have sex with men); and, d) the use of personal narrative to counter the silence and stigma which typically spoils those identities. Next, I explore each of these themes to clarify the problem of self-disclosure in the context of HIV, to summarize extant research, including contradictions and shortcomings, and, finally, to expand upon the ways in which such exploration responds and uniquely contributes to a deeper understanding of HIV+ status disclosure.

### **This Dissertation is (Inter-)Personal**

I write this dissertation to join a conversation that is always already underway (see Althusser, 1970; Butler, 2014; van Manen, 2014); the conversation started before my arrival and will continue long after I am gone. I write as a gay man not just from a standpoint that is non-heteronormative, but also about a relationship to, and through, lived experience that both values

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<sup>5</sup> These are just a few of the many scholarly examples in which authors do not disclose their HIV status.

<sup>6</sup> I use the word *intimate* in lieu of *sex* (i.e., intercourse) throughout this dissertation because HIV is not only transmitted through sexual means. For instance, intimate contact also includes the sharing of drug paraphernalia, which is a vector of ongoing HIV transmission than is not considered to be sexual. The choice to use *intimate* also challenges the continued and stigmatizing conflation of sexual behaviour and HIV transmission.

and embraces “uncertain, fluid, and becoming subjectivities, multiple forms of knowledge and representations, and research as an agent of change” (Adams, Holman Jones & Ellis, 2015, p. 108). I write to challenge the normalizing and essentializing pressures upon queer bodies, like mine, that expect, and many times demand, us to behave. I write to queer the broadly held assumption that rendering bodies like mine invisible will in effect make me go away. I won’t.

Self-disclosure’s effects on me are far more nuanced and complex than research has routinely and historically framed outcomes of this process. Disclosure is more than a “simple” choice to make personal details public or, deterred by potentially negative consequences, to keep them private. This is especially the case for disclosure related to HIV. For instance, people in the United States and Canada who are PLHIV continue disproportionately to experience stigma and discrimination (Herek, 2015; Skinta, et al., 2014; Spieldenner, 2014), elevated rates of depression, suicide, and mortality (Ferlatte, Salway, Oliffe, & Trussler, 2017; Kalichman, Heckman, Kochman, Sikkema, & Berholte, 2000; Marzuk, Tierney, Tardiff, Gross, Morgan, et al., 1988), threats of violence (Lockhart, 2008; Marchia & Sommer, 2019; Speakman, 2017; Stockdill, 2018), loss of employment (Derse, 1995; Evans, 1994; Mayfield, Rice, Flannery, & Rotheram-Borus, 2008; Miller, 2019), barriers to healthcare and social exclusion (Kurzban & Leary, 2001; Marmot, 2005; Rueda, Mitra, Chen, Gogolishvili, Globerman, et al., 2016), erasure (Alcoff, 1991; Ashford, 2015; Fox, 2013; Kagan, 2015), misrepresentation (Brown, Serovich, Kimberly, & Hu, 2017; Shahani, 2016; Strolovitch & Crowder, 2018), and criminalization and threats to human rights (Blendon, Donelan, & Knox, 1992; Crandall, Glor, & Britt, 1997; Crawford, 1996; Goldin, 1994; Green, 1995; Herek, 1996; Herek & Capitano, 1997; Herek, Capitano, & Widaman, 2002; Peterson & Panfil, 2014). In the most egregious circumstances, our “death was met with silence” (Yoshino, 2007, p. 220). The stakes remain high.

As I stroll the downtown city streets of Toronto, where I now live, even within the friendly area of the “gay village,” I have had people tell me disparaging things about HIV, and the advanced stage of progression by which the illness is widely known, Acquired Immune Deficiency Syndrome (AIDS)<sup>7</sup>. I hear all too often that “people [like me] deserve AIDS” and that “all FAGGOTS should die.” On the surface, heard once or twice, I can dismiss these comments as ignorant. However, across my lifetime they have accumulated and marked my body and bodies like mine, indelibly. I see their effect upon others. *My use of these derogatory terms remains contentious, but necessary. Every time I use them, I check their power over me and invite others to have visceral responses of their own.* Disclosure is still difficult, risky, and potentially life-altering. For me, non-disclosure renders people like me invisible. My choice to disclose or not remains personal and complex. I disclose because I don’t want to be unknown or unknowable. To disclose also feels like repaying the kindness of others who have revealed themselves to me.

For instance, my friend, Anton, flees from his native home in Uganda to Canada in the early 1980s because even the suspicion of being gay might result in his being murdered at the hands of a machete-wielding mob. Or take, for example, Dexter, a former roommate from university, who denies that HIV could be coursing through his veins. He dies at home alone. I wish disclosure could be easier, for them and me. I wish we could reveal ourselves to others more freely. Presently, we cannot. I undertook my study, in part, to help change that. I write with hope that practice will make disclosure ~~perfect~~ easier.

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<sup>7</sup> In 1985, HIV is an emergent illness. Its related terms, especially HIV and AIDS, continue to be inconsistently applied across the literature. For consistency, I will use terminology of the Centers for Disease Control and Prevention (CDC) by referring to HIV as an illness and AIDS as a clinical stage of advanced HIV infection when CD4+ T-lymphocyte cells/ $\mu$ L fall below 200 in persons 6 years of age or older (CDC, 2016). HIV, as a field, is complex and filled with terminology. To help make sense of its terminology and the context in which my study proposes to engage HIV experiences, I include a glossary (Appendix D) toward the end of my dissertation.

This dissertation also marks a personal turning point for me. I can no longer remain silent about the violence that HIV has done and continues to do. I must speak out about HIV, especially from my standpoint as a gay man who also has HIV. I speak out because I can, because I must, and because, despite popular opinion, I'm not "suffering from HIV." In fact, in the pages ahead, I will disclose how, in myriad ways, HIV has actually saved me.

Primarily, I write about HIV through disclosure because I want HIV to be less feared and unknown. I hope to cultivate compassion and understanding for the complexity that HIV introduces into the personal, cultural, historical, medical, and political economy of everyday life. I write into the cracks to uncover richer and thicker insights from the standpoint of people who are directly affected by HIV. I write not only for the sanctioned spaces of academic journals, conferences, and classrooms, but for the many "unsanctioned spaces" (Holman Jones, 2018, p. 1) in which HIV matters, such as office lunchrooms, subway platforms, shopping malls, adjacent tables at restaurants, living rooms, and especially, metaphorically and otherwise, bedrooms. For in these places that many of us dwell in from time-to-time, I simultaneously wonder and weep over how infrequently we truly and fully "see" each other.

I also write because, if you're sexually active, then you ought to know your HIV status and the status of your partner(s). You ought to be thinking about HIV *each and every time* you fuck. If you don't, then you and those with whom you are intimate may be at more risk than you presently recognize. *Wouldn't you want to know? Don't you want to disclose? Don't you have at least some responsibility for negotiating, managing, and mitigating mutual risk? Aren't we beyond the time when we can wait for such conversations to be initiated by others, especially when that emotional labour is expected from those who are HIV+?* I don't expect others to do my labour. Instead, I want to initiate self-disclosure, to share the burden and responsibility for the process.

Writing about HIV and HIV+ bodies like mine serves to primarily make our bodies visible and accessible and the stories told about them to be factual. Authoring our stories offers a way to challenge the prevailing social expectation that prefers POZ folks to remain silent and invisible. In the minds of others, I imagine that we PLHIV are off-putting and maybe even grotesque. Social expectations are policed hard. *Two men hug in an airport. Are they family members or lovers? Two men walk down the street arm in arm. Does one require help walking? Two men kiss, on the lips, for an extended period. Stop them! A man with Kaposi Sarcoma on the side of his face sips water from a glass at a restaurant. When he replaces the empty glass on the table in front of him, a waiter is reluctant to pick it up without first cradling it inside a napkin. As he removes the empty glass, he grimaces then decides to discard it in the trash rather than returning it to the kitchen.* Fuck the police. Their actions seek to replace the stories we wish to tell about ourselves with those told about us.

The act of writing is simultaneously defiant, a lamentation for those of my queer family who are no longer here in the flesh and able to tell their stories, and a call to be included and represented in conversations, including research conversations, that far too often tend to objectify “subjects” and talk “about” rather than “with” PLHIV. *Nothing about us without us. Right? When you talk about us, it feels like we must fit neatly into your flawed and partial understanding of our rich and diverse lives. We can't. We won't contort our reality to fit neatly into your ill-conceived rubric.* I write so that my audience doesn't need to become HIV+ to be able to understand the gravity of this illness more fully and accurately. Equally, I write to rein in the shame that is so often heaped upon bodies that read to others as “different.” In writing, I hope I can create a space in which we more readily lean toward compassion and enlightenment about the nature of everyday life for PLHIV. I write to make HIV less scary. That is, I write to make the “strange” more familiar.

Doing so invests in the opportunity to lessen the grip of stigma that so many PLHIV still feel. I write to regain and to keep control of my ill body (Frank, 2013). I write not to ask for permission nor to apologize for existing as I am. I write because many may not know or understand that, even though HIV casts an enormous shadow on many of the lives it touches, it also shines a brilliant light on these lives. My experiences with HIV and this dissertation are meant to stand as testament to that light.

My stories and the language choices comprising them are often explicit and raw, especially the accounts that convey sexual activities. This stance is reflective of thoughts, conversations, and arguments over many years and the process of inquiring brought to light in this dissertation. I did not arrive *here* overnight. Now, I feel it is necessary to relate my lived experience on these issues in ways that mirror and embrace their occurrence. My choice of language is deliberate, often of a sexual nature, and may, at times, be challenging to read. I think it important for readers to feel and understand the weight of this illness as realistically and fully as words can relate. I offer no apologies. I feel that there can be no place for the polite euphemisms which obscure the clarity of everyday phenomena. Grant yourself the time and good care that it may take to engage with this lived experience, as I have.

## **Methodology**

As previously mentioned, a lack of first-person HIV+ literature is the gap that this project aims to fill. Stories that center HIV+ experiences are essential to that fuller and more accurate understanding of HIV, how it is lived relationally across contexts, and the social movement to escape its deleterious effects. In the following section, I provide details about the methodological approaches that I use in the dissertation.



### *Autoethnography*

Autoethnography (AE) is an innovative approach to research and writing that “uses personal experience to describe and critique often limiting injurious cultural experiences, beliefs, and practices; identify weaknesses of existing research; and ascertain instances of injustice, privilege, and social harm” (Boylorn & Adams, 2016, p. 87; see also Boylorn & Orbe, 2016). In part, AE recognizes the limitations of traditional methods of knowledge creation and foregrounds issues of ethics, social identities, and research and identity politics (Adams, Holman Jones, & Ellis, 2015; Ellis, 2007). As such, the approach disrupts traditional modes of conducting research and representation (Spry, 2001; see also Holman Jones & Harris, 2019; Denzin, 2018) by using a diverse number of creative and experimental forms, including short stories, poetry, fiction, novels, photographic essays, personal essays/narrative, journals, fragmented and layered accounts, and social science prose (Bochner & Ellis, 2016). At the heart of AE is an evocative telling and examination of autoethnographers’ personal stories, using vulnerable and open storytelling with a heightened attention to emotion (Bochner & Ellis, 2016). Scholars’ personal epiphanies and turning points (Bochner & Ellis, 1992; Ellis, 2004; Denzin, 1989) as well as the personal transformations of subjectivities (Bochner & Ellis, 2016; Berry, 2013a; Berry, 2022) inherent to the enactment of this reflexive inquiry are often of particular interest. In these ways, autoethnographers lay bare the unique, private, and sensitive details of lived experience, which are often overlooked by mainstream and normative modalities of conducting research, to illustrate the complex connections between the personal and the cultural (Ellis, Adams, & Bochner, 2010), with an aim to be more inclusive and humane.

This pursuit, for me, is to use AE to improve and make more meaningful the everyday lives of my queer family, particularly PLHIV. Thus, I embrace AE as “an expression of the desire to

turn social science inquiry into a non-alienating practice” (Bochner, 2013, p. 53), which encourages rather than suppresses subjectivity and “embraces the fullness of living” (p. 53). No other method calls to me more strongly than AE does. Being able to put myself onto the page, to bring readers into my lived experience, and to create a reflexive space in which we might wrestle together with the messiness and complexity of everyday life are important, especially for disclosure. The intimacy of disclosure requires an equally intimate method and way of being. The emotional distancing that is common in mainstream research methods, and, more vividly, the ways AE seeks “to make readers feel that truth coursing through their blood and guts” (Bochner & Ellis, 2016, p. 66). Art Bochner (2017) astutely speaks to this participatory space for qualitative inquiry:

The kind of empirical inquiry that you practice is practical and dialogic; its truths are partial, situated, relational, and incomplete. Your work seeks conversation, encounter, and the fullness of an emotional and subjective life shared with others. You want to empower your audience, not control them and to wrestle with ambiguities and contradictions not resolve or exhaust them. You understand the language you produce as an instrument for dealing with loss, grief, injustice, and epiphanies through performative recreations of lived through experiences. Uneasy about the obscurity, insularity, and jargon of academic publishing, you seek to reach a larger readership that can benefit from your work. Thus, you think of yourself not only as a researcher but also as a writer and a communicator. (p. 2)

To summarize, there are at least three main ways that AE is important to my study. First, one of the greatest obstacles for PLHIV is the persistence of silence that bolsters stigma. AE enables scholars to tell stories from a first-person standpoint. Often such stories challenge what

we accept to be true or how we understand truth through lived experience (see Al-Solaylee, 2013; Ryder, 2010; Spieldenner, 2014).

Second, AE relies on and provides a space for an understanding of the interactive or social ways in which HIV disclosure unfolds in the myriad ongoing and mundane moments of people's lived experience. The approach enables me to relationally "study life in its natural settings, to think aesthetically, employ rich and expansive metaphors, give thick descriptions, and concentrate on meanings that can take readers [of our storied collaboration] into the heart of lived experience" (Bochner & Ellis, 2016, p. 32) and, in turn, "touch people where they live" (p. 55). I take this opportunity to be a calling to write my story as authentically and openly as possible, in ways that draw attention to triumph and hardship, and invite conversation and inquiry into the complexity, ambiguity, and sometimes other-world-messiness of lived experience.

Third, AE reduces the psychological and emotional distance between beings and invites readers into the experiences I relate as if they were their own (Bochner & Ellis, 2016). As such, readers can escape many of the perils of living a life with HIV while being invited to cultivate a deeper and rich understanding of related cultural experiences, beliefs, and practices that unfold because of it.

At first, one might think that heartache and grief predominate the experiences of PLHIV, and that our stories are, thus, inured, as many autoethnographic accounts are (Bochner & Ellis, 2016). Indeed, there are many trials and tribulations in everyday life. However, to be faced only with such aspects would make life unbearable. We are more than our suffering. In fact, despite the inherent grief and trauma present when living with illness, in my lived experience much joy and happiness abound. That I feel HIV has been a gift in key ways, and I also recognize is not the case for many PLHIV, is something that I will share in the chapters ahead. Some of my conversations

with friends in Chapter Five serve as an example of how adversity can yield to opportunity. Using AE provides an opportunity for readers to imagine, “remember, empathize, compare, and understand” illness (Bochner & Ellis, 2016, p. 158) through friends’ responses to everyday experiences. A goal of feeling and empathizing in this way is to create acute awareness for issues of social justice that may not be readily apparent in up close and personal ways to those outside the MSM community. Generally speaking, the gay community has contended with HIV for many decades. I am interested in engaging in intimate conversations with those in my study who identify beyond that community to learn what meanings HIV has for them and how they feel implicated, or not, by the narrative(s) of the normative social order. How might they be complicit in the production of silence directed toward and with untoward impact upon PLHIV?

Further, the very deliberate and purposeful enactment of self-disclosure with friends in this dissertation offers the opportunity to reconcile our “two selves, one that shows a believable journey from who I was to who I am, and how a life course can be reimagined or transformed by crisis” (Bochner & Ellis, 2016, p. 213). If the quintessential struggle of self-disclosure is to live more transparently and authentically despite perceptions that limit disclosure occurring, I’m all for it. Less explicit is the possibility that, even though disclosure may occur, it is also a partial enactment. That is, people “proceed to ‘uncover’ themselves one to the other at a mutually regulated pace” (Jourard, 1971a, p. 17). Even after thirty-four years together, my partner Andrew and I are still in the process of disclosing to one another. Thus, the study of disclosure is not about knowing all there is to know about each other, but what we might accomplish together because of this knowing. Thereby, our conversations become the basis for shared authority and co-authorship of the “web of significance” (Geertz, 1973, p. 5) offered through story in response to HIV and the emergent self-disclosure. Researchers and friends each share in the journey and its outcome through our

friendships. Again, this contributes to a relational understanding of illness and its impact upon each of us both individually and collectively.

#### *Exemplar Autoethnographic Dissertations*

Two autoethnographic dissertations related to mine motivate my study. First, Keith P. Cherry (1997), an alumnus of the Department of Communication at the University of South Florida (USF), wrote his dissertation titled *Ain't No Grave Deep Enough: An Ethnographic Study of a Residential Facility for Homeless People with AIDS*. The dissertation focuses on questions of perception (e.g., how HIV is represented in media and culture), self-identity (e.g., how hospice residents represent themselves), and meaning making (e.g., how hospice residents create an enduring legacy). Cherry uses his dissertation at least in part to correct categorical generalizations of his work on loneliness among PLHIV (see Cherry & Smith, 1993). He pursues this goal by exploring the stories of PLHIV that are messy, unabridged, unapologetic, and representative. In particular, he calls upon stories of “mundane details and practices of living that, given closer attention, were most revealing” (p. 24) and the ways in which these stories collectively constitute reality. In short, readers are invited to enter and “dwell” (Crites, 1971) in these stories where friendship matters (see Ellis, 1994; Tillmann-Healy, 2003; Rawlins, 1992), and we do so willingly, in part, because “[p]eople with AIDS have much to teach us about the persistence of human will” (Cherry, 1996, p. 56).

Second, USF Communication alumnus, Tony E. Adams (2008), followed Cherry’s lead by writing his autoethnographic and ethnographic dissertation *Learning, Living, and Leaving the Closet: Making Gay Identity Relational*, the project that later resulted in Adams (2011). Adams investigates problems of self-identity (how do gay men, and others, construct the “closet”) and self-disclosure (how do gay men come out), which in part intersect with issues concerning HIV.

He argues that “coming out” is a relational, multi-faceted, and consequential process. To come out is to make oneself visible, to claim a gay identity as authentic, and to mitigate or otherwise negate “the sources of invalidation [and erasure] of gay identity” (p. 16). However, being “out” and the desire to be this way is uniquely reflexive. To avow and claim a gay identity for oneself, as I did in the 1980s (see Chapter 2), entails taking a step toward living in ways that I want and choose, and to issue a clarion call about life’s potential for others who might be gay or HIV+ as I am. To come out makes narratives available to myself and to others, which offer contingent possibilities, rather than inevitabilities, which were previously hidden and unavailable, or marked only as “abnormal” (Hacking, 1990, 1999; Rosenhan, 1973).

Adams’s book motivates me to reflect upon my own experiences in coming out as gay and then HIV+. In hindsight, I appreciate that coming out does not happen in a day. It is the culmination of much thinking, rumination, reviewing, and evaluating in the course of being present in everyday experiences; of grappling to understand what identities are possible, and finally deciding which of them feels least costly and most authentic to debut to the world. In addition, it makes available to others and ourselves the chapters of one’s life story for others. For some, these stories may seem to be unfamiliar, incoherent, or strange. Yet, to others, they mirror similar struggles and point to a process of discovering a satisfying and tenable solution to this life-shaping problem of identity. As I reflect on Adams’s revelations again now in this moment of writing, I am convinced even more so of the need for us to be out with respect to HIV, despite the possibility of negative consequences. My study is, in large part, about finding a way to do just that.

### *Friendship*

According to Rawlins (1992), a friend is “somebody to talk to, to depend on and rely on for help, support, and caring, and to have fun and enjoy doing things with” (p. 271). The

participants (hereafter: friends) in my study are people who I have known for at least a year. However, many of the stories in this dissertation emerge through the bonds of friendship that have grown over decades, many originating during my university years of the 1980s. Also, many of my friends know each other, either through me or across dimensions of relationship and cultural membership that mutually connect us through shared interests and pursuits. I tend to choose my friends carefully, in part because my introverted disposition precludes me from superficial interaction and being (overly) reliant upon others. These aren't always personal strengths, but they are, nonetheless, indicative of how I choose to move through the world. While it is fair to characterize my relationships with my friends as predicated upon play and enjoyment, these are not the fair-weather variety of friends. We've been through a lot, even those with whom I've been acquainted for a brief time. Our lived experience creates many points of intersection among our stories which, in turn, serve as the bases for relationships that endure.

Through our friendship, I plan to explore everyday aspects of our relationships, with a particular focus upon HIV in this relational context. I focus on what HIV means to me, what is understood through self-disclosure of my status to others about my lived experience with HIV, and what meanings and possibilities emerge for us moving forward.

I hope the direct benefit of this work to friends will include the deepening of our bonds through inquiry and the joint authority and authorship (Lapadat, 2017) afforded by an ethic of mutual care when using relationship to explore the myriad implications for PLHIV. The invitation to participate assumes that communication, much like AE, is a collaborative, contextual, and cultural process in which we all have a personal stake (Berry, 2022). It underscores that "the tradition of individual responsibility – in which single individuals are held blameworthy for untoward events – has a chilling effect on relationships. It [individualism] typically isolates and

alienates and ultimately invites the eradication of the other – a step toward non-meaning” (McNamee & Gergen, 1999, p. xi). My aim with this project is to diminish opportunities for such inhumane eradication. “We are always already emerging from relationship; we cannot step out of relationship; even in our most private moments we are never alone” (Gergen, 2009, p. xv). This significantly implicates the presence and roles of friendship.

According to Tillmann-Healy (2003), friendship “lacks canonical status” (p. 730) in Western culture and is the weakest of social bonds. Personally, I value friendship highly, in part, because I am not invested in the institution of marriage—largely because of its close association over time with the church, a body that historically has not been kind to many people who live at the social margins, particularly gay men. In my life, friends are the family I choose (Weston, 1997; Schulman, 2009). I speak and relate from the standpoint of friendship. In addition, I value friendship as a primary means through which social life can be interpreted (Denzin, 1997). Yet, it is also through friendship that I expect to convey my social world to/with others, and how I suspect that they will do the same to/with me. In these ways, what begins as a localized phenomenon of friends interacting has, in turn, enormous potential to travel beyond that scope.

My hope is that the pre-existing relationships germane to my study will facilitate an exploration of identity across the event of self-disclosure. That is, how am I perceived by these friends before, during, and after self-disclosure, and what meaning-making occurs? Their responses will help to strengthen the personal stories comprising this AE by helping to culturally situate my personal accounts. That is, the experiences and reflections provided by friends will help to move my story from the specific to the general. They will deepen insights into the relational work of self-disclosure. To work with friendship honours the choice that others have made to become and remain friends with me. That choice presupposes a bond of inquiry through which we



can exchange ideas, understanding, and dreams about what can be. The cushion of friendship provides an opportunity to explore substantive issues more deeply. It does not presume, however, that our values, beliefs, and attitudes will always be aligned, but rather that we can through friendship continue to make sense of the world through our local experience with each other. As conversations progress, it is through conflict and divergent perspectives that I expect the richest stories to emerge. Conflict is not inherently bad; it is something to be productively managed (Denton & Ryder, 2009; Berry, 2016; Berry & Adams, 2016). Again, friendship offers a backdrop for leaning in rather than disengaging from and to a process of discovery despite any friction which may arise.

### *Conversations with Friends*

This dissertation begins in the middle of ongoing relationships with friends. We are already engrossed in conversations about everyday experiences occurring within a larger social context. There is no clear beginning; I do not expect to have a neat and tidy ending. We draw on, make, and use meanings from each moment of lived experience. Even though this project draws from more than 50 years of data, it remains a snapshot in the grand scheme of things. Yet, to be sure, much has happened in that span of time.

The shift from discursive to literary form happens by the “storying” of our conversations. Writing is itself a method of inquiry (Richardson & St. Pierre, 2005; Bochner, 1994, 1997, 2000, 2014; Ellis & Bochner, 2000; Bochner & Ellis, 2016). Writing “seeks to humanize the human sciences, placing people, meaning and personal identity at the center, inviting the development of reflexive, relational, and interpretive methodologies and drawing attention not only on the actual but also to the possible and the good” (Bochner & Riggs, 2014, p. 195). Stories will capture pivotal

moments in friends' lives, especially those moments that seem most important when called forth by our conversation and what develops through reflection thereafter.

I recall a story I once heard about a young girl walking along a sandy beach during low tide. Starfish dot the littoral sand, immobilized and far, at least from the standpoint of a starfish, from the water that gives them life. The girl runs to each one in turn, lifting them carefully as she cradles them back into the ocean. An adult stranger looks on then feels compelled to voice concern.

“You’ll never be able to return them all to the sea,” he cautions. “Your actions will not matter.”

“It mattered to that one!” The girl smiles.

So, this is our tale of friendship, and discovery, and insight, and sadness, and resilience. These experiences matter to us. I want them to matter to you, too.

Part of this study entails disclosing my HIV status to friends (Chapter 5). However, before we get to that point, I’ll use the next three chapters to flesh out experiences of “my life” which are essential to my understanding and which are the context through which I engage with disclosures in this dissertation. I do so to render myself visible and relatable in ways that implicate my being and doing. I make no apologies for who or what I am, nor do I seek absolution for the sometimes-contentious choices I have and continue to make. I ask for no permission to say what I feel compelled to say. As I write here, I hear and heed the advice of Keith Berry, my major professor, that, again, these things, once said, are irreversible (Watzlawick, Bavelas, & Jackson, 2011). His caution is welcome, yet the spark behind this dissertation feels essential. I tell these stories, in part, to recognize the importance of self-disclose over self-concealment and to encourage others who may feel immobilized at the precipice of self-disclosure to take their own leaps of faith. After all, there will always be obstacles along our chosen path and I have chosen to embrace those obstacles

rather than to turn away in search of an easier path. In facing those obstacles, I have been fortunate to have found a queer family upon whom I can rely.

The stories about disclosure in this dissertation emerge from conversations with friends, many of whom are members of my extended queer family. I list their names (alphabetically) and some key aspects of my relationships with them in the chart below.

<b>Character</b>	<b>Relationship</b>
Andrew	My best friend and life partner of thirty-four years
Argentia, Constance, & Isis	Friends within my doctoral program who suspect my HIV status, but have not asked despite freely sharing with me intimate aspects of their own lives
Arwyn	A university professor, mentor, and friend for almost two decades
Eamon	A friend I've know for almost forty years who recently disclosed his HIV-status
Hardin	The partner of one of my doctoral program friends
Milan	A friend I've know for almost forty years who has not disclosed his HIV-status
Stella	My Mum

The conversations that I have with friends are generative. The stories and dialogue in this study are composite responses to these conversations and expound upon how self-disclosure unfolds. I include Andrew, my partner, my Mum, Stella, and a limited number of health professionals to whom I have already disclosed my serostatus mostly for context. My experiences with them are relevant to this dissertation and will inform both my story and my responses to conversations held across friendships. Additionally, I could have chosen to include someone with whom conversation might be adversarial. Yet, I have chosen not to do so because these narratives already circulate widely.

In terms of the actual conversations, I meet with my friends together and privately, often at mutually agreeable and premeditated locations. All these friends know that I identify as gay. All know that I am in a relationship of longstanding with Andrew. All have met him and have known him for at least seven years, although not as thoroughly as they know me. Although some of my friends may have already begun to suspect that I am HIV+ because of their familiarity with the research focus of this dissertation, my in-class contributions, and anecdotal conversations we share while walking down the hallway in our department at USF, I never “spoke confirmingly” (Adams, 2011, pp. 91-95) with any of them about my HIV-status. Thus, I expect that my disclosures may surprise and even shock some of them. Their shock won’t be restricted to moments that center HIV.

As I have experienced in similar past disclosures, what conversation partners say in the moments immediately after disclosure is intensely meaningful. Immediate responses reveal how friends are inclined through their own experiences and perspectives to respond. In these moments I feel acutely aware that I am not neutral. Instead, I find myself “leaning in” with my own assumptions, expectations, and needs, wanting to be accepted all the while also adopting a stance that remains open to questions, or to rejection. Further, I envision that the prospective rejection of me as a PLHIV may not necessarily result in one or more friends wishing to depart from the project or from my life. I also realize that this could happen. Learning is possible regardless of what transpires. This modality of “qualitative inquiry involves researching with the practices, at the pace, in the natural contexts, and with an ethic of friendship” (Tillmann-Healy, 2003, p. 2) to emphasize what we can collaboratively achieve. This spirit of friendship, openness, and collaboration exemplifies the larger conversation that I would like to see continue in the world.

Further, by using friendship as method (Tillmann-Healy, 2003), I will write with added attention to the intersection of friends' personal narratives and my story, specifically as a result of HIV status disclosure conversations, but also broadly as we experience life together through the lens of friendship. The resulting storied framework in Chapters 3 and 4 will speak to the ways in which individual experiences unfold from everyday pivotal moments, to engage with HIV illness and self-disclosure in their relational moment and the broad contexts in which friends live. That is, HIV is neither relegated to, nor experienced exclusively at, the level of the individual; nevertheless, it impacts everyday life and is collectively experienced and thus can be meaningfully storied. To explicitly tell a story is to foreclose on the prevailing complicity and ambiguity amplified by silence.

To understand self-disclosure in its larger cultural context, I contend that the next logical step beyond knowing oneself is to disclose to friends. I chose to engage with friends for my study over strangers, in part, because I previously examined the interpersonal conflict present among *World of Warcraft* players (see Ryder, 2012). Some of what I learned during that research project, which led to the completion of my master's degree, implicates the lack of intimacy among strangers as a constraint upon their communication. I contended there exists a culture among strangers in an online setting that predisposes them to treat each other as though relationships and thus individuals are disposable. Disposability delineates the dialectical tension between instrumentality and affection (see Rawlins, 1992), strangers and friends. When friendship blossoms, it exemplifies the voluntary choice upon which friendship turns and how an affective investment in the value of connection encourages relational development. That is, friends *care* for one another. One of the benefits of engaging with "friendship as method" is that the approach backgrounds "traditional forms of data gathering" to foreground the "conversation, everyday

involvement, compassion, giving, and vulnerability” (Tillmann-Healy, 2003, p. 734). These dimensions will serve to sustain and often deepen the significance of friendship after our initial choice to enter it. Occasionally, the relational bonds of friendship deepen and allow us to be “truly present, meeting one another in our full humanity” (p. 732). This dissertation seeks to uncover those moments for their potential to unlock and free disclosure in and from its idealized case.

### **Relational Ethics**

Although this project is “exempt” by the Institutional Review Board (IRB) at USF, I still must think about ethical issues that affect this inquiry, especially in terms of working with participants in this research. After all, these are my friends. I wish not only to maintain our friendships but also to deepen these relational bonds. I heed the words of Ellis (2007a) who encourages “researchers to act from our hearts” (p. 210). In doing so, I invoke an ethics of care (Gilligan, 1982; Noddings, 2003) that foregrounds the situational, complex, and fluid nature of ethical engagement in lieu of traditionally rigid, institutionalized, and rule-based procedural ethics. An ethic of care encourages researchers to engage critically with the notion that however detailed and thoughtful a pre-meditated ethical plan may be, thorny issues may still arise. That is, I need to be situationally aware as conversations with friends unfold rather than to rely upon prescriptive responses to ethical issues (Ellis, 2007a). Therefore, I intend to honour that ethical concerns constitute an ongoing process of informed consent rather than a singular occurrence before research begins. These things being said, nothing is as consequential as honouring my relationships with friends that will not end when this project does.

Tullis (2013) encourages researchers who use autoethnography to prioritize the consideration of how we will reveal details of our research in presentations and publications that we might not otherwise share with participants, and not to underestimate the “afterlife” (p. 257) of

what we say in our stories. The interconnectedness of stories makes the landscape of their telling both rich and complex. No story exists in a vacuum; I cannot tell mine without revealing sometimes intimate details of others' stories. A collaborative approach to autoethnography would mitigate some of the ethical concerns that arise. However, I remain sensitive to how my lived experience and story, and those from across my queer family, have historically been reframed, usurped, or silenced. While this is not to suggest that my friends cannot or would not understand, relate, embrace, or re-tell my story with care and compassion, they would do so from their standpoint. Telling my story from my standpoint matters. It is at the heart of this dissertation and its call to action.

While I have chosen at this point not to share directly or “member check” (Tullis, 2013, p. 253) my formalized interpretations as they are written in this dissertation with the friends implicated herein, these representations emerged through many years of intimate interactions (2014-present in the case of my doctoral family, and since 1984 for my university friends of old). Objections, if any, have had decades to surface. This is not to say that they may not be present. I welcome any conversation which may arise and fully accept the consequence of my chosen approach.

Finally, writing from a first-person perspective comes with the risk of harm, not only to others but to writers ourselves (Tullis, 2013). I acknowledge, accept, and deem that risk acceptable. In the spirit of nonmaleficence, there is a “right to know” (Denzin, 2018, p. 117) and my story has potential to alter how others might in the future engage with HIV. An impact upon even one person, like the starfish, matters.

## **Dissertation Organization**

In Chapter 2, I provide a contextual framework upon which this project develops through sharing details from my early life and extending into young adulthood. By most accounts, I have an idyllic childhood. I am nurtured. I excel at school. I am loved. I include first moments of feeling different and the sense-making that occurs after “acting out” those feelings. As I will show, these feelings lead me to struggle during the transition into adulthood, through high school and into university. It becomes more difficult not to act upon the carnal desire that awakens during adolescence. My sexual orientation can no longer remain in the background; it is central to my identity.

In Chapter 3, I navigate my personal lived experience with becoming “out” and the existential threat of becoming sexually active in the mid-1980s. My stories reveal the ways in which my openly identifying as gay feels risky, even riskier is the spectre of HIV looms large. It stalks bodies like mine. How do I navigate the tension of feeling different than other boys and living that difference as an out gay man? I continue to learn about HIV, especially as it reveals itself through the lived experience of others. Throughout, I engage with the many important and often nuanced implications of (non-)disclosure to help answer, in part, the question of why disclosure matters.

Chapter 4 presents four pivotal moments which arise through my shared experiences with friends and the attending ways in which HIV instilled fear in us yet connected us deeply. Many of these stories are heart-rending. Each account adds to the nuance and complexity that HIV brings to my everyday (gay) life. The fear of becoming HIV+ is an ongoing source of fear and anxiety. Becoming HIV+ significantly shifts my outlook. I conclude Chapter 4 with an exchange with



Mum, made possible by the stories of HIV-disclosure, agency, and the many similarities between coming out as gay and as HIV+.

In Chapter 5, I turn to HIV disclosure experiences with immediate family and friends, exploring moments of both disclosure and concealment. Although I do not consider myself to be “suffering” with HIV, disclosing illness to others often feels scary. Through this chapter I engage with the social expectation for silence, ongoing identity work in respect of illness, and the breach of silence with disclosure(s) about HIV serostatus. I conclude the chapter with an epiphany about HIV-disclosure.

In Chapter 6, I conclude my study by conveying a series of descriptions that serve to answer the following question: “What do I want younger Steve to know based on what I’ve learned within this dissertation?” These notes speak to experiences across my lifespan and the sense-making that I engage when viewing my past through the present lens of self-disclosure. I foreground my newfound understanding of self-disclosure and how I hope it might also be more widely understood and embodied. Thus, I point to where future research might venture and how queer bodies might reveal themselves.

## **CHAPTER TWO: JUST THE TIP, HONEY**

In this chapter, I begin to self-disclose (to you). The narrative which follows (*my counter-hegemonic-narrative*) offers me a meaningful way to engage with and make sense of the (*oppression that I experience in the*) world. *It is a recipe that calls for a heaping helping of self-talk with a peppering of truth-telling.* Writing in this way simultaneously reveals and situates me in the context of my lived experience and its import. A caution: revelations are layered, can never finish, and are thus always partial and cumulative.

### **Flying from the Safety of the Nest to a Fabulously Fucked Up Gay World**

Eight months ago, in early September 1984 at age 19, I left home for the first time to attend university. I left with a secret. Since the age of seven, I have known that I am gay. Keeping this information hidden from my parents never made me feel uneasy. It does now as I return home to stay with them for the summer in May 1985 at the completion of first-year. While away, I take a leap of faith. I disclose my sexual orientation for the first time to another person. I “come out” to my steady girlfriend, Dorothea<sup>8</sup>, in September. But my news is unremarkable to her. In hindsight, I suppose we were both young kids just figuring things out as we each began to experience life away from home for the first time. That conclusion also unforgivably undermines Dorothea’s

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<sup>8</sup> Dorothea and the other names included in this dissertation are pseudonyms. Throughout this writing, I rely upon pseudonyms in lieu of orthonyms when identifying persons, to avoid the potentially confusing use of pronouns, especially when writing about interactions involving multiple simultaneous participants. However, I recognize that the use of pseudonyms is not without debate (Lahman, et al., 2015) concerning issues of representation, privacy, transparency, or power which position the standpoint of the author as always contestable.

advanced maturity. Despite my sexual orientation, our relationship not only continues but flourishes. She doesn't seem to mind sleeping with a gay man. In return, I am eager to have sex with her, often. However, irrespective of the pleasures our adventures bestow, I feel still incomplete. I wonder incessantly about what it would be like to "be" with a man.

In early February, I meet an upper-year Kinesiology student named Chase. With Dorothea's blessing, Chase and I have sex for the first time a week later. Being with him is everything I imagine gay life could be. He is the missing piece to the puzzle that I have laboured to complete. I feel freer, at ease, in lust, and in love. However, these feelings are also a source of much dis-ease as I return home for the summer. I am not ready to share with Mum and Dad the explicit details of my experiences with Chase. I sit on the bed in my old bedroom, looking down at the overstuffed bag of laundry that I have brought with me. I, too, feel overstuffed and dirty.

"Who's going to do this laundry?" I mumble to myself.

For how much longer will I be able to deny the feelings swelling inside me before I can no longer pass as "straight?" I assume that I am passing now. I reflect upon the numerous opportunities over the years during which I could have come out to my parents yet failed to do so. The timing never feels quite right. *Will it ever?* I am tired of the answers that I routinely give them. I equivocate. I misdirect or skirt around having to reveal my "true" identity when they innocuously ask how my day has been. They know of Dorothea. I want them to know of Chase. *How can I revise the story of the boy they assume me to be in favour of the man I actually am and who now stands before them with this burdensome secret?* I hesitate to share this fuller story of who I authentically am. At best, I have been withholding vital information about myself. At worst, I've been lying. I want to tell them. I want to be able to share intimate details of the wonderful things that have happened during the last eight months. I want them to be proud of me, of the man I am

becoming. A dissenting voice in my head repeatedly cautions that parents often abandon their gay children. My silence is steeped in the traditions of fear. I am afraid that others might not like the authentic me.

The summer weeks pass by slowly. Painfully. Being unable to live more freely is agonizing. Each Friday, I cannot wait to escape this small, conservative town to the welcoming, gay nightlife of metropolitan Toronto, a short two-hour drive south. I meet up with a few of the gay friends that I have made while at university and make a few new ones. We eat, drink, kibitz, and dance. We dance until sweat soaks us. Some of it our own. Much from other bodies in various stages of undress. Forced body-against-body intimacy in the close quarters of the dancefloor and within the purposefully dim, narrow, and sinewy hallways of queer spaces is by design. It's a huge part of why I love coming to gay bars. I feel at home with my queer family in these spaces. We come together intimately on waves of rhythm that compel our close dancing and flirty touching. Words cannot improve upon our being and binding together through music. Our being in this space is a de facto "being out" and blurring into one. The explicit disclosure of sexual orientation is unnecessary in the context of our communal sameness.

At the dance clubs that summer, I meet several boys by chance that I happen to know from high school.

"I knew you were gay," we often scream at each other in unison above the music upon seeing each other.

Our encounters underscore the impossibility of "coming out" in high school even when we "know" that others belong secretly to the same queer family. Our mutual silence, a tacit understanding ripe with self-loathing and fear, perpetuates our suffering and stifles the emergence of authentic identities. Traditional. Habitual. We see no bodies like ours represented in the sexual

education films we are forced to watch together after gym class. Everything we learn is about what boys do ... with girls. *Where is a self-respecting gay boy like me supposed to learn, in a pre-Internet era, about the kinds of relations I might have? Hey Dad, can you fill me in on the gay sex thing? Thanksssss!!!* We also hear what the jocks of the school threaten to do to faggot boys like us. Our silence is laden yet purposeful. *When will the cost of exchanging silence for safety become too great?*

Each weekend in the city, I dread that the music must eventually fade and the ways that leaving the bars will signify a return to the trappings of high school. The drive home is always an arduous one. I contemplate then begin to stuff this gay boy back into his “straight-acting” costume. I pray that I will again pass as “normal” even though I feel the opposite. For two hours in the car, alone, I repeatedly ask myself if today will be the day when I finally shed this ersatz skin to come out.

“Do you want something to eat,” she says. My mother is usually the first to greet me as I half-sneak into the house, often well into the next day. It’s her way of welcoming me back without judgement, as I appear through the kitchen door a little before noon. When I am slow to respond, she follows with, “did you have a good time?”

After meeting boys from high school, I think of the opportunity it presents to raise the topic of sexual orientation by “outing” them to her. She already knows or has heard me speak about some of them.

Telling her that, “I ran into Bobby last night with his boyfriend,” could test the waters ahead of my own admission but doing that would feel too slimy. *How could I use Bobby, a friend, so instrumentally for my own personal gain?*

“I had fun,” I say instead. “I met up with some friends from university. We had dinner then went out dancing.”

“Good,” she says. “It’s good to have friends.”

I’ve always thought of Mum as my best friend. I feel that I could tell her anything. Both Mum and Dad explicitly insist that I always can. *Is this their way of encouraging me to come out? I remain unsure.* They say these words too often and across contexts unrelated to any hints about my deviant orientation. I believe them, but coming out seems to require more certainty, an invitation, perhaps. The possibility of rejection, however slight, just won’t leave my mind each time an opportunity arises in which I could come out. Each time that I choose silence over disclosure feels like a renewed betrayal of the friendship that they so freely extend. *I think too much with my dick.*

With the arrival of each Friday night, I am off again to Toronto. When the bars close, my friends usually head off to one of the many after-hours dance clubs that stay open until dawn. Often, I join them. But tonight, I’m horny and can’t get men off of my mind. The midsummer itch. I masturbate chronically at home, so much so that when I enter a room I wonder if my face somehow betrays what I have been doing alone up in my bedroom. The freedom of being in Toronto means that I probably won’t have to jerk off tonight, at least not alone.

“I’m going to drive back to my parents,” I lie to my friends. “Good night, guys! Kiss. Kiss.”

On the heels of our goodbyes, a hunky man appears alone from the wide, wooden front door of the bar. I’m like a deer in the headlights. I recognize him as the taunted sweaty body I had brushed up against several times throughout the evening. *Who says that frottage should be private?* His eyes seem to flirt as he passes by and I manage to seize one more opportunity to coyly apologize.

“Hey! Sorry, that I kept bumping into you. It was so crowded tonight and that music ...”

“Yeah. Don’t sweat it,” he interrupts. “Great tunes tonight!”

I watch his lips mouth the words as he speaks. They’re so full, and wet. I’m getting wet. I wonder if I am his type. For most of the evening he has preoccupied himself with the furry little bear cub who smiled, drank beer, and overtly humped his leg like an untrainable dog. *Such decorum! Is there room for me on the other leg?* I am clearly not his type. No! My frame is skinny. I weigh 145 pounds soaking wet. My body hair is almost non-existent. I compare my smooth chest to the delicate yet masculine dusting of chest hair which swirls and glistens across his chest in the cool early morning air. I’m not a man. I’m still a boy! *A voice in my head is panting and yapping its deepest bow-wow, which expressed aloud would no doubt be yip-yip.* His brown eyes twinkle mischievously. His rugged face promises to sport a full beard if the stubble which has grown over the course of the day goes untrimmed much longer. Tantalizing beads of sweat glisten on one of the collar bones of his broad shoulders before beading to run down his ample, gym-prepped chest. He struts slowly yet directly down the stairs that lead to the sidewalk. He skates between me and the post connected to the adjacent railing against which I try awkwardly to lean. I smell his musky cologne as it impregnates the air in his wake. *One nostril thinks it might be Calvin Klein’s Obsession, the other knows better that it’s Ralph Lauren’s Polo.* I see him tug a white tank top loose from a back pocket of his tight-fitting denim jeans. I stare at the fullness of his ass-filled jeans as he passes. His thick quads stretch out his upper leg at either side by just the right amount, drawing attention to the way a man ought to curve if I were to build one (see Hwang, 1988). He stretches the tank top over his head. It slides snugly across his rounded shoulders and abundantly muscular V-shaped back as he squirms while walking to wrestle it down and tuck a corner into the waist of his unbelted pants. *How do those pants stay up? Never mind.* Three fingers stuffing cloth

beneath his trousers' waistband make his bicep bulge as he turns in silhouette to glance my way again. He smirks playfully and then halts his gait. This is a game he has played (and won) many times before. His stance enralls me. I follow.

My pants tighten at the crotch. I swallow my spit against the hard lump forming mid-throat. I want him. *Baaaaaad*. He knows what he's doing ... to me.

I catch myself. *Stop!* It's 1985. We're living at the height of the AIDS pandemic. The message of the day is that sex must *always* involve a condom. Flirting on the dance floor and brushing against each another casually in serpentine hallways is one thing. Acting upon desire would be quite another and potentially could be unsafe. Risky. Especially with a stranger I have just met. It is a pivotal moment about how bodies like mine ought to behave. Ought to act upon desire. It is how I must condition myself to think in the context of these times. I feel timid. I reluctantly follow the expectation to be wary. However, there have been a few times when Chase and I have fucked "bareback" (see Glossary)<sup>9</sup>, without using condoms. *How do I assess the potential risk of potential intimacy with this stranger? What should I be asking? Of him? Of myself? How low risk is low enough? Will low ever be near or reach zero?* I wouldn't want to bring anything back to Dorothea. Nevertheless, Chase and I converse only briefly and I, wanting sex, defer to his elder judgement. He suggests that condoms are a good idea given our tripartite romantic circumstances. In the heat of the moment, I want to fuck, not talk. Carnal lust overtakes reason. It is similar now with this hunk of a man. We utter few words, succumbing to raw, throbbing desire.

I smile at him widely but turn away toward my car. Immediately, I regret the choice not to pursue Mr. Hunk into the darkness like a puppy off-leash. I'm too afraid—of having sex with a

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<sup>9</sup> A glossary of useful conventions and terminology can be found in Appendix D.



man for the second time in my life, of being gay, of fucking strangers like gay men are expected to do, of ... AIDS. I wish I knew how to successfully negotiate the risks that gay men must always confront when meeting, lusting after, and daring to realize their love. I dread the two-hour conversation that is about to unfold in my head on the drive home during which I will waffle anew about whether or not I will come out to my parents. *Why can't I put into words my fear? My sexual frustration? Why is talking honestly and openly to a hunk of a man about my feelings and desire so difficult? Why are words considered an interruption to the heat of the moment? Why are gay boys like me expected to fuck first and fall in love (can we? are we allowed to?) second?* I wish I were *strai*.... No! I can imagine being straight but I'm certain that's not how I am wired. Yet, gay life as it unfolds in the early 1980s feels anything but certain. It is precarious. Gay lust/love is forbidden. To reconcile knowing with being gay feels hopeless. There is no obvious performance of identity that crystalizes the myriad fractured and unintelligible pieces ... of a whole, unified, authentic me. I feel lost.

Flash forward to 2023. Feelings from almost forty years ago are still visceral and raw. Their echoes etch my skin and bone. I glimpse the emotionally wrought faces of friends and loved ones across the years as if we had said goodbye only yesterday. Some I will never see again. HIV took them far too soon. With them, there were few if any goodbyes. Just a deep-seated, lingering emptiness in the gut brought about by their absence, a haunting sadness that enlarges each time I hear news of someone's passing. *Is it HIV? Again?* These feelings fade over time but truly never go away. They're slivers of lives lived, lodged beneath the skin, waiting to draw fresh blood upon re-surfacing. Losing a loved-one never gets easy. *"It gets better?" Fuck off.* Losing **hundreds** of friends is devastating. I live with the guilt of their passing. We had shared so many of the same

men in the bedroom. If that's where you had gotten HIV *Why them, not me?* I press on, living with the uncertainty that HIV may one day find me. It does.

In 1985, I think of disclosure as exclusive to the domain of coming out. Yet, there is little conversation about being HIV+ because at that time so few of my circle of friends were, at least to my knowledge. The first commercial test for HIV only arrived a few months ago, in March. That I might have HIV is inconceivable. (My *first* HIV test won't happen for another 15 years!) At the bars, I see numerous, colourful, and explicit pamphlets that advise gay men to fuck only with condoms and to practice something called "safe sex." I do not reckon that those pamphlets are intended for gay boys like me. I am not promiscuous. I have had only two intimate partners. In many respects, it feels like a simpler time. In hindsight, perhaps I was naïve to the life-altering-gravity of HIV. It was easier to deny things, especially aspects of my nascent sexual identity or a threatening but largely unknown illness like HIV. In 1985, I am not yet being called to reconcile the grief that will accumulate over decades to overflow in 2019.

In 1985, evidence for HIV is scant but grows quickly. As the 1980s unfold, the gravitas of HIV becomes more apparent and, for me, undeniable. The grapevine among gay friends has always been rife with information about with whom to sleep and not. However, not all that information has been accurate. It is the subtle yet profound change in Toronto's gay newspaper, *Xtra*, that resonates with me most. I often peruse the soft-porn descriptions of men who appear in its personal ads section and the promise of "knowing" them without the risk to safety that being with them might entail. Often accompanied by their handsome photos, the *personals* are both titillating and didactic. From them I begin to see how gay bodies construct identity through the stories they tell about themselves and how I might similarly position myself in relationship to them. However, my concern grows when I notice the once robust section of personals now yields to a sombre series of

obituaries. Each week, there are one or two obituaries that I'd note in passing. Now, there are usually half a dozen. Often, more. Many more. At first, I see few of the men I know. This changes rapidly, as the years pass. A weekly paper that now frequently dedicates several of its pages to men who have died stuns me into silence. Each time I see the name of someone I know, I pause. My heartbeat slows. A lump swells (*again!*) in my throat. Some of them I have seen in recent weeks at bars or on the streets of Toronto. I think of the conversations we've had, meals we might have shared, and the growing void that their absences continue to shape. HIV is closer to me than I think. HIV is intimately personal.

My 1980s began as a golden age of sexually-infused-post-high-school freedom and the promise of becoming "out" and living "normally." I did not expect the decade to conclude so haltingly with profound grief and loss. For a time, it knocks the wind out of me. I don't want to talk about it. I am not in the mood for sex. I don't want to be in love. I am too angry. Several times, I turn down the ardent attention of Andrew, the man who will become my partner for the next three decades. I feel unworthy of a serious, romantic relationship when too many of my friends have been denied this opportunity because of HIV. I need time to grieve. I struggle to catch my breath. I still need time to grieve.

In many respects, my grieving continues on the pages ahead in this dissertation. However, there is also considerable joy, connection, and personal insight. It is through hindsight (Freeman, 2010) that I work to make sense of my past. It is through self-disclosure that I render myself visible as I write through lived experience. It is through writing that I defy my erasure. Yet, I come to my study also with a lingering and profound sadness about how people continue to treat each other. It is a sadness exacerbated by how populated our planet is yet how disproportionately little intimacy we feel and share, and how shallow our understanding is, both of ourselves and others. HIV

intensifies that ennui, but HIV also challenges me to see and feel differently about the world we inhabit and construct together. One of the many gifts of HIV is the standpoint that it confers. *What if you could share this view? What if you could have seen life slip so effortless from an HIV+ body as I have done? What if you could experience the feeling of touch when your naked hand comforts the desiccated forearm of your neighbour, wracked by HIV and laying atop the crisp white sheets of a hospital bed during the last few days of his life? What if you could live with less fear of HIV? What if you could act with more empathy toward people with HIV and others in general? What if ... we made fewer assumptions about others instead of turning our gaze more deeply inward to summon the courage to be more wholly present?* Currently, I feel enlightened and hopeful.

The turn toward self-disclosure is born of my wanting to live a more agentive and authentic life. I want to be present as the author of my own story. I want to be seen. Specifically, I want to help others to understand me in context of illness. I hope to accomplish that by sharing my life experiences in and around the crucible of HIV. I want others to realize how their interpersonal choices may impact the lives of people, like me, who live with HIV. This is essential when others attempt to write or re-write stories to favour a more comfortable narrative. In doing so, I hope that the space between us will diminish. In close proximity, I want the strange to become more familiar and for the fear and defensiveness that others often display to yield to curiosity. In turn, I want those who would claim to be HIV allies to actively build inclusivity into the spirit of their newfound curiosity. I imagine this emerging through conversations and self-disclosures that allies initiate rather than those who are HIV positive. In my lived experience, conversations continue to demand that HIV positive folks do the bulk of the emotional labour and disclosing to others still risks a lot. Allies need to share in these risks more equitably. Knowing that others care enough to engage by taking steps to make impossible conversations only difficult ones truly helps. The

emergent space that we co-create through our mutual disclosure honours and encourages a more deeply intimate way of being in the world together. This is the kind of world in which I want to live.

“Make the world better, one day at a time,” self-disclosure says as it calls to me.

To that end, I earnestly want to reveal myself without apologies for my story. I do so to be seen, to represent myself well, and to be a beacon who calls to others. I write my story through self-disclosure in the hope that others will congregate to share stories of their own. I write seeking intimate relationship. It has taken me a while to get here, to this place in which I strive to live more authentically. I recognize that I am not alone. However, I long for a time when this place feels crowded yet kinder and its sense-making stories cannot easily be denied.

### **Becoming the Fag I’m Expected to Be**

By age eight, I emotionally *sense* that I am different than other boys who are my age. Being different<sup>10</sup> saturates everyday moments with the prospect of self-disclosure and the need to explicitly account for the widening gulf between others’ perceptions and my intuition. Yet, this eight-year-old boy does not yet fully grasp the nuanced ways that “boy” can be performed or the consequences of diverging from that script. Attempting to account or not for feelings that seem to lie beyond what boys are or can ever be has a price. I need time to learn how convention and expectation operate before attempting to breach the social rules of normality. Difference feels taboo. To announce these inner feelings and thoughts would speak against the social order and risk identifying myself as something less than, something damaged, incomplete, or irrecoverable.

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<sup>10</sup> I experience difference in nuanced ways that do not always manifest visibly through my performance of identity. I am drawn to activities that many of my female peers seem to enjoy like jumping rope, hopscotch, or helping the teacher rather than tug of war, tossing a football, or play fighting that are more commonly the prevailing activities to which other boys gravitate. While it would be transgressive for me to join the girls in full view of other boys, I want to.

Unsure of the consequences for breaching the social order but reliably certain that they will be bad, I remain silent and hope that someone else might take on the mantle of exemplar so that I can learn vicariously from their choices of expression. In this moment, words like bravery and cowardice begin to take shape.

“Kissing girls *is* yuck!” I blurt out.

Boys by my side and girls within earshot, my assertion emphasizes that I am “like” any of the other eight-year-old boys in my classroom. Such statements have a cost. To feel different inside yet proclaim sameness aloud is the cornerstone of every “closet.” I mark these first moments of sexual awareness as my metaphorical entrance into it (Adams, 2011). Passage is unopposed because my lapse to be authentic solidifies the socially normative order’s power over what—and therefore who—passes as acceptable. “Kissing boys is yum!” is what I should have said. Non-disclosure of authentic yet inconsistent details serve as tacit agreement to appear heterosexual, like the other boys. The longer I wait to speak in opposition, to correct the original sin of omission, the deeper the fantasy of conformity forces me into the closet.

Having only ever kissed my Mum and Dad, I can only guess the difference and significance of one type of kiss over another. The idea of kissing boys that grows inside me *feels* different than the way I feel when I kiss either parent. I look at other boys like I witness Mum looking at Dad. When my brother and I arrive home on the school bus each day after school, Mum has dinner ready. Dad is still at work when my brother and I eat, usually in front of the television. Mum waits for Dad to arrive home before eating. She keeps the additional meals she has prepared warm until he arrives, at which point she joins him for dinner. Dad usually arrives from the construction site dirty, covered in the grime of the day and the sweat that makes it adhere tightly to his skin. He teases my pristine mother with hugs that she summarily rebuffs with shrieks of disapproval. He

closes his eyes and puckers his lips, his arms at his side obligingly. When she moves close enough for a kiss, it's never just a coy peck. He invariably waits until Mum commits, then he opens his mouth and seems to lick half of her face as his arms struggle simultaneously to obey yet be devilish. The overture, repeated nightly, ends with laughter and her command that Dad ought to wash up before sitting down to dinner. I wonder if and how I might act on this idea and kiss a boy the way that my parents playfully kiss one another. I learn from other boys that boys do not touch or express feelings in that way toward each other. Instead, we are supposed to wrestle. We fight. We push each other around to demonstrate—mostly for the girls, but also for each other—that some of us are worthier of attention, especially from girls, than are others. What I have yet to figure out is what performance(s) will garner the attention of other boys, without confessing aloud any of the desires that I feel for them, desires which I am made to feel are too divergent and, thus, taboo in terms of the customary rituals in which good boys participate. As if repressing these feelings is not difficult enough, the summer break, which might on the surface seem to offer a reprieve from torment, only amplifies my desire for a subsequent return to school to begin a new year.

During summers away from school, which typically last from late June to just after Labour Day in September, I see none of the boys. Living in a rural area for most of my formative years means time spent within my family, or time alone with myself. However, returning to school I see those boys again. I am not supposed to notice the peach fuzz of the spring before that has slowly begun to darken and thicken. They all seem to be taller than I am, with shoulders broader and chests deeper than my own. I see the twinkle in their eyes, especially as they look toward the girls. I wonder if my eyes twinkle, or if I can fake twinkle when looking at girls while thinking of boys. I struggle not to notice the movement of their increasingly prominent Adam's Apples which seem to move more noticeably as they talk to me. Will my gaze give me away? Furtive and peripheral

glances into the distance seem more easily camouflaged. Having boys up close and personal is quite another matter. At recess, we run around the playground, play tag, Red Rover, and generally push each other around. My performance seems satisfactorily passable, but when one boy slings his arm over my shoulders as we walk back into the school at the sound of the bell to end recess, I am unsure how to respond. Do I sling my arm around him, in turn? Do I make eye contact while he speaks to me? Instead, I stare at the ground while we walk and hope that the friendship he expresses, and the accompanying intimate contact might quickly pass so that my cover is not blown. If I can make it to the classroom undetected once more, I will feel safer. Although I excel at my studies, they also feel like a distraction from having to think about boys. A welcome distraction. The classroom saves me from yet another recess, yet another lunch period, or the awkward lingering after school awaiting the arrival of the school bus which never seems to arrive fast enough to whisk my brother and me home again.

For now, in the oasis of Miss Bee's third grade classroom, I am a good boy. Miss Bee dotes on me. Several times I have offered to help her in lieu of recess and she has accepted. In many respects, she feels like a surrogate mother, at least during the school day. I sit up straight, stay quiet, refuse to fidget, and arrive each day with my homework done. Each effort to conform to my teacher's grand plan advances my status as her pet. Other children notice but do not seem to mind my performance of good student. They offer their friendship; in return, they share in the special attention that Miss Bee confers, becoming good students by association. Thus, as an eight-year-old boy, I learn how to fit in by deflecting attention from simmering sexual urges through the instrumentality of friendship. That is, until I pitch to Miss Bee a creative idea that I should write and direct a play in which my male classmates should feature prominently.



The plot involves my being kidnapped and tied to a chair. The other boys are intrigued and readily join in the “play” as I reveal it to them. They are especially obliging when it leads to time to ourselves in a quiet corner of the library away from formal classroom studies which they uniformly regard as boring. They seem to lack the words to articulate explicitly their gratitude but the way they look at me shifts. I have figured out the system and they are in awe. Unexpectedly, I become a leader and they obligingly follow. Their trust works in my favour as I guide them through the execution of the play’s story. The story, not written down, is being made up as I feel my way along. *I wonder how far I can go. How far will they be willing to follow?*

As I describe the kidnap scene further, I explain that any realistic kidnapping scene requires that the person who is kidnapped, me in this case, needs to be restrained. Because we have no rope available to our production, I convince two to agree to hold my arms against the chair behind my back. Another two readily join in to hold fast my legs to those of the chair in which I sit. A fifth encircles slowly, interrogating me sternly like a prisoner. He seems to relish the power of his role. Meanwhile, I cower and appear helpless which seems to egg him on. Secretly, I am not helpless. I feel empowered. This “scene” is an enactment of my desire for the boys. It also feels dangerously close to admitting my true feelings, especially in the context of the play’s interrogation. I tremble along not with any fear the scene intends to evoke but to conceal further the electricity now surging beneath my skin and the firm yet wandering hands of boys upon my struggling but still restrained limbs. This feels as psychologically close to an adolescent orgasm that I come.

When Miss Bee arrives to observe our progress, it does not take long for her to conclude that our play must stop. She says nothing that would reveal my inner monologue. I wonder if it is apparent to her. We simply return to class. In hindsight, I wonder if this incident prompted her to

make a private call to Mum at home or to enter notes on what had happened in my official, school record. The vehicle of the play, and my life within it, are a momentary awakening that coalesce to become a pivotal moment.

I constantly look back upon this experience and search for understanding in the feelings and meaningfulness of boys' hands touching my body. I appreciate how girls seem to behave more freely, especially with each other. I notice that their playful touching tends to build more affinity than distance, establishing a collective rather than a hierarchy. My male body gets in the way of boys touching me like they would a girl. *Why am I so different?*

*Why does the silence that hides this difference feel so imperative? Could I be a girl on the inside? If so, how would I know? Who could I tell or even talk to about this?* To move beyond the silence that reinforces the closet is a giant leap of faith. Breaching silence trusts that understanding and safety, rather than fear or harm, will emerge at the hands of others. So, I remain silent to stay safe. This is a giant leap for an eight-year-old boy which risks alienating teacher qua surrogate mother. His sexual awakening precedes the language that could transform awareness into understanding. Leaping on faith dares to abate or outright incapacitate the fear, stigma, and shame that habitually suppress and sequester sexual orientation in the closet. Leaping on faith risks everything. There is no going back.

### **The High School Angst of Just Wanting to Kiss the Boys**

During my adolescent years of high-school, North American media coverage of gay news, events, and lives in the mid-1980s fashions a stereotypical and pejorative reality. The editorial policy of Canada's largest daily newspaper, *The Toronto Star*, prohibits printing of the word "bisexual" in its "Personals" classified section. Toronto mayor, Art Eggleton, refuses to proclaim Lesbian and Gay Pride Week. Legal challenges to sodomy laws persist across the United States of

America. Larry Kramer publishes “1,112 and Counting” on the front page of the *New York Native* (Kramer, 1983), a turning point and rallying cry—especially for the gay community—at the onset of the fight against AIDS. Hollywood icon Rock Hudson shocks the world with his HIV diagnosis and gives the illness a ground-breaking public face. San Francisco becomes one of the first cities to provide anti-discrimination protection to people with AIDS. Dire Straits croons seductively in their North American chart-topping hit *Money for Nothing* about the “little faggot with the earring and the makeup” (Knopfler & Sumner, 1985). These phenomena function as both signposts and vectors for me and others like me, simultaneously announcing who and where I am, and how I ought to orient toward both others and myself. Identities emerge through a social process of meaning making (Giddens, 1979), within a disparate “pastiche of sensibilities” (Eisenberg, 2001, p. 544) comprised of unique individual experiences that both contribute to, and borrow from, a rich repertoire of culturally indemnified identity performances. During this time, I begin to uncover authentically who I am.

Music is central to the ways in which I discern and use meaning in my adolescence. In fact, it remains instructive throughout my high school years and into early adulthood at university. I listen. I dance. My mouth learns to shape itself in sync with song lyrics. Music is social. Its rhythms somatically instruct how I ought to move and behave. As Frith (2011) writes, “Music constructs our sense of identity through the direct experiences it offers of the body, time and sociability, experiences which enable us to place ourselves in imaginative cultural narratives” (p. 124). Through music, I notice others, how their bodies move and how they begin to relate through music with each other. By trying music on, so to speak, I experience how it mimetically instructs me to fashion myself, especially within the context of dancing with others. Yet, the music does not seem to fit how I *feel* about myself and the boys I continue to notice in advance of girls. Despite music’s

influence, I feel out of step. These dancers are not *my* queer family. This music is not really *my* music. It fails to provide order or a sense of belonging to the social setting in which I find myself. As a result, the narrative that music evokes is usually also one of resistance.

Music is a tool of cultural reproduction. It broadcasts the many expectations that specify what it takes and means to conform. It cautions against the calamitous social risks of deviance ... should I surrender to identifying as that little faggot as popular yet wanton song lyrics homophobically urge me to become. "Society establishes the means of categorizing persons and the complement of attributes felt to be ordinary and natural for members of each of these categories. Social settings establish the categories of people likely to be encountered there" (Goffman, 1963, p. 2). To perform selves that diverge or are incongruous to the "mainstream" risks being a "spoiled identity." An identity marked as "different" in this way disqualifies full social acceptance. As a young, teenage boy who is attempting to find his way in the world, the tension between living authentically and performing acceptably is palpable and omnipresent. The demand for compliance is strong, and so I must wonder: Where *is* my "queer family"?

I know that I am different, through the secret desires I have had from early boyhood for same-sex attraction. However, I learn to tone down those stigmatizing aspects of my identity that fall too far outside of what society considers to be normal. In this way, my performed identity is more likely to garner acceptance. I did not learn this way of being overnight; rather, it is the culmination of many years of practice. As the dominant storyline tends to go, "real" boys do not skip rope at recess on the playground with the girls. Real boys put their physical abilities on consequential display by playing football with the other boys. However, it would be a mistake to think that I, alone, engage in this sort of social and existential performance. Identity is a practice and an ongoing process of negotiation that is constantly being evaluated, adjusted, and re-evaluated

around the goal of mutual acceptance in social settings (Berry, 2007, 2016; Bardhan & Orbe, 2012; Jackson, 2002; Carbaugh, 1996; Fairclough, 1995; Urbach, 1996; Mooney, 2005; Herek, 2015). I never think to question the identities of others during high school. I notice what others are doing, but I am too busy maintaining my cover to examine more than cursorily their performances. To break cover feels too risky. Although disingenuous, I pretend to like girls in the ways that are expected of male bodies. I flirt with girls and go on dates with them. On a double date, I make sure that the way I touch my female partner's body is noticed, approvingly, by the other males who are near us bearing witness. I hope that these performances will allow me to return to my studies, to graduate high school unscathed, and then to escape to university without detection.

According to Duncan, Prestage, & Grierson (2015), "Very few studies have explored the characteristics of young gay men's relational lives, particularly in regard to the social norms and expectations they may have grown up with and those they encounter as they come out, meet other gay men, and venture onto the commercial gay scene" (p. 799). As I think about my own "coming out," instructions for being gay seem complex and ineffable. Living in a small town further demonstrates this reality. No one in the 1980s is willing or able to explain to me that bodies are cultural sites (Adams & Berry, 2013) that instantiate gendered identity "through a stylized repetition of acts" (Butler, 1990, p. 519).<sup>11</sup> These performances of identity are often tenuous and volatile negotiations enacted through the measured and iterative process of self-disclosure. Repeatedly, participants constitute and revise themselves within communication, as it is "situated against normative expectations guiding and limiting social interaction and perceptions of appropriateness" (Adams & Berry, 2013, p. 311). My journey of coming out, much like the journey

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<sup>11</sup> Throughout my study, I will use Butler's definition of "performance" to speak to how identity emerges, remains fluid, is negotiated through performance, and is enacted over time. Thus, performances of identity are subject to being rehearsed, contested, negotiated, adjusted, and performed anew.

of conveying and examining my HIV disclosure story within this dissertation, is largely one of self-discovery and the quest for relational knowledge that seeks to answer the question “How can I perform in accordance with the expectations of others yet maintain a sense of integrity with respect to who I know myself to be?” Knowing myself is a requisite condition for self-disclosure, but knowing is always incomplete. It heightens the awareness of how disparate I often feel and how painful an experience that difference creates in terms of others’ real and perceived perceptions of me. Unrelenting social pressure “often entails being others’ versions of ourselves” (Berry, 2016, p.7). However, being someone else’s version of oneself feels inauthentic. To be as I wish to be means countering the dialectical tension within communication that elicits my social conformity. As Canadian, gay activist Tom Warner (2002) contends, to be who I really am despite others’ expectations involves breaking free of a normative narrative to discover the inherent value of queer identity:

Like all victimized groups, bisexuals, lesbians, and gays have had to tackle how they see themselves in order, in turn, to change how others see themselves they have had to come to terms with their sexual orientation, not only accepting it as healthy and normal, but also celebrating it as special and liberating. (p. 8)

I feel that I lack either the social tools or mental tenacity and never quite get there during high school. However, as I venture off to university, I hope that being in a new place and with new people will allow me to be more of myself in my relationships with others and, thus, in the ways I relate to myself.

### **Fucking and the Awkward Training-Wheels of “Coming Out”**

It is 1984 and, having graduated from high school, I am attending the University of Waterloo (UW) and live in first-year residence, on campus. I am living away from home for the

first time. This transition provides me with a different social setting and new people with whom to practice negotiating my identity.

By the end of the first month of the first semester at university, Dorothea and I have sex for the first time. The day before, I had met her during lunch in the cafeteria when she joined the table at which I sat with mutual friends. I think she is pretty. A few bodies down and across the table from me, she smiles, laughs at my jokes, then looks away coyly. Later that night, I slip a note under her door. The following morning, a Saturday, she knocks at my door. My roommate is out, and I lay in bed across the room from the door, naked, covered by a thin, white sheet. I shout for her to come in. She enters slowly, sees me still in bed, and turns slightly away. I tug at the sheets to ensure that my chest is still covered, and she seems willing enough to turn to face me, my note neatly folded in hand. She expresses her surprise at the content of my note. Extolling her beauty, I have written that she should be my girlfriend. I pat a spot above the sheet to my left and she obligingly sits, her legs slung over the side of the bed, her torso turning obliquely to face me as I shuffle the pillows under my shoulders to prop myself up. As we talk further about the note, she notices the sheet move but both my hands are plainly in view. It does not take her long to figure out what it is that is moving. I smile. She smiles. Laughter ensues.

In this encounter I blindly follow the cultural script of heteronormativity that I learned in high school, even though I know these rules do not fit me. I do so even though I suspect that these rules will lead us to unfortunate consequences. In a fit of guilt over how disingenuous the intimate performance with Dorothea feels—this is not *my* music—I tell her that I am gay. She is confused by my disclosure but accepting of me. We fuck. Sometimes she comes to my room. Sometimes I venture to hers. Because she lives on an all-girl-floor in residence, the trip to her room feels like a violation each and every time. Once I climb the stairs to the third floor, I peer through the glass

panel of the stairwell door, before sneaking it open. It feels as though I tiptoe down her hallway and rub rather than knock upon her door. I neglect to ask her if the trip she makes to my room feels anything similar. One day during the exam period before Christmas as we ride up four floors in an elevator to the library, I begin kissing her neck as I hug her from behind. She giggles and cocks her head to the side exposing the flesh of her neck more fully underneath layers of winter clothing. My hand slides up from her waist to find a breast. More giggling. Just as we pass the second floor, I turn to the elevator doors and jam my fingers between them to force them open. The elevator stops mid-floor. We fuck. I am shocked by how familiar that having sex with her has become. I am shocked by who I seem to be becoming.

As the months pass, I notice that several of our friends have become couples. In our expanding circle of residence friends, I am the only one who I know to be gay. In our second semester, after returning home from the Christmas holidays, I confront Dorothea. I tell her how kind she is, how much fun we seem to have, but that I feel a constant need to explore sexuality further and in ways that she is biologically unequipped to help. I remind her of my interest in men, to be with a man for the first time. She encourages my exploration.

Soon after Dorothea's compassionate response, I discover in the university's student newspaper that an on-campus gay group, GLOW—Gays and Lesbians of Waterloo—runs a coffeehouse every Wednesday evening in the Campus Center, affectionately referred to as the "CC" by students. I decide to check it out and stroll by the room a day before the weekly meeting to try to get my bearings. However, when Wednesday arrives, I cannot summon the courage to enter the coffeehouse.

Each Wednesday is movie night in the Great Hall of the CC. The large, central room is mostly dark except for the light of the projector and shadowy reflections from the screen upon



which the movie plays. Along the side of the Great Hall, chairs and tables have been pushed out from center to create more floor space upon which students now sit, their gaze directed toward the movie screen. I stand behind them, pretending to join in while I survey the comings and goings of the coffeehouse. During the screening, the Turnkey Desk, a kind of community hub service run by students, continues to operate next to where the projector noisily clacks out frame by frame of the film. In these ways, the backstage area of the screening feels particularly liminal. It remains busy while also being dimly lit. I stand, observing, while wrestling with a decision to move. *Should I enter the coffeehouse? Will I be noticed by the moviegoers? What if someone from residence sees me going in? Will they even know what is in that room? Might they follow, thinking I have discovered something that they should attend?* A million thoughts flood at once as I attempt to weigh the pros and cons of acting upon either desire or fear. I continue to notice the men who enter. Surprisingly, I see a few women entering, too. In my earnestness to encounter gay men, I had not pondered long enough to think that there might also be women! There are too many variables and unknowns to make good sense of what to do.

When I return to my residence, I telephone Dorothea to chat before bed. She repeatedly asks how my exploration is coming. I am at a loss to explain how stuck I feel. For so many months, I have gone through the motions of being “straight” with her. Now, with the prospect of finally walking through that coffeehouse door, I feel reluctant to jump with both feet. I feel that if I do there will be no coming back. She notices my nervousness but is unable to offer any advice on how to proceed. To conclude our call, I tell her that I will probably muster enough nerve to enter the room next Wednesday. When Wednesday arrives, I am relieved after what feels like an unusually long week of waiting. I interpret the relief as a sign that finally I have made peace with

what to do and that I am ready to find people like me: *my queer family*. After arriving at the CC, I hover only for a few minutes before racing at last down the stairs.

### **Finding My Queer Family**

Once inside I immediately notice the room's dim lighting, which puts me at ease as I begin to survey unfamiliar surroundings to orient myself. The aroma of coffee wafts from across the room. Several people are milling about the table upon which it sits. Nearby, an assortment of donuts is neatly arranged atop a plastic serving tray. A thin, stylishly-dressed, blonde man gracefully lifts a fruit filled beignet. Its coating of confectioners' sugar dusts his cheek, just below the rim of his red tortoise-shell glasses, as he takes a first nibble. He looks so gay. *I think to myself as I muse about his performance and my own.* The way he dresses. The way he moves. The way he holds the beignet. All seem alien to the performances of men on the other side of the coffeehouse door. *Men are not supposed to behave in these ways, I have learned.* Yet, I still feel at ease as I witness for the first time a group of people seemingly unafraid to express the myriad and subtle ways that mark their difference. Could this be my queer family?

I feel that I stand out as a new face to the other men in the room. Beignet-boy, Jake, I quickly glean from his nametag, turns and flashes me with a smile. I try not to panic. Jake's eyes sparkle warmly through his glasses. His wide, beaming smile maintains my ease. He grabs a nametag from the table near the coffee and hands it to me then gestures at the mostly rainbow-coloured markers laying nearby. I regret almost immediately my choice of black, but continue to write my name in uppercase letters—S T E V E. I try not to overthink while writing or else the letters would no doubt become contorted and illegible. I slowly peel off the backing then press the nametag firmly into the flannel of my shirt, just to the left of my heart. Jake shakes my hand as he introduces himself. His palm is clammy; his grip much less firm and aggressive than that of my

construction-worker dad. I relax the power of my grip to meet his. Conversation seems sluggish but begins to feel less awkward as Jake turns to others who, in stride, warmly greet me. I am thankful for their interest in welcoming me, but I also feel like fresh meat. Many of the men in the room casually look in my direction as they continue to converse with others. I feel them seeing me in ways that resemble those that I have for so many years been furtively stealing from the boys I notice. As I continue to make sense of being with men, like me, for the first time, I come to the realization that outside of this room, gay men exist largely as stereotypes. Inside, I am discovering, for the first time, how gay men can and do relate to other men. Prolonged stares. Warm smiles. Intimate and lingering touch. Even kissing. I am struck that I have never seen a man kiss another man before. And although these are just cheerful pecks on the cheek, I feel disquieted and simultaneously unlocked by what I witness. For so many years I have wanted to express myself in these ways but in the 1985 world beyond these walls such ways of being still feel impossible.

I decide to take a seat at the end of one of the couches next to a man whom I recognize from the week before when I saw him enter. His nametag is written in pink marker—C h a s e. He has drawn a pink triangle above the letter “a,” like I have seen some girls occasionally draw a heart in place of the dot atop the letter “i.” He smiles incessantly. We shake hands briefly and he returns to a conversation with the woman at his left. I watch and listen, yet only half pay attention to the conversation others are trying to have with me. I am more interested in Chase. I am smitten and cannot stay my focus from his lips as they move in conversation. I notice his one-or-two-day-old stubble, the wave in his dirty-blond hair, and the pierced lobe of his right ear which sports a silver-embossed miniature of the pink triangle that emblazons his nametag. I have looked at boys before and felt attraction, but this is the first time that I see a man and become sexually aroused, not only by him but also by the prospect that this feeling might also be, for the first time, reciprocated. As

the coffeehouse draws to a close, people slowly trickle out of the room. Chase helps several others tidy up the room, straightening furniture, and toss what remains of the donut crumbs into the garbage. As I turn toward the exit, I take one last l-i-n-g-e-r-i-n-g glimpse of Chase. I stifle a sigh while leaving.

When I get back to my room that night, I immediately call Dorothea. Her groggy voice reveals that she is half asleep. Still, she wants to know how the evening went. *How can I tell her that I am lusting for a man, a man who has a name? She has been so kind and patient. To tell her this would feel like a betrayal.* I stammer to share a few of the details of my night. She counters by interjecting with the open-ended question, “Who did you meet?” I tell her about tortoiseglasses, messy beignets, and pink triangles. *I wonder about the relevance and context of my description for her. I am describing, for both of us, the strange and yet familiar. What sense will she be able to make when hearing how current events connect to my private years-long-gay-fantasia which only now risks becoming real?* I tell her that I might attend the coffeehouse again, perhaps in a week or two. As the call concludes, I wish her sweet dreams and that I will see her at breakfast. “I look forward to hearing more then,” she entreats as she sleepily hangs up the phone, which seems to bounce a few times in its cradle before the line clicks into silence.

I curse at the recurrent frustration of untangling the long, black, curly cord of the rotary telephone before returning my own handset to its cradle on the wall. As I do so, I wonder if any of the other rooms with which this telephone line is shared have listened in. If so, I will surely be questioned about the news that I have shared with Dorothea. I turn toward bed, a single mattress atop a low-rising, wooden platform that juts out perpendicular to the concrete, painted wall of the residence. My head upon the crisp white cotton of the pillowcase, my eyelids close sleepily as I stare toward a ceiling which drifts gradually out of focus. I have trouble falling asleep. My eyes

close, but my brain refuses to slow down. All I can think about is Chase. I replay the evening over and over on the canvas of my eyelids. Like a film, I stand outside the frame to visualize myself in interaction, noticing particularly not just what I said but also how I said it. *I should have been gayer. I should have flirted more. I shouldn't have been such a dude. What the fuck was I thinking when I wore a plaid, flannel shirt?* I keep hearing Chase speak and imagine that we are still chatting. As I finally drift off into sleep, I think about his lips.

When I see Dorothea at breakfast the next morning, she sits next to me and gently squeezes my hand under the table. Our friends slowly trickle in to join us. They are all straight, as far as I know. For Fau Mei and Chester, who always sit side-by-side, I wonder how long it will be before they dump their respective boyfriend and girlfriend from high school to announce their coupling. These folks whom I have known now for a little over six months are still strangers to me. We are still learning about one another. It seems obvious that Fau Mei and Chester are a couple, yet they shy away from discussing their feelings openly with the rest of us. *I wonder what I contribute toward stifling their news while pondering how they, and my other friends, inhibit my own sharing.* As we carry on with eating and chatting casually, I feel that I cannot share any of the details from the night before with them. However, Dorothea finds my hand again and seems still eager to hear about the night before, now face-to-face. I turn to her silently. As my eyes meet hers, I sense that she knows implicitly how I feel about discussing openly what I had already begun to share privately with her. Breakfast concludes, without sharing, and we scurry off to attend to our individual schedules. I catch up to Dorothea later that afternoon while we walk to our respective classes. I finally gush.

## Between Two Worlds—Stretching my Whole

She and I stop at one of the wooden bridges traversing the creek that meanders noisily below to punctuate the residence zone from the sprawling, brutalist architecture of the main campus. My butt against the railing, I hug Dorothea who faces me. As I quietly begin to disclose the details of what happened and the resulting feelings that welled up the night before, I am struck by the *mise-en-scène* we create for those who pass us by. They will recognize our embrace as boyfriend and girlfriend. None will suspect that I am gay. None will know that what I now crane to whisper in her ear is no confession of my love. Most would recoil at my admission of lust for a man named Chase. Dorothea holds me tightly, her expression unflinching.

What I gush to Dorothea is that in the time between breakfast and our walk to class, I looked up Chase in our residence phone directory. I know from my conversation of the evening before with him that he moved out of our building after the fall semester, but his name and number still appear in the listings. I call his number and his former roommate answers the phone. I ask for Chase and am told that he has moved out. I do not let on that I already know this. Instead, I ask if he has a new phone number, which the roommate readily gives me. I write it down, thank him, and then hang up the phone. I stare at the piece of paper upon which I have written three things: Chase, a phone number, and a triangle above his name. Dorothea asks if I will call him. “I want to,” I admit, “but I am not yet sure.” She kisses me lightly upon the cheek, and as we step off the bridge, we walk in diverging directions and onward to class. *As I walk, I think about how struck I am by her capacity to love, her willingness to hear me, and that there is never even a hint of judgement in either her responses or her being. I also think about how incredibly unfair our relationship seems. A man who is now finally able to act upon fantastic dreams of being gay should not be with a woman.*

That night, I call Chase. He is surprised to hear from me and wonders how I have gotten his number. I tell him, plainly, how I have come across it. Aggressively, I confess that I want to see him and that I always get what I want. He chuckles aloud into the phone but seems intrigued by my advance. "Let's chat some more at the next coffeehouse," he says before we hang up. The next coffeehouse arrives quickly. I am thankful that it does. Chase and I chat some more but the three hours of Wednesday's meeting passes by so quickly. As the evening wraps up and people begin again to disperse, Chase thanks me for the chat before turning once more to help tidy and straighten the room. I thank him too but leave crestfallen. I stand on a bridge outside the CC, and after about twenty minutes, see Chase and another man, Austin, leaving together. I decide to follow them at a distance. For about ten minutes, they walk and chat while I try to discern if there is obvious chemistry between them. When they finally notice me, they smile and ask me to join. We walk a little longer to Austin's apartment where we continue chatting until the middle of the night.

*Though I participate, I wonder how well I manage when all I can think about is Chase. Through most of our ongoing conversation, I stare at him. The three of us lie like the sides of an equilateral triangle atop the area rug of Austin's bedroom floor and my mind helplessly wanders. The thick, woolen, work socks that Chase wears are near my face. They disappear behind the cuffs of his loose-fitting khaki trousers as my eyes follow upward. The crotch of his trousers seems full, his butt amply strains the buttons holding pockets closed in behind. His torso, cinched at the waist by a woven, brown belt broadens marvellously toward his chest and shoulders. His colourful shirt is open at the collar. One button, conservative. Two buttons, comfortable. But opening three buttons feels almost wantonly available. I register no protest to my wandering eyes. I follow the wisps of chest hair that playfully tickle the cotton of his shirt up toward his neck. His Adam's apple bounces as he talks to Austin. I relish in the customary stubble of his cheeks down to the tiny but cute dimple*

*at the tip of his chin. When I arrive at his lips, every thought is about how they will feel when pressed against mine. I'm glad, in the moment, to be reclining lest I topple over.*

As the night wraps up, Austin hugs us both and sees us to the elevator. I ride down alone with Chase. Neither of us speaks until we exit the lobby. When he hugs me good night, I ask if we can see each other over the coming weekend. He agrees. It is all that I can think about on the elated twenty-minute walk back to my room. Once home, I wonder if I should call Dorothea. I check the time and it is pushing 3:00 AM. It can wait until breakfast.

I wake up the next morning feeling energized, and then realize while looking at my schedule that Bart, a friend from high school, will visit me this weekend. At breakfast I tell Dorothea everything about the night before then ask her if she will entertain Bart for a few hours while I sneak away to meet Chase at his apartment. Dorothea has yet to meet Bart but agrees to spend some time with him. I spend most of Saturday with Bart, introducing him to my circle of new university friends during dinner at the residence cafeteria. *The food, as always, remains questionable. The company decidedly less so.* After dinner, I leave him with Dorothea while I return to my room with the excuse of needing to study for an exam. There is no exam. I rush back only to shave, to shower, and to dress. I wear the same plaid, flannel shirt that I wore when Chase and I first met at the coffeehouse. *I enjoy the shirt's fuzzy texture and think that Chase might as well. Besides, the green colour brings out my eyes.* My walk to meet Chase takes about twenty-five minutes, but it seems to pass in one. When I step off the elevator and knock at his door, he greets me with a hug. He wastes little time introducing his straight roommate (he marks his sexuality for me) before showing me briefly around his condo on the way to his bedroom. Once there, he closes the door behind us.



His room is small and a bit unkempt. Previously worn clothes are strewn about. Books are stacked on the desk at one end, behind which a window extends the width of the room and from floor to ceiling. The sheets on his bed make it look recently slept upon, but nonetheless inviting. He hugs me again. His hands begin to wander and pull me in close. My back, my shoulders, my waist, and then my butt. *It has been about twelve years since my first thoughts of same sex attraction. I have waited so long to act upon those moments. I want this to happen.* We undress each other and roll about on his bed for about a half an hour, tracing every curve and exploring every nuance of each other, before we have sex. I fuck him first. We don't use a condom. I cum inside. I want to continue laying there on top of him, with his knees pulled up on either side of my naked torso, my face nuzzling the turn of his neck between shoulder and jaw. He smells so damn good. I inhale deeply. (As I type this now thirty-eight years later, I can still smell him.)

He stirs after caressing the scruff of my neck with his hand. From some point in our previous conversations, he recalls that I have never had sex with a man before. He asks if I am sure. Without hesitation, I roll onto my back then pull him on top of me. That he penetrates me so easily surprises him. "No pain?" he asks. "None," I reply. I have wanted this for too damn long. It is everything I have imagined it would be and more. Afterwards, he is a little shy when I peer from behind the shower curtain to see him standing there peeing. *I pause while registering the hierarchy of intimacy, noting those which can be shared and the few which cannot. We experience skin inside skin intimacy, but I cannot watch him pee.* Despite a shower, Chase's scent lingers on my skin and clothing as I walk back to my room. Once there, I call Dorothea and then walk over to collect Bart. I thank her for spending time with him. No kiss on the cheek tonight, but I am thankful. I do not want her to detect Chase, his musky passion still marking my skin. Bart is none the wiser.

## Practicing Homosexualsssss

Three weeks later, Chase and I walk on campus one afternoon after class. He lilt.

“I need to stop by Needles Hall [the administration building], is that okay?”

“Sure,” I dotingly respond, “It’s on my way back home, so why don’t I walk with you.”

“Sounds good,” he confirms.

As we walk together, our outward appearance is that of friends. This performance does not disrupt the social expectations of the more formal and straight setting of the administration building through which we pass. I enter the Registrar’s office with him and watch his transaction from a chair in the lobby. It’s the little things in how he moves that catch my attention: how he holds the manila envelope of important papers in his hand, the direct eye contact that seems to come naturally to the conversations he strikes, and the playful curl at the corners of his mouth that delimit his perpetual smile. As he finishes up, we walk down a set of wide stairs in the atrium and toward the main entrance. I notice we are standing closer than male friends tend to stand. *I think about how dangerously close to one another we stand and how taboo any public display of affection would be with him in contrast to Dorothea. Why can’t I just hold his hand. Or kiss? I long for these things.* As we step outside, I see a small group of students standing on the curb and at the city bus stand. Chase and I are about to head in different directions; he is going to his apartment and I am going to my residence. So, as we navigate the last steps onto the sidewalk, I smile and lean in for a kiss.

I didn’t care who was watching

Students, faculty, staff, passersby

Faceless people melded with the background

It was just he and I

My eyes, closed, but I could see and feel everything with such precision

The moment seemed to last an eternity,

I could have lived there forever—and perhaps a part of me does still.

...

And, as my lips parted from his

I turned to walk down the last few steps toward the sidewalk

Shocked faces began to emerge

Piercing stares of disapproval focusing acutely on me

And on him

As feelings swelled into their throats and onto curling lips

On the frosty air a single word pronounced their judgment

FAGGOT! (Ryder, 2010, p. 322).

Daring this boldly, in public no less, is not something I could have done only a month earlier. *Is this the same guy that lingered outside the coffeehouse before finally rushing down those ominous stairs that he had counted for weeks? Who is this new Steve? What happened to the old Steve? Chase is making me gay. He helps me to realize what being gay is and can be. I want this. I feel so alive.* Others notice our behaviour. This is not the first time I have the word FAGGOT hurled at me. In public school, I first heard it around the time I became a student in Miss Bee's class when I was eight years old. Then, its meaning felt so different. Then, I did not do anything (at least, nothing that I was aware of doing) to warrant its use. More often, my contemporaries would use FAIRY or GAYBOY. FAGGOT is a grown-up-word. Here, now, on these steps of Needles Hall, Chase and I are grown up. As I lean in to kiss him, our participation in this action

warrants the label. We are FAGGOTS. However, we choose to let the word fall behind us as we walk away, and that feels strident and affirming.

I look at Chase. A canvas backpack emblazoned with activist buttons—Silence=Death, ACT!UP [sic], a circular black button with pink triangle, stands out from the many others—slung over one shoulder. He looks obviously<sup>12</sup> gay to me. I know him, though. *What do others see? Are they looking at all? For what are they looking? What can they see? What can be seen without a context for understanding that gay exists and what it is? Is gay just a catchall for difference?* For many years I ponder the gay fantasia that precedes this public display which reifies who and what I am, and, thus, the galvanizing characteristics of who I am for others who look at me. Suddenly, I become self-conscious about my own appearance. *Do I [finally] look gay?* Before this kiss, both Chase and I could continue to hide who we are by “passing” (Goffman, 1963). Although I initiate the kiss, within our communication the act also has public implications. Such breaches are necessary to challenge the normative social order. Kissing becomes a means of exerting “meta-control” over the contingency of our identities (Frank, 2013). In 1985, because the normative social order’s rules for kissing preclude same-sexed bodies, especially those of males, our choice is transgressive. Men do not kiss other men in this way. To kiss another man is, therefore, to be rendered not-male. Since men are the de facto apex predators of the social order, not-male is hierarchically less than. “Every society exerts close controls over the transfers of persons from one status to another. Where transfers of sexual statuses are concerned, these controls are particularly restrictive and rigorously enforced” (Garfinkel, 1967, p. 116). Control over our display could have

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<sup>12</sup> I learn about “gaydar” from my friends within the gay community. Gaydar, whether real or myth, is the ability to intuit who might be gay within the presumed “straight” surroundings in which LGBTQ+ folks routinely interact (read: hide) by observing various social cues such as verbal and non-verbal communication, manner of dress, or grooming, to name a few. Because many LGBTQ+ folks spend years perfecting performances that pass as straight, we’re often able to selectively reveal aspects of ourselves to others.

taken the form of “don’t do that” or “please, stop” or any of the guttural sounds synonymous with disapproval, but none of these would brand our skin so clearly as “FAGGOT!” attempts did, and continue to do. Our breach illuminates the ease at which sanctions arrive in others’ attempts to maintain control.

“FAGGOT” calls attention to the social constraints that inform identity negotiation, including the power others tend to have over those who are most vulnerable (Berry, 2016). Calling me a “FAGGOT” attempts to classify me as “less than,” “abnormal” and strip me of power and status, and, again, to “ascribe” to me a spoiled identity. That is, the speaker presumes to know who and what I am because of our kissing, while simultaneously asking me to confirm the authenticity of his exclamation through a response. No response or an inadequate response in the sole judgement of the speaker serves to avow my authentic faggot identity. By now I have heard many familiar labels from contemporaries on the playground at school—FAIRY, GAY BOY, FAG, QUEER, and FAGGOT. However, this experience feels different. I feel defiant. I know who I want to be. These words have lost much of the power they held over me because I understand more clearly their use. I feel ready to accept myself as gay. As jarring and pejorative as the label intends to be in this context, I do not wish to object; indeed, I am a FAGGOT. My acceptance of this identity in public marks a profound coming of age for me. I realize that I do not always need to do the work to reveal my authentic self when others have already decided who (and what) I am. Yet, I recognize that this label and this approach to living remains challenging for others, even in the present.

Chase and I walk away without turning to face the speaker. Our nonverbal response to them helps to draft our story, an account that I finally feel comfortable to author in public. I know who I am. I know what I am. FAGGOT is not just a damning label. It is also an invitation to let the

floodgates open. FAGGOT is the pistol shot that reverberates and ricochets to signal the start of my being OUT.

### **Experience Speaks**

My time with Chase burns hotly but briefly. By the time the semester ends in April, we go our separate ways. I return to live with my parents for the summer; he takes a job as a lifeguard at the other end of the province. Dorothea and I continue to date and remain sexually intimate well into the next year before deciding that the sex is probably not a good idea anymore. Soon the dating stops, too. We remain friends for a while, but that too soon fades. I am thankful for experiences with both her and Chase yet recognize that my journey of self-discovery beckons me still. My path lies elsewhere. Emphatically, I am not straight. But I also don't yet feel fully gay. I still have work to do. With each of Dorothea and Chase, I have been able to be more my authentic self myself. Yet, living in this way is an ongoing process of disclosure. These first few steps have been a good start toward making the habit of disclosing feel easier. Nonetheless, I feel a lump forming in my throat at the prospect of disclosing my orientation and emergent identity to my parents. The thought of losing them weighs heavily, more heavily now that I face the choice to come out than during any of the years growing up at home. I return home for the summer after my first year of university. As I arrive, I wonder how long I will be able to continue to call this place home. I await the right moment to come out.

### **The Complex Calculus of the Most Consequential Coming Out**

My next significant experience with others, sexuality, and self-disclosure occurs soon after I turn twenty-two years old, early in the spring of 1987. I face the milestone dilemma of whether or not to come out to my parents. It feels like a titanic leap, bigger and more significant than anything I have yet faced. Should I continue to remain in the closet or risk sinking by disclosing

to my parents that I am gay? The few practical models I have for *being* gay come mostly from within the communication between new coffeehouse friends of the past year. I struggle to breathe under the weight of the choice to come out. It feels liking coming out will require another leap of faith. Such a turning point is difficult to express either wholly or permanently (Adams, 2011). This moment is always relative to one's relational context and marks the culmination of events and experiences that have led to, and now challenge, the existence of the instant, that moment when one consciously turns to thinking about it. The myriad ways in which a soul can torture itself to make sense in this liminal vortex at the boundary between private and public seem endless. It wasn't long ago, just last year in fact, when I stood outside the coffeehouse door, weighing the choice to enter and what doing so would affirm, both for me and others who might witness my passage. I dance on the head of a pin, in a space delineated by who I pretend to be and who I am authentically, who you think me to be and who I am allowed to be. Coming out suspends pretense. It rights assumptions. Coming out reconciles perceptions and contradictions of how I perform across time with the prospect of who I *really* am. Coming out challenges belief in a singular author of reality and reimagines one's identity as a conversation between certainty and possibility (Eisenberg, 2001; Blommaert, 2013). The notion of certainty prescribes that our ways of knowing through categorical ideas are fixed and constrained by how we relate from and through these anchoring points of reference. Certainty removes possibility. It clarifies not only what I am but also what I can be. It is drummed into me through moral parables and innocuous nursery rhymes that encourage singing along until, finally, the sounds I mimic through recitation coalesce into a singular, clear, yet counterfeit reality. "What are little boys made of? Rats and snails and puppy dogs' tails. Girls, sugar and spice and everything nice." This is the context in which I grew up. Of course, the rhyme could be interchanged to produce a soothingly queer possibility which I privately

continue to hope for and relish. What are little boys made of? *Wry grins, strong chins, and a penchant for sins. Sigh.* Sugar and spice, and everything nice. Thus, the process highlights the complex evaluation and negotiation of the dialectical tensions of private and public, possibility and certainty, and the identity that the organization of the everyday relentlessly ascribes to supplant the identity I wish to avow.

Before coming out to my parents, however, I want to be absolutely certain about my sexual orientation. Until now, whenever I have seen gay people represented in the media or on television, I am informed within communication between friends that it is “wrong,” or that it is “just a phase.” Although they regularly avoid saying such things directly to me, they offer their thoughts aloud as explicit exemplars of what, for them, passes as acceptable behaviour. *How can I determine that my feelings and inclinations are not just a phase?* To do this, I often rely upon the help of others to arrive at a confirmation of who and what I can or am allowed to be. *I begin to realize that there is another question burning to be answered: what can I do for myself?*

The other guys on my residence floor back at school are highly active in sports—in short, they are jocks—and express through myriad ritual performances of masculinity just how men are expected to be in every social setting. One of them, Jerome, passes by my room on his way out to class. He hears my stereo blasting tracks from the Bronski Beat’s *Age of Consent* album and tells me that “people will begin to think I am gay” if I continue to play “that music.” I smirk and turn the stereo’s volume up. *All the fucking way up. The windows begin to shake.* Not wishing to engage further over the impossible volume of the music, he resumes his course down the hallway toward the stairs and exit. Through my window, I see him emerge into the quad below. He turns to look up at me, shrugs as he hears the music still blaring, and then continues on his way to class. I feel that I will be made to pay later for my noncompliance. *Look how Jerome dresses and acts. He*



*seems to make an obvious effort to conform to how jocks ought to behave, especially in front of the other guys but also in front of the many women who seem perpetually to be present on our residence floor. Do I need to worry about his talking to the fellow jocks on my floor about my music? Would I be willing to call his own behaviour into question should the other boys challenge me to account? I wonder, should I forego the tiresome charade and just own up to being gay?*

The paradox of passing makes it difficult to find others like me. *Whereas I have some concern for my physical safety, I no longer want to hide (especially from my queer family).* Finally finding my queer family in the few people I have come to know through the coffeehouse emboldens me to take risks in performing differently than what conformity prescribes. It is difficult to miss how performances that garner acceptance in one setting may be different in another and that sometimes these performances are mutually exclusive. For instance, playing loud music in my residence room is an affirmation of “university student” for my fellow residents. Doing so within earshot of community neighbours, however, performs a different and likely undesirable flavour of “university student.” I begin to absorb how identity performances are coded within my queer family and how I can use emblematic performances to my advantage to go mostly undetected, as they seem to do, when in mixed contexts. That is, what constitutes being enough (Hutson, 2010; Blommaert, 2013) when navigating the nuance of identity. Across contexts, what aspects of my identity performances do I play up, or down? Smiles. Extended eye contact. Bodily proxemics and playful touching. These familiar ways of being take on new meaning with the dimension “gay.” However, there are so many rules and variables about what constitutes a performance that passes. I am still learning in which contexts I can/should/ought to be in ... or out.

## Coming Out to Parents—Your Kid’s a Gay

According to Crites (1971), “Stories, and the symbolic worlds they project, are not like monuments that men [*sic*] behold, but like dwelling places. People live in them” (p. 295). Wrestling authorial control of my story provides a place in which my gay identity not only dwells but thrives, despite the inevitability that coming out is, and might always be, risky. *Why do I feel the telling of my story to be so risky unless others first planted that seed then watered it habitually to ensure it grew?* Earlier, I recounted the details of my kiss with Chase. Doing so does not entail merely the telling of my story; rather, it is also a mechanism of “constituting identities on the page” (Berry, 2016, p.100). However, this story, much like my story at the center of this dissertation, cannot be told without mindful consideration of its relevance to the relationships that I maintain with others. To tell my story means, in part, that I must also tell the story of others, a complicated and powerful mode of representation (Alcoff, 1991). Telling has implications for both me and others. I tell my story out of a deep-seated desire to challenge the erasure of stories like mine and people like me. I do not take lightly that my journey toward visibility can be a violent one, especially for others. By engaging in self-disclosure and the stigma that often precedes it, I appreciate that the story I tell will require others “who are confronted with the stigma [to] have to react to it” (Frank, 2013, p.31). Therefore, the need to tell our stories also introduces a need to negotiate their mutual telling (Frank, 2000; Richardson & St. Pierre, 2005; Tolich, 2010; Moore, 2017).

Jourard (1971a) contends that self-disclosure “reduces the mystery that one man [*sic*] is for another” (p. 6) by invoking “the courage to be known, to be perceived by others as one knows himself [*sic*] to be” (p. 7). Self-disclosing sexual orientation feels like an act of conviction, a choice to resist inauthentic categorization rather than to surrender to heteronormative expectations on human existence. “Coming out” serves to rupture taken-for-granted assumptions and to correct

inauthentic perceptions of me that are held by others. An open declaration of sexual orientation renders me not only visible, but also affirms my unwillingness to remain complacent with passing. However, this telling will always have some risk. *I take a deep breath.*

Putting pen to paper, I write a handwritten letter (see Appendix A) like I have done each month since moving away from home to university. I write because I fear the possibility of rejection. I write two identical letters, one for each parent, because I want them both to be able to read what I have to say together, thus, absolving them of the complex choice over who will read first. I write because, as much as this letter is for my parents, it is also for me. I write to make the future certain. An immediate concern is that with plans to return home for the summer, I need to determine if I will be welcome. In the longer term, I need to know that I can stand on my own two feet and that I will be okay.

Because of the geographic distance separating school from home, the letter will take about a week to arrive back home. I tuck the two envelopes, one labelled “MUM” and the other “DAD,” inside another envelope. It sits on the desk in my room overnight. I imagine it watching me while I sleep. When I awake in the morning, I stare at it from across the room, in bed. *Am I doing the right thing? Will everything be okay? What will happen next?* I break the stare, pull back the covers, and spring from bed to shave and shower and get ready for class. When dressing, my stomach is growling so loudly that I decide to skip breakfast. I address the envelope, seal it, affix a stamp, and walk to the mailbox which is adjacent to the cafeteria. I pop the envelope through the slot and hear it hit the bottom. I feel relieved as I walk away. The deed is done. It’s a leap of faith. Now, I wait.

I try to focus on school but doing so is impossible. My friends notice something different, but I cannot acknowledge the real reason. *I’m not ready for the need to come out as gay, over and*

*over and over again.* Each day seems to pass progressively slower than the last. I am not eating well. I get little sleep. On Sunday night, the phone rings.

“Hello?”

“Hi, Steve. It’s Dad”

“Hi. Is Mum ok?”

“She’s fine. We got your letters. We just want you to know that everything is fine. We love you.”

The rest of the conversation escapes my memory, as if the real tears falling down in that moment wiped it away. The call was overwhelming. I mark that Dad called, not Mum. *For a straight man to reach out to his gay son in this way feels abundantly meaningful. Butterflies.* Mailing those letters home is the most difficult thing I have done in my life. The immediate relief I feel authenticates gay self-identity and the realization that, relationally speaking, no one “can come to know himself [*sic*] except through the act of disclosing himself [*sic*] to another” (Jourard, 1971a, p. 6).

## **Risky Business**

The risks that accompany challenges made against the normative social order concerning sexual orientation, and, for that matter, many other aspects of cultural identity, are often great, and sometimes dire. Despite consciousness-raising, watershed moments like the Stonewall Riots in the United States in 1969, or the many prominent and public figures who have identified themselves visibly as gay exemplars ever since, daily life for gay people like me who wish to publicly identify as LGBTQ+ continues to be legislated and mandated through mainly heteronormative worldviews. Without counterexamples, this trend of erasure continues with attempts to “re-ban” transgender troops from military service, as well as posturing to remove workplace protections for LGBTQ+.

This reality renders LGBTQ+-identified bodies perpetually marginal, unwanted, and less than acceptable or normal. Invisible bodies, pushed to the side, cannot be seen when passing by. The need to come out, to become visible, is a vital step in negating the continuity of social ease that encourages marginalization of people like me.

Taylor (2000) writes, “[c]oming out under any circumstances is an uncertain business. No matter who you’re coming out to and no matter what you already know about them, there is no way to predict how anyone will respond to this disclosure” (pp. 69-70). However, the choice to not come out serves to perpetuate, at least in part, the normative social order’s call to action that gay bodies like mine ought to shut up, remain quiet, and remain invisible. I do not want to be either out of sight or out of mind. My coffeehouse friends agree. Every Wednesday night, and often into the days between, we talk about activism, gay rights, if I will march in the Pride parade this summer. A few months earlier, I could not have even considered these things. Now, I feel not only capable but also willing. The love and acceptance of my parents means and changes so much.

As I reflect upon the process and risk of coming out, with the benefit of love and acceptance from my parents, I realize that I must answer at least two important questions. First, do I feel able and ready to claim a stigmatized identity as my own? That is, am I prepared to live with the consequences of my choice to come out and its corresponding identity? Second, could I cope with a process of repeatedly having to come out when accounting for an identity that remains today, even amid marked progress, contested? After all, when “heterosexuality is presumed, coming out can never be accomplished once and for all” (Urbach, 1996, p. 69). Even when I reveal information about who I am to others, like the sexual orientation that feels right for me, the inescapability of the process that is typically necessitated by “the deadly elasticity of the heterosexist presumption” (Sedgwick, 1990, p. 68), in effect, insists that I must explicitly come out, again and again.

Prudently, each new social situation in which I wish to be out will require the repetition of risk assessment before choosing to self-disclose or not.

Actor David Hyde Pierce once observed, “My life is an open book, but don’t expect me to read it to you” (Voss, 2011). With great esteem for Pierce, I feel compelled to do exactly the opposite of what he refuses to do: to read (my story) aloud. The explicit revelation of who I am, of who we are, is a means to claim authorship of, control over, and to express a strident, authentic, and reflexive *making* of self-identity (Giddens, 1991). I look to recent experiences, especially those with Dorothea and Chase, to strengthen my resolve not just to come out but to remain out.

### **Self-Disclosure in Hindsight**

In review, self-disclosure of sexual orientation has become more common and acceptable. Yet, many barriers to disclosure still exist (see Berry, Gillotti, & Adams, 2020). The ground is always shifting, uncertain, as is the process of being and the myriad ways one continues to reify, abandon, then perform identity anew. In my own experience, becoming financially independent of my parents made the choice to disclose easier in that I knew that I could remain solvent irrespective of my disclosure’s outcome(s). However, being financially solvent is but one of the many dynamic and complex factors to weigh. In hindsight, I wish I could have disclosed sooner but I also appreciate that this disclosure was not forced upon me. I conclude that disclosure of orientation is a navigable process which is best accomplished in my own time and when I am its principal author.

### CHAPTER THREE: HIV STALKS GAY BODIES (LIKE MINE)

In this chapter, I re-visit the tensions of everyday navigation between hormones and HIV-hysteria. Working in hindsight (Freeman, 2010) readily teases out themes of finding home and heart from the mundanity of lived experience. Yet, these years were highly nuanced and complex. Returning to them brings a sense of comfort, pride of endurance, and continued disbelief at their hardship and heartache.

#### **Returning Home**

In mid-summer of 1987, after having just “come out” to my parents, I return home briefly. Going back there feels awkward and regressive. My forward momentum stalls and daily toils seem catatonic. The streets are familiar, but the buildings and people are smaller than I remember. Also, arriving back at this place that was once home feels constrained, like going back into the closet from which I have only just escaped. Going back into the closet means performing the “small-town-Steve” version of me that this context and many of its inhabitants that I know will find familiar. *I wonder if others will notice that I have changed and how they will inquire. I wonder if an opportunity will arise for “university-Steve” to be out in this context. Importantly, I wonder about the selfishness of coming out, potentially negative consequences, and the ability to just leave (things unfinished). What kind of mess might my visit leave for others to attend to?* The problem is my old costume no longer fits. Stuffing an expanded Steve back into the factory packaging is

neither neat nor tidy. It yokes me with the prospect of attempting to pass in everyday encounters that takes considerable effort.

I return home mostly to benefit my parents. They have missed me while I have been away. This is especially the case for my Mum. Despite my coming out, life within our home feels unfazed and unchanged. Conversation jumps from topic to topic, inquisitively, and with the same dry, British humour that has imbued everyday life growing up. For instance, my father recalls a time during my high school years when, thinking I might be sexually active, he advised, “You can’t go messing around with little girls’ pee holes and expect to get away with it!” “Don’t worry,” I respond. Of course, now, in the context of coming out, he appreciates that his concern was misplaced, and my response becomes wildly amusing. We both laugh. However, despite the seeming everydayness and levity of our conversations, I begin to notice that there is one topic that now seems to be off limits: my sexual orientation. I appreciate the latitude they offer for me to express myself, but I want them to ask questions. *What is their starting point, from which I can begin to add to their understanding? Why have they now decided to resist acting on our familial disposition toward curiosity by interrogating me for more specifics of what “being gay” entails? Surely, I muse, they must have questions to ask that my coming out letter (Chapter 3 and Appendix A) did not address.* The event of coming out appears insufficient to spark a conversation. *What questions ought they to have? What questions did I have as I began to act upon my sexual orientation and desire in the context of my coffeehouse friends?* While the task of engaging specifics falls largely upon my shoulders, I defer to the silence. In a few weeks, I will return to school and to my friends. Then, perhaps, I can start to talk with my coffeehouse friends about their own experiences and find ways to open up space for the conversation I would like to have with



my parents. Until then, the silences trouble me, not so much because of my sexual orientation, but moreover about addressing their fears about HIV.

In my letter to my parents, I let them know that I am concerned about the “scary” disease, AIDS. Yet, neither of them asks about my concerns, frustrations, or dreams in the presence of the looming threat to my continued good health. *Already at a loss for words to engage sexual orientation, I am even more hesitant to engage them directly on the topic of HIV.* I conclude that both the conversation and specifics of orientation and the consequential intersection with illness must be avoided in equal measures. I interpret their reticence as not wanting to know or perhaps not being ready to know. I don’t ask. When I leave three weeks later, there are hugs and kisses, and many assurances that nothing has changed. But something has. I have.

### **Normal Hearts**

When I arrive back at school, I meet, through mutual friends at the coffeehouse, a gay, theatre student, Scott, and audition for his capstone project which is a staged production of *The Normal Heart* (Kramer, 1985). In highly intimate and personal ways, this award-winning play depicts the HIV and AIDS crisis taking place in New York City between July 1981 and May 1984. With no formal theatre experience, I am selected to play a minor role that includes playing three small parts, one of which is a character, David, who has AIDS. David’s face bears several, disfiguring, purple lesions called Kaposi’s sarcoma (KS)<sup>13</sup>. As production advances into dress rehearsals, I sit upon one of four stools in the dressing room in front of a bank of mirrors with bright, white, incandescent lights above them. As Angela, the makeup artist, enters, I see her reflected in the mirror as she crosses the room toward me. I pivot on the stool, putting my back to

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<sup>13</sup> Kaposi’s sarcoma is a form of skin cancer that manifests as an irregularly-shaped often purple-coloured mass. Its existence is used widely as a determinant of HIV progression to stage 3: AIDS.

the mirrors. Rolling up the right sleeve of my pressed, white, cotton shirt, I rest my arm across my thigh. I watch as she applies makeup for the first time to a patch atop my mid forearm, to begin my transformation from Steve into David. I stare at the lesion. It is purple with hues of red and pink, which add the illusion of depth and texture in varying degrees, irregular in shape, and seems moist to the touch. I gently pull down my sleeve, but leave the lesion just peeking from beneath the semi-rolled cuff. Another lesion is applied, just inside my open collar, on the right side of my neck. It remains visible only from an intimate distance, and from an angle immediately in front of me. The final lesion, begins on the bridge of my nose, runs down one side, and fades into the swell of my left cheek. I pivot to look into the mirror behind me, and for the first time I see the face of AIDS. It feels impossible to hide. I want to look away but find it difficult not to stare. Angela looks on, behind me, awaiting my reaction to her work. Steve disappears and David responds with his left hand tracing the jagged outline just below the wound, "I have AIDS." *What must someone feel like to be ill in this way? How do they still manage the tenacity to go outside, to face others, and to carry on?* As I return to the rehearsal studio, my castmates see me in makeup for the first time and also stare. Some approach, reaching out. "I know," I say. "They look too real." I *feel* ill.

As we work together on the play, my appreciation for our fellowship and heightened sense of community deepens. We find ways to laugh, bond, and thrive, insisting that life and especially laughter must continue despite the spectre of AIDS. The laughter helps when, during a pivotal scene in the play, Ned Weeks comes unglued over his partner, Albert, to Bruce Niles. The rest of the cast sits off-stage silently watching as Ned relates recent events. As I see the scene for the first time, I am stunned. Ned, played by a strapping, handsome university student, falls to his knees and breaks down into tears. Cowering, he sobs, unable to look at anything but the floor when relating the excruciating treatment that he and Albert's family were forced to endure during the last few

days before Albert's death. The gripping monologue ends with the lights going down on the scene, and the cast and crew sitting in blackness, sobbing. After what feels like ten minutes, but is in actuality only ten or fifteen seconds, the lights fade up. Ned and Bruce are still on stage before us, standing, sobbing, and in each other's arms. Wiping away real tears, their characters fade as the actors return, still hugging. I sniffle, and wipe my cheeks dry with the right sleeve of my shirt. I make out the faint outline of the lesion beneath the moistened cotton. Then, as I look up toward the faces sitting quietly around me in the audience, I realize that I am not alone in my grief. The fear of AIDS looms large for us all. It's always present, quietly stalking, waiting for one of us to stray from the herd. However, this scene that makes the humanity that underscores illness so raw and tangible stirs also the bonds that bring us together defiantly. In this moment, friends become family.

Our summer together is glorious. While we work on the play, we also find time to share meals and drinks. And, during the time we spend together, we share more and more about ourselves with each other. A common topic is coming out. I am glad, as I want to hear about other's experiences, and especially how conversations unfolded with parents. Until I hear their experiences, I think mine to be just average. Soon, I find that Andreas ran away from home before finishing high school. Strict and religious parents insisted that the "gay" could be "prayed away" for Tom. Domestic violence by a former boyfriend still torments Seb. Their revelations alter my perspective significantly, making me now feel thankful for the love and acceptance that my parents so freely lavished. *I wonder what it would be like to have to run away, to live on the streets, to fend for oneself, and yet make the incredible journey from there to university. I recall my mother recounting her own escape from the church, staring, cross-eyed at the end of her nose until she would pass out, thereafter to be excused from Sunday school. I find it difficult to fathom domestic*

*violence from a “loved one” so I listen attentively and try to offer non-verbal support.* Not every coming out experience is rosy.

When the curtain falls on the play in late July, none of us want to say goodbye. We have become close. We enjoy each other’s company. I have grown close to Scott, Tom, and Seb. Through the month of August until school starts up again after Labour Day, we venture on weekends from school to nearby Toronto. Scott usually drives. The rest of us pack his small, powder-blue, Honda Civic so completely that when we disembark, we look like a parade of clowns who erupt from the circus clown car that impossibly contains their disproportionately-sized bodies. In such close quarters, we do more than get along; we feel like one body. None of us seems to mind. For us, seated practically atop one another with limbs interwoven for the entire duration of the one-hour drive, conversation is effortless, deeply intimate, and joyful. I feel at ease being in their company, feeling more and more like my “real” self and being—*comfortably*—gay.

### **Gay Bars—It’s Raining Men**

When in Toronto, we go out dancing. During the 1980s, as it has been for years, Toronto’s Gay Village is THE place to be for gay men on the weekend. On a Friday night, the gay bars are packed. The summer heat ensures that most men are scantily clad, even walking along the street. Their attire would not pass in other areas of the city. Ultra-short jean shorts. Tight-fitting black mesh tank tops. Chunky bracelets. Beaded necklaces. Hair bleached and coiffed toward Jesus. Every embellishment seems a statement of rebellion against the conservative restraints placed upon gay bodies in the urban elsewhere. Here, in the Village, however, standards of public comportment move to a different beat.

We go dancing. At *The Barn*, a three-story gay staple, the first floor offers a quiet, upscale, piano lounge known as *The Cavalier*. Many of the patrons are older men who seem to relish belting

out campy show tunes, especially for their often-younger companions. It's a great place to start the evening, but we usually stay for just one drink before the thumping from upstairs beckons our ascension. Most of the dancing happens on the second floor. It is also quite cruisy. In contrast to the flashy lights that encircle the centrally located dance floor, replete with slowly spinning disco ball, the surroundings are dimly lit, with many dark cubbies and corners. Men line the walls, watching the energetics of the dance floor while they smoke and suckle, mostly beer, straight from the bottle. Between songs, we grab a drink from the front bar, then slowly meander through the serpentine pathway between bodies around the perimeter. Quarters are close. Bodies sweaty. Often, shirtless, especially when or having just returned from dancing. Tight shorts make it feel like skin-on-skin contact as I brush past body after body. Sometimes eyes meet. Sometimes the urgency to pass against hot bodies slows into forced intimacy. Mostly, it's a throng of men engaged in titillating frottage, passing body after body until Scott, Tom, Seb and I find each other again. Talking over the loud music is difficult, leading to hoarse, gravelly voices for those who try. Mostly, we stand, drinking, watching bodies move about us, while being sure to point out those who are particularly appealing. "Fuck! He's hot," I confess to Seb. He smiles wryly and seems unconvinced. The game continues: who do I think are the hottest men and who among them receive the approval of my friends? *More importantly, I wonder, who will I fuck tonight?*

Around midnight when the crowd has swelled, the DJ usually queues up one of several gay anthems that never fails to start a stampede to the dance floor. Gloria Gaynor's *I Am What I Am* is a popular favourite, as are Wham's *Careless Whisper*, Cyndi Lauper's *Girls Just Want to Have Fun*, or Diana Ross's *I'm Coming Out*. Tonight, The Weather Girls trumpet *It's Raining Men*. The dance floor fills to overflowing with shirtless men. I watch several men near the center passing

around a bottle of poppers.<sup>14</sup> I wonder how they can be so energetic and remain upright after snorting so frequently in this heat. We watch the dancing, continuing to notice and comment about which bodies garner favourable attention. As the hour advances toward 1:00 AM and last call, I can tell that Scott and Tom are beginning to tire.

Scott's parents live in Toronto, and he will probably spend the night there. Tom has friends with whom he usually crashes. Seb always hooks up. He knows just what to wear—tonight it's a pair of white linen shorts, burgundy, faux-leather penny loafers sans socks, and a loose-fitting, black tank top—to get noticed and how to move among the bodies to maximum effect. *I wonder if he makes himself too available, crossing over the imaginary line between available and slutty.* He makes me self-conscious about my own performance of availability. Am I too conservative? *Would poppers help me to relax more than the three beers I've had tonight? I can't remove my shirt, can I?* With the crowd slowly beginning to thin, Scott and Tom make their exit, and Seb and I venture up to the even cruicier third floor. The music from the floor below is reduced to basal thumping. Bodies line the walls. Lurking in shadows, many suggestively touch themselves or drink their beer so seductively it makes me blush. Seb and I mingle separately. The last time I see him that night, a much older, bearded man is examining his tonsils with his tongue while, in plain view and without apology, thrusts his hand down the back of his shorts while still clutching a bottle of beer with his other hand. It's a lot to take in. At the height of the AIDS epidemic, acting upon desire comes with life-altering risk. I learn quickly that many gay guys often sleep around. A lot. I am quickly becoming one of them, despite the cautionary tone of the play.

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<sup>14</sup> This term references a vasodilator, often composed of amyl nitrite, originally formulated to relieve angina, but which the LGBTQ+ community has widely adopted as a party and sex enhancer because of the almost immediate sense of euphoria that it imparts upon inhalation.

I fail to find someone to take home and so I decide to leave. Sometimes guys who have yet to find a mate will linger outside, especially on a breezy summer evening such as this. When I finally make my way down from the third floor to the sidewalk, there are only a few guys standing to chat. I pass them, then turn to walk up Church Street while wondering if I should venture to one of the after-hours clubs—*The Twilight Zone*, *RPM*, *Catch-22*, or *Boots*—to dance or just call it a night. I stroll while musing about what next to do. Because I am starting to get tired, I decide to walk over to *The Romans II*, one of Toronto’s many gay bathhouses. At this point, getting a room to catch some sleep feels enough.

### **When in Rome**

Attending a bathhouse still feels taboo in 1987. Only a few years earlier, in the winter of 1981, police “armed with crowbars and sledgehammers” raided four bathhouses (“Remembering the Toronto bathhouse raids,” 2016). Although these actions took place before I came out, the effects of their violence still resonate eerily upon the conscience of Toronto’s gay community. I hear about those proceedings largely through the rumour mill. Never sure of what may be true and what has been embellished, I still approach the baths cautiously. Nonetheless, I begin to venture there more and more frequently, and in particular to the *Romans II*.

Although tired at 1:00 AM, the many attractive men walking about the hallways of the *Romans* makes it unlikely that I will choose sleep over exploration. Sporting my own white towel, tucked over neatly to cinch it about my waist, I stroll along the cool, painted-concrete floored hallways. Many doors to rooms are ajar. Open doors are an open invitation to join whoever awaits inside. However, there is little to no talking. Most of the negotiation to initiate contact is non-verbal.

When passing a room, lingering at the entry threshold while making eye contact with the room's desirable occupant is a common way to initiate contact. If stares are returned, chances are good that interest is mutual. However, in some rooms the lighting is low making it difficult to see inside. When I can glean few of the details of the body resting inside, I usually continue down the hallways, fearing my advance may be rebuffed. In other rooms, the occupant may be facing away from the door, often laying with their face obscured by the pillow. In these instances, I learn that the men are less concerned with how others look. They most often just want to get fucked.

Still new to the bathhouse scene, I feel too shy to approach many of the men outright. My 6' 140-pound body reads still as more boy than man. I am not hairy. My face is clean-shaven. I still have adolescent pimples. A late bloomer, I am still coming to terms with how men who have sex with men engage each other. My introverted nature prefers instead to let others initiate, and to learn from those experiences.

After an initial survey of the premises and its men, I prefer to return to my room, leaving the door ajar to wait for others to approach me. Usually, I dim the lights, prop a pillow against the wall, then sit facing the door and wait, the white towel loosely draped to obscure my groin area. Most of the men who pass by, and peer in, seem older, to me. I am only 22-years old so most of them probably are. My age, and my slight frame, make me popular among them. *I am fresh meat.* Feeling inexperienced, I look for the company of men who appear to be more dominant than submissive, and more masculine than feminine. Although I am not interested in finding a "daddy," someone who takes care of his "son," I lean toward men who are inclined to take charge, who will tell me what they need, and instruct me what to do. *I feel as though I am reliving elements of the aborted play with boys in Grade 3. Now, however, the fantasy seems more refined and has a heightened probability of becoming real.*



A thick, muscular man stands in my doorway. His hair is short at the sides, and wispy blonde yet thinning on top. His face is chubby and round, though neither fat or unappealing. His shoulders are broad and meaty. A dusting of blond hair lightly covers his bulging chest. His arms look more like my legs, thick and powerful. Although his towel is short and tight and looks a size or two too small, I entertain the thought that he is simply a size or two too big. He's perfect. I stare. He enters without words, closing the door softly behind him. I slide off the pillow, adjusting it behind my head as I lay flatter on the bed, while running my hand across his thigh and up under his towel as he walks toward the head of the bed. His leg is solid, like oak. My hand, caressing the side of his ass, finds it, too, as unyielding as his leg. He cups the back of my neck in his hand as he presses his full weight on top of me. It is perfect. He is everything I want in a man: attractive, powerful, muscular, present, and assertive. *I will do anything he commands of me.* Afterwards, he nuzzles my neck. Still laying on top of me, he whispers in my ear. He reveals that he is a wrestling coach for the provincial team. He is certainly built like a wrestler. *I swoon.* I cannot wait to fuck again. Maybe next week.

At this time, having only been with one man, Chase, I still think of myself as HIV-negative (HIV-). Even though the sex that Chase and I have had is unprotected, I still feel that we are both safe. Tests to confirm this are, however, neither widely accepted nor available. The overall threat of AIDS continues to loom large but still feels distant. It may happen to others, but it will not happen to me. It is talked about as something to be avoided, but the practical details of what avoidance means are less clear. If I am having anal sex, particularly as the receptive partner, I know that I should always use a condom. I do. But what if the condom breaks? What if it slips off while he is pulling out? What if he pretends to put one on but stealthily removes it before insertion or during sex? What if he makes me perform oral sex and he cums in my mouth? Neither

school nor my peers have prepared me for such pragmatic concerns. I learn on the street and from my queer family. The fulfilment of pleasure that the baths offer interferes with my critical assessment of risk. As I continue to venture to Toronto, and almost weekly end up at the baths, I feel statistically more at risk for contracting a sexually transmitted illness (STI). Chief among them is HIV. Yet, each time I meet guys at the baths and have sex, HIV is not discussed, either prior to, or during, sex. I don't raise it. My partners don't either. Something important feels missing.

### **No, We Won't "Keep That Shit to Yourself"**

I try to come to grips with why talking about HIV prior to sex feels so impossible. *Every sexual encounter feels like rolling the dice and hoping for the best while worrying about the worst.* In the heat of passion, discussing HIV is considered a "buzz kill." However, the issue preventing disclosure has deeper roots. Gay people are instructed how to speak about HIV through examples commonly in circulation. For instance, in newspapers and television media, and in the messages from, particularly the United States, government, HIV is defined as affecting only homosexuals and intravenous drug users who, when infected by HIV, are "getting what they deserve" (White, 2004). HIV is depicted as a matter of little concern for a heterosexual population.

To avoid discrimination, this behaviour translates into a message offering tolerance in lieu of full acceptance. What I commonly hear is, "I don't mind if you're gay, but keep that shit to yourself." Unfortunately, such assertions affirm that sexual orientation is meant to remain a secret. Thus, HIV continues to be even more marginal than the disclosure of sexual orientation which might precede it. This behaviour is reinforced by government. In the United States through the 1980s, the leadership of President Reagan is shamefully absent; he fails to address AIDS by name until close to the end of his second term (White, 2004). By then, it was too late for too many

people. I already know people who do not look well. I have learned that inquiring is taboo. They are unable to articulate why. The drumhead of disquiet swells.

At last, some good news begins to circulate on the gay grapevine. In New York, often considered an HIV hotspot, a small group of activists devises a strategy to breach the short-sighed and insufferable phenomenon of silence. They call for marginal voices to be heard. Their galvanizing cry is a watershed moment for the gay community in the fight against HIV:

The SILENCE=DEATH Project was a group of six men who had started meeting a year and half before the formation of ACT UP, made up by Avram Finklestein, Brian Howard, Oliver Johnston, Charles Kreloff, Chris Lione, and Jorge Soccaras. They were men who needed to talk to each other and others about what the fuck were they going to do, being gay men in the age of AIDS?! Several of them were designers of various sorts--graphic designers--and they ended up deciding that they had to start doing wheat-pasting on the streets, to get the message out to people: 'Why aren't you doing something?' So, they created the SILENCE=DEATH poster which at the bottom said: 'Why is Reagan silent about AIDS? What is really going on at the Center for Disease Control, the Food and Drug Administration, and the Vatican? Gays and lesbians are not expendable...Use your power...Vote...Boycott...Defend yourselves...Turn anger, fear, grief into action.' A short time later, several of them were at the evening event when Larry Kramer spoke, which motivated the community of people to found ACT!UP (SILENCE = DEATH, 18 June 2018).

The utterance "SILENCE = DEATH" introduces a new and essential conversation. At once, gay people have a narrative to counter silence, stigma, and fear. Finally, we have a tool to try to help

dismantle the non-disclosure that feeds the anxiety that folks feel, especially surrounding the myths that commonly circulate about HIV transmission.

I hear some say, “You can get it from a toilet seat.”

I hear others say, “You shouldn’t drink from the same glass as someone who has AIDS.”

My own friends earnestly say, “Don’t sleep with that one. He’s got AIDS!”

Stigma is rampant, even within the gay community. We have been taught ... to hate even ourselves. To act up offers an opportunity to exit the silence. Feeling able to engage “unspeakable moments” brings a modicum of relief from the pervasive shroud of paranoia.

### **I Just Want to Fuck**

I am, again, in Toronto dancing with friends at a gay dance club, *Komrads*. All it takes is one Pet Shop Boys song, *Always on My Mind*, and the dance floor is chocked full. Bodies. Gay bodies. Intermingling freely in ways that transcend the observed boundaries of personal space. An attractive, energetically gyrating man peacocks nearby. It is a ritual performance of the gay oeuvre that we both have learned, mimetically, by observing others. He is close enough that under the rhythmic train of dance floor lights I can see radiant beads of sweat forming along his thick, football-player neck. Secretly, I lust for him. I have seen him on the UW campus with mutual other friends and at the local gay bay in Kitchener. Yet, now in the big city of Toronto, he seems finally to be attainable. In the rarefied air, a delicate whisper of moistened hairs at his mane stands visibly on edge in sensory unison with my own. Transfixed, the boundaries of intimate space remain intact. My smiles, extended eye contact, and undulating overture have yet to elicit acceptance. But I hope that will soon change. Then, taking advantage of an up-tempo turn in the music, I feel his hand wrest my shoulder. Our bodies draw instinctively closer as gay cultural ritual demands. As the stubble of his sweaty cheek brushes against mine, I turn my head slightly away to relish the

moment of stubble gliding intimately upon stubble. I feel his head turn inward as if to grace my neck with lips, then unexpectedly feel his breath seductively exhaling at the threshold of my ear.

My head cocks backward. My eyes are closed. *I wonder if we'll fuck tonight.*

He's a fucking stud. I'm sure he knows it, too. The way he moves—effortless, confident, with purpose—from flower to flower to flower .... My desire feels ready to bloom in his enveloping, muscular embrace.

Emerging from the shadows of clouds of cigarette smoke, flirty strobe lights, and raised glasses, I see a mutual friend snag him away and just as abruptly I am left to dance alone. The dance floor can be harsh.

A few months later, the shocking news crackles along the gay grapevine like ten thousand volts of electricity. Caleb. AIDS. 27. Dead.

I am stunned. I can still feel Caleb in my arms. His scent still fills my nostrils. *Had the friend that yanked him away saved me? Could I talk about these events with my parents, despite their reluctance to inquire directly about the everyday happenings of gay life?* This is the harsh reality of not being able to speak openly about HIV.

### **Death Never Calls Ahead**

Again, HIV comes. It asks by name for Anton – the Italian scholar from Uganda whose political aspirations I continue to admire; Jeff – the interior designer, and former neighbour, whose faux-fur coats made heads turn with his every entrance to the weekend Bacchanalia at the local gay bar, *The Half and Half*; Brian – the hemophiliac whose hospital blood screening program had failed him; Andreas – who managed to snag my first gay lover away before he, himself, was snatched; and, Tim – whose whistle-blowing antics on many a dance floor failed to alert his slight

frame to the danger that made him slip from view that much faster. Friends, every one of them. They all left the party distressingly early. I miss them.

### **Chance Encounter**

In the summer of 1988, I meet Andrew at *The Half and Half*. It is a typical Wednesday evening escape from the temporary work I have secured for the summer. I am there with Austin and Jasper, two friends from university who are also my housemates. Andrew stands next to us sipping a beer. He turns toward us and says mostly to me, “Great weather we’re having.” I have no interest in engaging him. I just want to dance and be with my friends. Austin smiles at me, recognizing immediately my need to be left alone with friends. Fortunately, saving us further awkwardness, Jasper responds. Shortly thereafter, he and Andrew wander to the dance floor. Austin and I continue to chat. I thank him for understanding my desire not to be pestered with idle chit chat and the complexities of “new” relationships.

Jasper and Andrew end up dating for a few months and Andrew becomes a regular visitor to our apartment. I am civil but keep my distance. I am thankful that he has found someone and, in turn, that it is not me! I move out of the all-guy apartment that fall and into an apartment shared with three girls, the upper floor of a house above a clothing store. I no longer see my gay friends much. Work keeps me occupied during weekdays, and I have less interest to go out to *The Half and Half* as much on weekends. *Maybe I need a break from boys?* I resign myself to talking to the girls about their roller-coaster adventures with boys rather than to look for a boy of my own. I hear from Austin occasionally. He mentions that Jasper and Andrew are no longer dating. It feels like just another piece of idle gossip to which I give little heed.

However, a month later during what have become rare visits to *The Half and Half*, I see Andrew and stop to chat. He’s charming and still eager to be with someone. He buys me a beer.

We dance, drink, and chat. This time, he manages to offer more interesting topics than the weather. He talks about his travels and attending school at *Wilfrid Laurier*—the university down the street from UW. He graciously drives me home that night.

“It’s on my way,” he insists.

When we reach my house, he parks in the driveway, leaving the engine running. We sit and chat for another hour before one of my roommates, Lola, passes by and taps her fingernails playfully across the somewhat steamed-up, driver-side window. She is unaccustomed to seeing me escorted home by boys, probably because this has never happened before. As Lola ascends the short flight of metal stairs to our door, she manages one last turn to smile and wave playfully in approval, before her key finally grants her access and she disappears. *I expect her to be waiting up to chat about my “date.”* She glides through the door and graciously turns off the porch light once inside.

Andrew leans in across the storage hump between car seats and kisses me. I meet his lips but soon pull back and tell him that I enjoy our friendship, but that I am definitely not looking for either a boyfriend or commitment. Nonetheless, he leans in for another kiss. In the weeks ahead, I am smitten by his earnest pursuit. We go to movies. We go to dinner. We sneak into the apartment late one night after going out drinking and dancing. We fuck, using protection, then tiptoe to the shower, together. He stays the night. We sleep together on my bed, a makeshift, single mattress that rests directly upon the floor. I feel that my sleeping arrangements will disappoint him. He does not complain. He sneaks out early the following morning. Lola asks about the squeaking floor she heard when she awakens later that morning. I admit to my overnight guest. She laughs and says, “This must be getting serious!” *I think it might be.*

The next day, I use my Mum's recipe to bake an Apple Crisp for Andrew. I give it to him that night after he drops me off after yet another evening out. Later that week, he confesses when returning the clean baking dish that his mum ate the whole thing herself while he was away at school. "She loved it," he admits before sheepishly asking, "Could you bake another one?" I oblige.

I feel at considerable ease with Andrew. One regular guy in my life negates the desire to venture to Toronto, to dance clubs, cruising bars, and then to the baths. The diminished contact with multiple sex partners is a welcome departure from more than a year of searching and always returning home to feel empty. The novelty of sex with strangers eventually wears thin. I feel ready for love. I feel more than ready to stop thinking about the fear of getting HIV. *Who are gay men when they stop being promiscuous? Is monogamy right for me? Us?* On New Year's Eve, 1988, Andrew and I decide to become, officially, a couple. We awake in each other's arms on the first morning of 1989 and have been together since.

### **Failing to Come Out**

Andrew and I have been together for thirty-four years, twenty-one while his mother was still alive. "Erika" to most, but affectionately "Eko" to us, she never asks explicitly about us. But somehow, I feel that she can see beyond our silence. In her grace to leave the muck of life undisturbed, she never acts upon her clairvoyance. Instead, I live in that place somewhere between familial acceptance and outright rejection, being welcome at birthday and holiday dinners, but constantly reminded—by myself, at least—of the metal bolts which seem to protrude from my neck, as it was with Dr. Frankenstein's infamous monster. Maybe if we ignore it for long enough acceptance will eventually come. I'm sure Andrew thinks so. When one partner fails to speak, the onus falls upon the other. I sometimes tire of this responsibility, so much so that I remain silent.



Even though I realize that perpetuating silence is not good, it is less work than navigating reality, which invariably means attending to questions. It is too much work! *Other people need to do some of this heavy lifting. Help!* I regret that he and I do not engage the many opportunities to be authentic about our deep and growing devotion to one another before Erika, equally dear to us, passes. In hindsight, our silence reinforced hers. We didn't want to upset her with disquieting circumstances and she didn't want to broach the subject out of abundant concern that it might upset us if she did. After all, wouldn't we raise it if we wanted to? The double bind and ambiguity of silence is perplexing indeed. All the more reason to embrace a life in service of self-disclosing.

Yet, I learn that making people uncomfortable with your own body-contorting gestures of dis-ease garners silence more than conversation. The closest that we ever come to confessing our *sin* is when Andrew's hand purposely finds my ankle and holds on. I'm seated at the top of a short flight of stairs that leads to our front door. His mum has a hand on the doorknob in preparation to leave. She is turned toward Andrew, who starts to sit on the stairs between me and her. As their long goodbye continues, his hand on my ankle lingers longer than it ought to have, at least within this closet. It crosses over into tacit meaning as we sit on the front stairs of our first house together while bidding Erika an after-dinner farewell. Andrew's touch has never been unwelcomed, but in that moment, I feel the weight of his deliberate choice to reach out and what this attempt to disclose means for him and for Erika. I mark that she notices the dotting, physical contact. The conversation continues, uninterrupted. Nothing changes among us.

Andrew's decision to not disclose matters of orientation with immediate family complicates my own desire to speak. *How can I speak for others without disrespecting either their agency or privacy? How can anyone insist upon speaking for others? What can I do to help others speak for themselves?* My speaking would mean explicitly "outing" him to his mother and

potentially to other family members. To author such a revelation would feel like a violation. It's his news to share, when and if he wishes. In these ways, remaining silent further complicates and widens the chasm between our perceived and authentic identities. Nonetheless, remaining silent feels like an appropriate choice in the moment, and something to be discussed privately thereafter.

### **You Thought I Didn't Know**

A few years earlier, at the local gay bar in which we first met, Austin rushes to my side to alert me that Andrew and another man are kissing on the other side of the room. I laugh. My laughter takes Austin aback. I am supposed to express rage, betrayal, and jealousy that my partner is being unfaithful with a stranger and in this very room. I laugh because, in actuality, what I feel is love for Andrew concerning his exploration. I want him to be happy. He wants the same for me. Jealousy feels like such a useless emotion upon which our relationship will never be based. However, the moment gives me pause. So many Hollywood gossip magazines, tabloids, and television broadcasts rely upon stereotypical and monolithic assumptions about relationship. All are artifacts of the Master's tools (Lorde, 1983), which attest that being in "good" and/or "real" relationships requires both parties to agree to be monogamous. Each instantiation of relationship invokes the image of what our parents have without first questioning if the relationship they share together is monogamous. Similarly, how do we know that Hollywood couples, amid their busy schedules and geographically complicated lives, do not have sufficient forethought to attend to the parameters of their individual relationships, as Andrew and I have, before living them out? Anything but monogamy is a threat to the (hetero)normative social order. Straying from monogamy must be kept ... quiet. Quietly, Andrew and I celebrate the absence of a need to own each other in ways that feel limiting and stifling to growth (see Berry, Gillotti & Adams, 2020).

Publicly, we confess that it just feels right to make choices about which the church fervently objects.

### **New Job and the Complications of Desire**

A new job means that I will have to commute daily for an hour or more, each way, between our home in Kitchener and Toronto. I welcome the change of pace afforded to me by working in a larger city. Welcome, too, is the opportunity to be closer to, and participate in, a larger and more visible gay community. Kitchener is a conservative community. The weekend routine of *The Half and Half* feels increasingly narrow and stagnant.

My practice of letting out steam back in Toronto on a Friday night after work feels like revisiting the last summer of living at home with my parents before coming out, when I would sneak away each weekend to cut loose. Still, Friday nights now also create a tension between what it means to be “faithful” to a partner of longstanding and the continued exploration of sexuality and desire. *Nonetheless, choices made to spend time with others has relational consequences.* Early on, Andrew and I decide that our relationship will be open; in other words, neither one of us seeks to possess the other, and that acting upon desire to discover happiness is an opportunity for growth on both intrapersonal and interpersonal levels. Being open and being faithful, however, intersect. Being away from him in the city on a Friday night tests the ideological beliefs from which our relationship springs. *Do we both believe in openness as something practical and not merely ideological?*

It is Friday night and I am at a bathhouse named *The Barracks*. I find rough looking men who fit well within the Tom of Finland<sup>15</sup> stereotype to which this venue caters. Like the many

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<sup>15</sup> Touko Valio Laaksonen, known widely by a pseudonym “Tom of Finland,” was a Finnish artist who expressed through his art a highly sexualized (tending toward pornographic), homo-erotic, and hyper-masculinized male form.

other bathhouses of the city, men entering can request a locker or a room. Lockers are large enough to secure clothing and personal effects. These rather Spartan rooms come with a single bed and usually a small locker. More elaborate rooms may have slings, gloryholes, or decor meant to enhance the playfulness of encounters. As I walk through the maze of hallways on the lower of the two levels of this converted Victorian-era row house, I enter a communal dark area. I can discern little from the bodies who are already present in the near pitch lighting but am able to navigate slowly with my hands outstretched and the proximity of heavy breathing. As my eyes adjust to the darkness, I can make out the muscular shape of a man, prostrate, his arms and legs securely strapped with inch-thick leather cuffs to an Iron Cross resting against the wall nearest the entrance.

At first, I find him highly desirable. Broad shoulders, wavy black hair, curvy and muscular in all the right places, especially his ample ass, thrust out invitingly, clad only in a thread-bare, black jockstrap. I soon notice that he refuses none of the men who earnestly caress his shoulders, then his back, until the sweat rolling down his form guides their probing hands to his waiting ass into which they shove in rapid succession their unprotected dicks. No words, only bodies in motion. I stand ten feet away, in shadow, leaning back against the cold, black-painted-brick wall of the dark area, watching. I am silent. Complicit. I watch at least a dozen men fuck him, each failing to quench his insatiable desire. I imagine myself strapped in his place but appreciate that imagination is my vicarious limit. Actions have consequences in a world in which HIV stalks, especially given the duty to be faithful in an open relationship—Andrew trusts me to act responsibly, to safeguard not only my health but also his. When I return home in the early morning hours, we often talk about our experiences with others. I wonder about those who play openly, as we do, and either do not or cannot share meaningful details of their experiences with intimate others in their lives. That Andrew and I can experience others in this way feels reaffirming for

what we share together. It positions us in particular ways with one another relationally; it feels loving yet unfettered. Our exploration of individual and collective sexuality, acting upon desire, whether shared or solo, feels like an essential part of what love requires to flourish for us. This is not to say that such a framework would work for others as it does for us. This is what works for us, and we strive to discuss our feelings and desires as openly as we can, with each other and any who inquire.

### **Don't Wash Your Hands**

Andrew and I have not seen Jeff for some months. I see his partner, Martin, at the mailboxes outside of our condo and ask how they are both doing. Casually, he mentions that Jeff is in the hospital. I ask, "what for?" Until that moment, I do not know that Jeff is HIV+. I do not know that he is dying of AIDS. We had thought that he might have issues with alcohol. *Was this our assumption or what we were led to believe?* My having come to such an obviously faulty conclusion perplexes and simultaneously upsets me. *Why did they hide his status during those many nights when we had gone to dinner and out for drinks? Caching away the truth feels like a betrayal of trust. After all, we were close. Weren't we?*

Andrew and I visit Jeff in the hospital. In Toronto General Hospital, he has a private room on the sixth floor, which is the designated AIDS Ward [sic]. As we walk down the wide, sterile corridor toward his room, we see nurses in scrubs, some wearing masks, flutter between many of the other rooms we pass. I assume that because it is close to dinner time, they may be administering medication, as it is often taken with food. When we arrive at Jeff's room, his sheets are disheveled, but the bed is empty. I hear the toilet flush, and Jeff emerges from the bathroom.

His body has changed so radically. There is no longer any need to disclose why. The one-size-fits-all hospital gown hangs from his shoulders and is tied delicately in back. *We've seen too*

*many bodies like this.* As Jeff measures every step from the bathroom back to his bed, I hope that my shock does not register on my face. I have seen bodies like this on the news, in documentaries, and sometimes on the street. All were strangers. Yet, Jeff is a friend. He squints to discern who we are. While he complains of a terrible headache, we must announce explicitly our names before he realizes fully who has come to visit. I fight back tears.

His descent into bed and retreat under its white cotton sheet takes almost a minute to complete. I want to help him, to provide some comfort, but wonder if letting him complete the task himself might help him to feel in control (when his capacity is clearly and greatly diminished). I feel unable to move anyway, petrified, still registering the drastic change in his appearance. As he struggles to lodge the sheet up around his chest, he places his arms on top, and by his sides. I sit beside him on the bed and place my hand just above his elbow where his now emaciated biceps used to be. I can count the bones in his arm as if I have x-ray vision. His skin is cool and dry. It no longer feels human.

Andrew stands behind me, his left hand on my shoulder. We chat with Jeff only briefly before he seems too tired to continue. “We were both surprised to hear you are in hospital,” I say. Jeff begins to respond. His speech is slow.

“I can’t ... work ... anymore. I’m ... on disability.”

His brain seems foggy. His world seems to have narrowed to the preceding five minutes and what might occur in the five minutes yet to arrive. He wonders where the nurse is with something for his headache. Andrew offers to go find her and inquire.

Jeff’s eyes close.

“Ahhhhhhggggg....”

He exhales loudly while trying to stifle the coughing that the sudden passage of air from his lungs evokes. We ask him if he needs to rest, and he manages a small nod of affirmation. We are thankful for the visit, however short.

My hand has not left Jeff's arm. I rub it affectionately as I get up and turn to leave. By the time I step into the hallway my face is already soaked by tears. My throat closes under the terrific weight of illness and thoughts of what is soon to become of Jeff. Andrew rushes to the bathroom to wash his hands. I understand his fear. I share it. However, it is more important that my fears not be allowed to snuff out the spark of life to which Jeff now clings. As I stand there, alone, I look to the other rooms on the ward and wonder how many patients have not had visitors. *Too many people are washing their hands.*

HIV continues to stalk us.

I wonder who will be next.

**CHAPTER FOUR:**  
**YOU GONNA DIE, GURL**

In this chapter, I write about fear, an essential element to surviving HIV. For me, fear and anxiety arise primarily because of my experiences with other gay men. For instance, the uninvited caution offered by caring friends when they say, “Don’t sleep with that slut. He’s got *IT* ... for sure.” Fear leads me to question the need to address my own sexual health. In an everyday experience riddled with fear, the focus on death becomes acute. However, death is the fate of us all. Therefore, I try to shift focus onto living and what that entails and means.

**Tales of Gay Bodies**

Stories about HIV and the people it affects/infects are often short, poignant, pain-filled, and whispered. I think about my first moments of “coming out” with my queer family and the rumour mill, it’s advice about who was safe to pursue and who to avoid—like the plague. *Should I listen? Is it all idle gossip? None of these guys look ill.* But here’s the truth: the sickest have already slunk from view to die, and they often die alone. Their absence goes undetected, like their illness, for months or years after their passing. It’s a shock each time I discover that someone I know has died from AIDS. The news bids me to revisit last moments and lingering memories. *How could I not have noticed? Why did they not say anything?* The silence, even across close friendships, illuminates stigma’s pervasive power on self-disclosure. I lean into those silences to make sense of lives lived. Yet this understanding can only ever be partial, constructed around paragraphs written by authors who are no longer here, their stories ripped from existence like pages



from a book. Rituals of remembering feel important (see Paxton, 2014). As I run a finger along the jagged edge of what remains, I struggle to remember enough.

### ***Jeff***

Jeff's passing still feels raw. He died in 2001, at a time when HAART medication had become widely available. *I wonder why he could not or did not find the medication needed to live. I struggle to make sense of the end of a life being reduced to a conscious choice, as it seems to have been for Jeff. How could I have made it easier for him to speak? For me to listen? If Jeff had self-disclosed, would he be here to laugh again through dinner with us now?* Easy answers do not emerge in the years after Jeff's death. I think of him often. Each time folks come to our house for dinner, we break out a set of metal napkin holders that Jeff once gave us when he came to dine. Seldom do our guests ask us about their origin, but when they notice them, we tearfully recall that night with Jeff and the good cheer he always seemed able to impart. His gift of the napkin holders is elegant yet simple. They blend into the background of our setting, much like Jeff does now. *Imperceptibly present.* Holding a space for him feels important. It reminds me of life's delicate and ephemeral nature. It cautions that the consequences of ignoring HIV can be dire. It exults the enrichment that others, especially through the bonds of friendship, can and so often do bring to life. He is sorely missed.

### ***Ryan***

Ryan, too. I regularly see him at the baths each time I go. I am there frequently. Most often, he foregoes a towel and instead struts around wearing only a tight, white jockstrap—a size too small, which makes his slight torso seem to bulge against its elastic construction. Shaking his butt, like a bee signals its hive about nearby flowers, he traipses throughout the maze-like corridors of the baths to lead man after man back to his room. I appreciate his appetite and tenacity. When I

finally notice his absence after a few visits, I ask another one of the frequent bathhouse visitors who I recognize about him. He confirms the sad news: Ryan died six months ago. I'd like to say that I am surprised, but it's a tale I've heard too many times before. Also, here I am, writing my own coda.

In a rare, chance meeting outside the baths, I saw Ryan on the street just a few weeks before he passed. He looked great and our interaction, although brief, was light-hearted. Light-hearted even though meeting regular bathhouse patrons outside of that space sometimes feels awkward. *Discretion often forecloses on conversation outright, relegating acknowledgement to a nod or a wink in passing.* Seeing folks wear clothes in the context of the street can be jarring when you have only ever seen them scantily toweled or naked. It was not long ago that Ryan had bee-wiggled his memorable ass down a hallway in front of me, summarily beckoning that I follow him back to his hive. Of course, I did.

He unlocked the door to his room, flung off his towel, and fell back upon the mattress, his legs splayed in the air. He left little to the imagination about what he offered or wanted. When I arrived, I couldn't get my towel down or dick up fast enough for him. He was ravenous. Boyishly good looks, stylish yet short-cropped hair, bedroom-brown-eyes, devilishly cute smile, and enticingly masculine V-shape from shoulders to waist all contributed to his appeal. We needed no words. He grabbed a plastic bottle of lube, squirted an ample gob onto his fingers, then rubbed it around and into his ass. From the metal table beside the head of his bed, I grabbed a condom wrapper, tore open a corner with my teeth, unfurled its contents, draped his ankles up and over my shoulders, then began to pound him mercilessly—just like he wanted. After he came, I lay on top of him nuzzling his neck with my mouth and nose while caressing, in one hand, the back of his

head and the short, prickly hairs of a freshly buzzed military cut. We lay silently and tenderly in the sweaty mess that we had made together.

I reflect upon that street encounter with him and wonder about the circumstances surrounding his death, especially since he “passed” for healthy, as many post-HAART bodies tend to do. *Without asking specifically about HIV, how would I know? I guess we’re supposed to have THAT conversation before doing anything with each other. In the heat of the moment, conversation feels counterintuitive.* The conversation about good health, social responsibility, and an ethic of mutual care about risk is a silent and snap judgement. If he lets me, I’ll do it. Hardly our finest hour.

Most of the time, musing about health leads to one, inevitable conclusion. I pick up a copy of *Xtra*, the free, weekly, gay newspaper available in many of the bars and clubs that line Toronto’s “Gay Village.” As I alluded to earlier in the dissertation, since the mid-80s, the obituaries are never its thinnest section. It doesn’t take much skimming before I stop with sadness. It’s Ryan’s obit. Died due to complications related to AIDS. I sigh. *How many more men must I hold in my arms in the moments before they die?* These deaths matter. They make me wonder about the impossibility of enduring queer love.

### ***Eamon***

I go out to *The Barn*, one of the many gay bars in Toronto. This one is a little on the edgier side. It’s not quite a leather bar, though the atmosphere is similarly casual and hyper-sexual with men wearing a range of clothing from leather vests and harnesses against bare chests to jeans and white t-shirts. Soon after getting to the bar, I run into Eamon, a friend from university who I haven’t seen in many years. It is lovely to run in to him. I buy him a beer.

“The long, stubby-neck bottle is sooooo phallic,” I say.

Without a pause, the bottle's neck disappears down Eamon's teasing throat. He wipes some froth from the corner of his mouth, exhales noisily, and chuckles at having beat me to my next, predictable thought.

"You're a whore!"

"Duh, ya dirty bitch!" he says laughing.

We stand and reminisce awhile about our university days as we stand beside the pool table. Men in tight blue jeans take turns bending over in front of us while attempting to show off how powerfully they can strike pool balls into pockets. I notice handkerchiefs draped from some of their pockets. Red, white, lace, ... I urge Eamon to jog my memory about the cultural significance of each, and the significance of its placement in either the left or right back pocket. He is more enrapt by the buffet of asses parading about us. I nudge him, curious to know what he has been up to in the years since our last meeting.

Eamon has been away in the United States. After attending nursing school there, he became an Emergency Room (ER) assistant in a hospital in Texas. *I am happy to know that his dream, from our university days together, of taking care of people in some health-related field seems to have been fulfilled.* He speaks well of the work and seems more knowledgeable about matters of health than I remember him being. While we're talking, he mentions a foot injury that has left him in debilitating pain and a burgeoning addiction to opioids to mitigate it. This is his reason for leaving the ER to return to Canada. At age 35, his career in healthcare ends. As we talk and meander through the bar, I notice that he is limping.

"Botched plantar wart surgery," he says, "What can ya do?"

He takes it in stride, swigs a mouthful of beer and takes some of his weight off his ailing foot by leaning upon tables, walls, and people as we pass. Eamon knows almost everyone here.

After a few steps, hugs, embraces, and kisses interrupt our conversation and progress through the sea of men. I smile and resign from conversation to watch.

An unapologetic flirt, he wears his heart on his sleeve. He cares about people and has been this way for as long as I have known him. It's one of the qualities I adore about him. When we finally reach a darkened corner, we set our beer bottles, now almost empty, atop an oil drum, painted black, and re-purposed as a table. He lights a cigarette, and our conversation resumes between puffs.

Eamon is not shy when reminiscing about the many good times we had during our university days. He offers no apologies about the harder moments he has faced since then, including his diagnosis with HIV, a fact that he casually drops into our conversation. *I love that our chance meeting seems to pick up exactly where we left off, years before. He is a dear soul. We hug. I feel a need to let him know, beyond what words can express, that I am fully present. HIV will never stop me from hugging or kissing people who I love. I am thankful for an education about it. Abundantly thankful to control my lizard brain and its often-involuntary impulse toward fight or flight.* Between drinking beer and flirting with men nearby, he pauses, raising his beer to some of the men who we know in common who are no longer here. Unsurprisingly, many of the gay confabs of the 1980s are punctuated with lament for a litany of obituaries. He swallows hard at the mention of one, in particular: Dexter. He had been a former roommate for both of us at separate times during our university days. May the next chapter bring him the peace he so desperately sought but seemed unable to find in this one. Amen.

### ***Dexter***

I have not seen Dexter much since we lived together in the late 1980s. From time to time, I see him here at *The Barn*. Invariably, he arrives glassy eyed after smoking a joint or two before

venturing out. Once at the bar, he hits the sauce hard. At his best, he is misunderstood and aloof, but at his worst, he is a troubled soul. He is handsome, tall, and Scandinavian—blue eyes and wispy blond hair. His wry smile and dry wit rival my own. We feel joined by our cynical and often disdainful view of life. Our relentless banter when at *The Half and Half* never failed to eviscerate anyone who came near us. *Gay men can be so unnecessarily catty.* Now, Eamon recounts the frequency with which he and Dexter would venture out in Toronto, most often here to play pool, dance, smoke pot on the rooftop patio, and cruise for men. Eamon looks longingly toward the pool table where he and Dexter used to stand.

He hangs his head and explains, “Dexter was found slumped in a chair of his apartment after being dead for several days. He never got tested for HIV and preferred instead to live his life without thinking about illness.”

The news gives me pause. Yet another one of our friends is gone. *Why?*

My own experience with testing has been fraught with angst. I get it. Yet, adherence to HAART should be simple. *No? Just a few pills a day ... life over death.* Nonetheless, I appreciate that death from HIV after the widespread availability of HAART remains prescient. HIV activists rioted in the streets to ensure these medications became available. To refuse to get tested and, thus, deny treatment altogether, or to access medication but fail to take it as prescribed feels wrong from my standpoint currently on the outside looking in. *Why, Dexter? Why? Does ignorance really lead to bliss? When does quality of life become more favourable than quantity of life?* The choice is both controversial and complex.

I respect the weight of Dexter’s choice but I cannot say that I truly understand it. I admire Dexter for *living* on his own terms. Nonetheless, his loss leaves me and Eamon to contend with

yet another hole in the roster of university friends picked off, one by one, year after year. HIV is relentless.

### **Testing Avoidance**

Some men test for HIV with regularity and, if they test positive, get themselves linked to appropriate care—medical, social, psychological, etc. Others prefer to live by looking (i.e., orienting) away from illness, thus, becoming avoidant, favouring instead to devote themselves to the pursuit of pleasure with what time they have left. However, the news about Ryan and Dexter prompts me to discuss HIV testing with Andrew. Neither of us has grave concerns for our immediate health. We both “*play*” safely. Neither of us is experiencing any ill effects. Yet, we concede to the many forces that compel us to live in ignorance. *Being sexually active comes with a responsibility to know one’s HIV status.* However, we feel that not knowing our respective HIV status while continuing to be sexually active is problematic, for each of us and for our other partners. *How can an accurate negotiation of risk occur with partners when HIV status is unknown? Why do so many men who have sex with men assume that their partners are HIV-? We last tested for HIV almost a decade ago. Now that suddenly feels too long ago.*

Jeff’s passing last year is also prescient. Silence shrouded the illness which slowly ate him alive. As I mentioned above, neither Andrew nor I knew he was so gravely ill until the day before we visited him in the hospital, just a few weeks before he died. *What does Jeff’s silence with us, his friends, say about us in the context of our own silence with those we love?* Silence conveniently means not having to deal immediately with the emotional labour that accompanies *being gay*. However, silence only postpones that work and death, when it arrives, foists that labour upon loved ones. Thus, getting tested feels like a relationally responsible choice.

HIV testing is still a chore. There are no labs near us that will test anonymously. A negative result isn't the problem. Testing positive is. Receiving this news at a lab that offers no anonymous testing would mean that results would be passed on to public health, and to our family doctor for follow-up. *With whom might HIV+ news be shared beyond systems of government and medicine—police, insurance companies, and the local news media?* We understand the rationale behind tracking illness as a matter of public health, but not having control over those results feels oppressive. HIV affects people where we live.

A positive diagnosis could be used against us. For instance, despite being together as a couple, we both live pretty normative lives by downplaying aspects of our relational status and sexuality to “pass” as “normal.” But normal folks don't contract HIV. Becoming positive would mean having to account for the lack of parity between how we present ourselves and who we actually are. In social circles, we might retreat into our relationship. In our working lives, being out about sexual orientation and potentially HIV thereafter feels riskier, especially for Andrew whose career path is rooted in the mostly conservative financial sector. Thus, these thoughts deter us from regular testing and the maintenance of good health. The anxiety of the potential to test positive and the systemic machinery that would begin to churn as a result of that diagnosis contribute to our longstanding and mutual desire to delaying testing. Neither of us wants to be treated any differently either because of our sexual orientation or the men with whom we, from time to time, have sex. However, not getting tested shirks a responsibility to safeguard good health, for ourselves and intimate others. *If you are sexually active, gay or straight, then failing to test (regularly) is avoidance.* We agree that testing should happen more frequently, regardless of results.



In the summer of 2000, just before Pride Day celebrations, we look up the *Hassle Free Clinic* in nearby Toronto, which provides one of the area's only anonymous HIV testing services to specifically target men who have sex with men. Because HIV testing is done anonymously, each of us is given only a file number. No identifying information is requested. Only the file number can link a blood sample back to the person being tested. HIV testing remains straight forward. Blood is drawn using a single injection to fill only a single vial. However, our anxiety increases after we leave the clinic. Results will take about a week to arrive. Testing brings the possibility of infection into acute focus. For years we have not worried about it. However, in the week after testing, all those moments of not having to think about HIV arrive, hauntingly, at once. It seems to weigh more heavily upon Andrew. *Have there been men in his life who I do not know about, despite our general leaning to discuss with each other, in granular detail, our respective activities with other men? What might he have done with them, if anything, that gives rise to anxiety? I have had my share of men, but I have been careful. Should I interpret Andrew's nervousness as tied to a potential risk?* Andrew worries more than I do. We agree that living with heightened uncertainty for another week will not kill us no matter the discomfort it now brings.

The following week we call in to the clinic to inquire if the results are available for our respective file numbers. They are ready; however, results cannot be disclosed over the phone. We must come back to the clinic, for an in-person appointment. Now, my anxiety kicks up a notch. *Why would they need to see us in person if the results are negative? Uh oh.*

The next day, we hold hands, squeezing each other gently back and forth, as we walk back up the stairs to the clinic on the second floor. The waiting room is busier than it was when we were last here. After checking in, we find two chairs that are situated opposite to each other, sit, and wait for our numbers to be called. I look at Andrew and then scan the room. Many of the other

men seem as nervous as we are. They fidget, wring their hands, and look nervously about as I also catch myself doing the same. As we wait, a nurse beckons some of the men by first name, others by number. I figure out quickly that the numbers are for anonymous tests, like with Andrew and me. I cannot help but watch the person being summoned, each time I hear a number called. I observe their faces, when I see them return from having received their news. Many seem relieved. Statistically, this makes me feel less comfortable. If all the preceding results are negative, our risk for being positive feels higher and higher. Which of us might be the next new diagnosis of HIV? *I need to get out of my head. Overthinking does little good. Nonetheless, overthinking about HIV is what keeps HIV negative boys vigilant but safe. Overthinking is the available outlet in the context of people who prefer to enforce silence about HIV.* Andrew is called in first. I am called in soon after, while he is still getting his results.

I walk by others sitting in the waiting area while following the doctor back to his consultation room. They, too, look up at me as I pass. I feel like a dead man walking. On the cusp of knowing, I want to and yet do not want to know my HIV status. I especially want to hear the words HIV- but fear I might hear differently.

As I sit, the doctor's first words are, "What do you think your status will be?"

*Yikes!!!!!!!*

"It's probably positive," I say.

"You're negative," he confirms.

I am stunned but relieved. Sexually, I have been highly active since our last HIV tests near the start of our relationship a decade ago. On average, I guess I have had sex with one or two new men each month during weekend cruising at gay bars. When I have ventured to the baths, about once or twice a month, I typically fuck another four or five men during the space of an eight-hour

visit. I mentally do the math over a ten-year span since my last HIV test. *The number of men who I have had sex with would make even a professional basketball player blush.* I have been careful, played safe, but sexual activity with strangers, however safe, has risk. Statistically speaking<sup>16</sup>, I feel that I have dodged a bullet when delivered the news of being HIV-.

The conversation with the doctor takes less than two minutes. It is anticlimactic after a week of anxiety and waiting. *Why did I need to attend in person? Why the prolonged anxiety over results which are good news?* Anxiety will return and slowly grow because no matter how many HIV- results that tests may deliver, uncertainty is always about if and when the result could be HIV+.

Andrew is in the waiting room as I exit. He looks at me worriedly as I approach. "I'm negative," I say. "Me, too. Let's go home." The drive home is mostly silent. It should be a happy occasion, but the experience feels so emotionally draining. Getting tested feels like something we ought to do together. What would happen, for instance, if we tested individually and one of those results were HIV+? I don't want to be alone when getting such awful news. Andrew feels the same. Waiting for too long makes anxiety build too much. But how often we ought to test feels equally perilous. The ride home feels better spent in silent contemplation rather than deep discussion to resolve the matter. We are thankful to have this most recent testing event behind us. We are thankful to be HIV-. *How long will it be before we will need to put ourselves through the anguish of testing again?*

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<sup>16</sup> I'm mindful that sex feels risky, like a game of Russian Roulette, each time I find random men to have sex with. Not all of them will be HIV-.

## Everyday Anxiety

Soon after, the relief of being confirmed HIV negative translates into a desire for more sex. Fifteen years into our relationship and our sex lives have yet to let up. Sex happens daily, sometimes twice daily. In addition to Andrew, I am having sex with other men, lots of men. Through the rest of the summer, into the fall, and on through winter. Men. Men. Men. I know that men who have sex with men are disproportionately at higher risk of contracting HIV (Prejean, et al, 2011; Bourgeois, et al, 2017). As a group, MSM historically and presently have both the highest incidence and prevalence (see Glossary) of HIV (MOHLTC, 2016). The frequency at which I play increases those odds. But I am a special boy, a good boy. I practice safer sex, always making sure to use a condom when fucking. After all, I am sleeping around, consensually, for two. I have a responsibility to safeguard not only myself but also my partner—Andrew or otherwise. The frequency at which he and I have sex, and the extent to which I have sex with others, in particular, makes me wonder how long our negative test results will last. *Being careful feels like a statistical oops is just waiting to happen because of the number of men involved.* Our doctor advises that getting tested once a year is recommended. *I don't think he sees the big picture, for gay men like us.* Although we are out to him, and I assume that his advice is tied to that context, I cannot help but wonder.

*“You know we're gay, right?” I don't think straight men fully understand this “lifestyle.”*

He never asks about how often we have sex with each other during a typical week. An open relationship seems equally off his radar. *The allure of silence is its convenience. Saying nothing magically mitigates doing any of the heavy lifting that can follow self-disclosure.* I fail to volunteer that information as well. An HIV test once a year though seems ... understating it mildly, infrequent if not downright inadequate. We are now approaching the one-year anniversary of our

return to testing. *Should we soon test again? Maybe we should plan to get tested more regularly, just to be sure. Maybe the routinization of testing will abate our anxiety.* We generally agree but take no overt steps to operationalize those sentiments, such as writing a note into June 2001 on the calendar.

In 2001, the following summer, our one-year testing anniversary comes and goes. Memories of the anxiety we faced last year have faded. Today is September 11<sup>th</sup>, and as I drive to work, the highway seems particularly quiet. As usual, I listen to music from one of the many mixed compact discs that I keep in the car. The radio, with its incessant advertising and anecdotal interruptions to music, is off. The week unfolds quite differently than anyone could imagine. However, the catastrophic events of September 11<sup>th</sup> also provide a gift, a reminder that life can change quickly and without warning. It centers attention acutely upon loved ones, both living and dead. It challenges the resolve of New Yorkers, in particular, who typically do not shy from the task of banding together. During that month, I feel a pressing need to hold and to be in the arms of those most dear to me. Testing for HIV seems inconsequential and falls to the wayside.

As a semblance of normalcy slowly begins to return to everyday life post-9/11, I am told by my boss that our small company of ten will soon have a health insurance plan for the first time. For the last six years since leaving my previous job which had robust health insurance, I have piggy-backed on Andrew's plan. So, the prospect of returning to a plan of my own is welcome news. However, I soon discover that a blood test will be required for the additional level of coverage that members of the senior management team, of which I am a member, will receive. I bristle. My last HIV test was now over a year ago. I want to be certain that I am still HIV negative before enrolling in this new insurance plan. To be tested now, and to have that test come back

positive, would have consequences for work. At least some of my colleagues would find out. More importantly, my boss would know, and I would be faced with explaining why I am positive.

I am not certain if I will test positive. However, my commute to the sprawling metropolis of Toronto for this job over the last six years has provided many opportunities to interact, after work, with men of the city's thriving gay scene. Often, these interactions have been sexual. Testing positive might require me to account for these behaviours. It will certainly require that I disclose how this illness, which is still widely understood as gay, chose my body. The thought of having to come out not once but twice—once with respect to illness and again with respect to sexual orientation—is upsetting. Whereas sexual orientation has had no negative impact on my being able to perform my job, I cannot say the same for HIV. Although I feel healthy, I worry that wellness may be fleeting given all that I have witnessed firsthand within the gay community.

When I joined the company in 1995, I did not expect my sexual orientation to be at issue. Nonetheless, I did not disclose during the process of interviewing. It seemed irrelevant. Now, the error of omission feels difficult to correct and is further magnified by the prospect of complications related to HIV. My co-worker, who is also gay, would likely understand. I worry more about our boss, who does not hide the fact that he is an Evangelical Christian. I don't wish to disclose because I assume his response will align with problematic religious stereotypes that he may hold about gay men. *I don't wish to disclose because it means having to confront my own ignorance about Evangelical Christians, especially if my boss is compassionate.* My continued silence, however, is complicit in the perpetuation of the stigma often experienced by gay men, especially those with HIV. Being silent postpones having to deal with stigma or judgment, but it implicates me in my own erasure. Out of sight. Out of mind. "This closeting of HIV status is as double-edged as any closet, since it confers a measure of protection through deniability while incarcerating in silence

those it shelters” (Dean, 2009, p.7). *How do we escape from such prisons, especially when directly implicated in their construction?*

I need a plausible excuse to opt out of the health plan, considering I have not had a recent test result to confirm I am still HIV negative, the need to wait an additional one to two weeks to get one, and the urgency to remain silent about both my sexuality and its implied risks. Anxiously, I speak with my boss and tell him that I already have private coverage elsewhere. Therefore, I will not participate in the new company plan. However, when the nurse arrives to take blood from my colleagues the following week, I am summoned to have my blood drawn. I remind them, again, that I have private coverage and will not be giving blood. *I wonder if my cheeks are flushed enough and my nervousness on display to warrant further scrutiny of my excuse and my withdrawal from testing.*

The anxiety that circulates around testing always feels inescapable. I do not wish to become a person of concern over a positive report to public health. I fear being forever branded as “less than.” *How much less than must a gay man, already living at the margins, become? Performing the rote mental calculus to evaluate my worth in the context of each and every social situation feels apologetic, a kind of excuse me for being gay. How much more complex would this math become if I tested positive?* I feel well. I have no visible signs of illness. This illness that I see expressed through the taught skin, sunken cheeks, and protruding skeletons of others. *Living with the constant fear of HIV doesn't feel like living at all.* I think of Dexter and wonder if my excuses to thwart regular testing are a form of HIV avoidance or denial? I do not *deny* that HIV exists. It is real. I do, however, want to control what HIV does to me, physically and psychically. *Can I?*

## Diagnosis

Receiving a diagnosis is a pivotal moment. I think back to the times when I have been tested for HIV. Each time, anxiety peaks in the moments before I know my test results. *Is it the unknown that I fear most?* The fear of the unknown is a large part of my everyday life. However, what I fear more is loss of control. Control over what I can and cannot do after a diagnosis. Control over who I can and cannot be. My greatest fear is over the systemic practices in the guise of health policy that control how cattle are culled from the herd to safeguard the greater good. I fear being just a cow. The jurisprudence of such largescale machinery once set in motion feels difficult to escape, to stop, or to change. That fear seems appropriate when, as innocuous as it might seem, a single phone call might change everything.

No. You do not want to get a telephone call from Luis Hernandez. It is his job to tell people that they might have been exposed to HIV, the virus that causes AIDS. When a client at the San Francisco Department of Public Health's sexually transmitted disease clinic tests positive for HIV, Hernandez is often the one who breaks the news in a face-to-face counseling session. For the past year, he has had an added responsibility—notifying sexual partners of newly diagnosed HIV-positives that they, too, should come in for a test. He will call them on the telephone, send them a letter, shoot them an e-mail or even drive to their home to knock on their door. (Russell, 2006)

Public health policy, such as this, safeguards the greater public good in that people who may be at risk are informed and engaged about those risks. These efforts can be more thorough and wide-reaching than similar efforts of individuals, themselves the source of risk, may be. However, in practice, as in this example of surveillance (the call from Hernandez, above), policy intended to safeguard the masses also strips individuals of our agency.



No longer is it solely up to an individual to inform others with whom they may have had sex. Neither is it desirable. I know, rationally, that public health policies aim to provide oversight to curb the spread of illness and to mitigate further risk. However, they also absolve individuals of a degree of moral responsibility to engage with partners, thoroughly and in timely ways—and preferably *in situ*—about matters of risk. Thus, these policies contribute to bringing about harm as they purport to, and actually do good. In the face of such policy, my capacity to engage matters of risk, especially with intimate others, is challenged. Simultaneously, I feel compelled to account for the level of risk inherent in my sexual behaviour, intimate contact, and my capacity to engage appropriately, meaningfully, and transparently with partners in the mutual negotiation of risk and (potential) consequences. These are the expectations of public health, even when it fails to address its own efforts to “deal with structural realities, political circumstances, biological factors, and the pathways of interaction between these” (Ostrach & Singer, 2012, p. 268). My point is to blame neither individuals nor systems for ongoing failures that have enabled the spread of HIV. It is my aim, however, to encourage greater awareness that issues created by HIV are complex and cannot (presently) be contained within a single story or perspective. *What could be possible if we were to shed the skin of illness as stigmatizing? What might we accomplish together?*

### **My Telephone Rings**

I have avoided contracting HIV despite decades of intense sexual activity. It affects only “others.” Today, however, the ringing telephone brings a different type of news from my doctor. It’s mid-morning, toward the end of March 2005. As I answer, I prepare for the worst news and plan for the best. Until now, I have dreaded to know my HIV status with certainty. Living in ignorance has been blissful, a comfortable delusional bubble in which truth about my health is of my making rather than a reflection of authenticity. Who will I become after that certainty arrives,

especially if it enters in the company of illness? The reconciliation of a multiplicity of realities brought on by illness threatens to turn my world on edge. Yet, knowing will reconcile the stress and anxiety of uncertainty and lead to being better able to plan rationally.

The telephone rings. The wonders of “caller id” confirm that it is someone from my doctor’s office calling.

“Hello, Steve speaking,” I say, nonchalantly. I am slumped in a chair. My breathing is laboured and interrupted by persistent coughing. I feel generally unwell. These circumstances have prompted my visit to the doctor to ascertain why.

“Hi Steve. It’s Dr. Spark. I’m calling with the results of your blood test. Is this a good time to speak?”

“Sure.”

“I’m glad you went for testing. This will help us in the long run. The test has come back positive for HIV.”

“Oh. That’s unfortunate. Thanks for letting me know. What do we do now?”

“Can we make an appointment to see you this week?”

“Ok. Let me know what works best.”

“How about Wednesday at 9:00am?”

“Ok. I will see you then. Thanks for the call.”

The first few moments after HIV diagnosis—as I have experienced with others, and I now feel through my own diagnosis—are fragile and fleeting. I am heartened by the inclusive language that my doctor uses. His “us” prompts my “we” in response. Yet, despite the subtle assurance of language that I am not alone in this, in the handful of heartbeats which follow, the burden of knowing one’s HIV status yields to myriad related contingencies as a newfound reality emerges.

Time stalls. A million questions come to mind at once. *What now? Will I live? How much will this illness cost me? Us? Can we afford it? Should I just wander off and die somewhere, alone, like so many of the stray kittens who happened upon our farm when I was a boy, and who as suddenly ambled away so as not to burden the living? Is this what life is supposed to be about? Should I reasonably expect to share this burden? Am I being selfish to have such thoughts? Who have I become, just now? What sense will I make of illness? What sense will we make?* The moral and legal obligation to disclose HIV status to “intimate” partners brings my attention back to the room. My intimate partner watches stoically from the kitchen as I finally begin to exhale while hanging up the telephone. In the same breath, our eyes seeing as deeply as eyes can see into one another, I tell him, “I’m HIV-positive.”

Silence follows. Silence is the quintessential problem of HIV.

My brief sigh melts into relief. At last, I have a diagnosis. Although my fears are also read and impactful, the transition away from uncertainty feels like a gift. It is the first of many gifts that HIV offers as it begins to reframe ways of seeing and being in the world. After years of expectation and a slow decline in health, having a diagnosis marks a turning point. No longer do I need to contend with the fear and anxiety about HIV that has infused everyday life for many of my gay friends since the mid-1980s. A diagnosis delivers certainty. Yet, paradoxically, my diagnosis replaces everyday thought and action of contracting HIV with a sentiment that echoes frequently among my newfound HIV+ peers. “I just want to wake up and live through a day without once thinking about ... it,” they lament. From one perspective, a desire from the normative social order that encourages blissful ignorance and continued silence about HIV. From another, PLHIV who wish for days of respite in which their thoughts of illness can be quieted. Despite the certainty

offered by diagnosis, being HIV+ intensifies the fine line between private silence and public self-disclosure.

### **Illness Echoes**

Diagnosis invites me to reflect upon the journey that has led me to this point. In my social circles of gay men, even now everyone I know knows someone who has died of complications related to HIV. Everyone. The somatic experience of HIV has been readily apparent, if not obvious, prior to advances in treatment of the late 1990s and the introduction of HAART. The most telling sign is a significant loss of weight that makes bodies appear gaunt and frail. I still remember standing at Andrew's side while waiting to cross a busy intersection in the heart of Toronto's "Gay Village." There we watch a couple of men walking arduously across the street toward us. One looks down to measure his every step, a cane in one hand, the arm of his partner supporting him. *Soon he will be dead. Though presently able-bodied, his partner will no doubt soon follow. It is easy to look away from such bodies or pretend that their display is normal and unremarkable.* We must not.

Physical and psychic pain etches their bodies. Both men are strangers to us, but we could easily be them. In Toronto's gay community, we collectively partake in their individual lament over illness. Any of us could be these men. Pages upon pages of photographs followed by the final words of loved ones fill *Xtra*. Words evoke tears, but the photos are more haunting. Beautiful, handsome, beaming snapshots depict men in their prime, prior to illness wracking them. Photos of the body-altering-reality brought on by advanced HIV would be too painful a memory to publicly display. *Who will tell the stories of these two men after they pass?* These two men are emblematic of so many others, some of them the friends I have known ... and now only have memories. *I think of my last moments at Jeff's bedside, fighting to hold back tears while quietly caressing his*

*forearm.* The emotional lump of empathy that swells inside me in their presence, and the haunting memories that they evoke, cinches my throat into insufferable silence. This same lump speaks to the social pressures which demands complacency and silence in exchange for desultory acceptance.

Despite the historically negative experiences that I have witnessed concerning HIV, I think my own diagnosis will be different. I refuse to believe that the cough which has dogged me for nine months since the fall will lead to anything serious. Nonetheless, within two months, I lose almost twenty-five pounds from the body that I have maintained for all of my adult life. Walking becomes difficult. Breathing is more laboured. At one end of our house, I sit and stare outside for hours. The onset of early summer heat and humidity now makes it impossible to venture outside during the day for any extended time. I am as stubborn as a boat anchor and as unwilling to move. Andrew instantly connects my deteriorating condition with the two men we had seen walking arm-in-arm across the street in The Village. *How could I not agree to abide by his wishes to seek help? I did not want the same fate for myself as we had witnessed for those two men. Yet, I felt unable to act despite what I knew would be in our best interest.* Andrew intervenes.

“You cannot continue to just sit there and watch the world pass by on the other side of the glass. We have to do something.”

I do not want to move my ass from the chair in which it rests. I am devoutly stubborn. However, Andrew’s words crack the armour of my resistance. Despite HIV, there is still a “we.”

The next day, he drives me to a referral appointment with an infectious disease specialist at the hospital. In midday heat, I am too weak to walk from the car. He ventures inside the hospital and returns a few minutes later with a wheelchair. He lifts me from the car into the wheelchair, hoisting each of my feet, in turn, onto metal footpads at its base. People stare as he pushes me

along the sidewalk to a side door. Once we reach the door, someone exiting, in polite Canadian fashion, holds it open as Andrew coaxes the wheels upon which I ride over the raised threshold which is the least resistive obstacle before entering that we've faced today. I sigh. My mind races. *How will I continue to be seen as mentally capable despite my diminished physical capacity? I feel trapped inside the withering husk of who I used to be. I catch a reflection in the polarized glass as we enter. I am about to whisper excuse me before I recognize the contorted figure is my own.*

The doctor's visit is brief. Andrew must now shuttle me across town to another hospital where I will be admitted immediately into intensive care.

### **This Must Be Serious: Intensive Care Unit (ICU)**

Until the doctor's calm insistence that my condition requires investigation, I do not think it serious. I still don't. I know that I am ill and HIV is slowly working away inside my body, cell by cell, eating me alive. Aside from the nagging cough, the process is neither unpleasant nor painful. *I have watched so many people waste away from HIV. Why do I not recognize the obvious ruin that has befallen my own body? My diminished physical capacity cannot be ignored. Nonetheless, my situation feels to be anything but dire. Gurl. You know it's **intensive** care, right?*

The trip across town from my doctor's office at Grand River to St. Mary's takes us about fifteen minutes. With a loving shoulder from Andrew and a modicum of self-esteem on my part, I manage to navigate the short distance from the car to just inside the front entrance before once again taking a seat in a wheelchair. He kisses my cheek and promises to check in on me later. An orderly has already replaced Andrew's hands on the grips of the chair and summarily whisks me off. *Are they trained to be this swift? Does their behaviour always foreclose on the tears of dilated goodbyes amid the gravity of emergency medical situations, as it seems to have in this instance, for us?*

The ICU is a short distance from the main lobby of the first floor, which is situated along a typically sterile hospital corridor and through a set of swinging doors. The orderly spins the wheelchair around and pulls me backward through the metal door with glass panel. I watch it spring closed after us. I read, from right to left, and sound aloud the letters on the sign suspended at eye level on the glass. "B I O H A Z A R D." Feels like home. Obviously, HIV finds my sarcasm indigestible.

The room is spacious but uncomfortable. It feels claustrophobic and self-contained. Most of the cinder-block walls are painted an institutional mint green colour. No exterior windows mean no natural light filters into the room. The fluorescent fixture on the white and concrete ceiling above hums with the strain of producing what stands in for natural light. A hospital gurney below seems to be its wary benefactor. Two side chairs sit to the left of the door to the ensuite washroom, itself a means of helping to ensure the integrity of biocontainment. I suppose they cannot have unidentified pathogens wandering to expose the already vulnerable ICU population. The orderly helps me onto the gurney, out of my clothes, and into a hospital gown. Despite my emaciated frame, the gown won't close in the rear. *Do they ever? I will be the butt of my own ICU humour.* I cough and wheeze. I blame the backdraft.

I have been admitted to the ICU today so that the doctors can determine the reason for my persistent cough and its potential role in my accelerated weight loss. In October when I first noticed the cough, it seemed innocuous enough. Just an annoying tickle. I assume it will go away in a few days to a week. When December arrives, I think that perhaps the cooler weather prolonged its departure. When January concludes, I begin to express concerns. By then, I notice a shortness of breath and an overall feeling of weakness. The weight loss that gradually begins thereafter is tougher to dismiss. It is the reason I finally go to the doctor to have the bloodwork done which

ultimately confirms my HIV status. Though HIV+, I feel well enough into April. However, once the summer weather and heat of May begin to arrive, weakness and labored breathing add to the queue of symptoms that now, ensemble, warrant earnest attention.

Over the next few hours, machinery on carts begins to arrive. I try to identify the purpose of each, but the task proves more daunting than I had initially imagined. Surrendering, I instead start to notice the staff who are pushing the carts. They are all in full hazmat gear, wearing gloves, boots, face masks, and protective head gear. The works. A few hours earlier, I walked in the front door of the hospital.

I ask an orderly, “Is my condition this serious now?”

“It’s just precautionary, Steve, until we can determine why you’re coughing,” he says.

The muffled tone of his voice through protective gear fails to fully satisfy my mounting anxiety. I stick my finger in the glass of water that someone has brought me, half expecting the interface between my skin and the liquid to erupt in flames. Nope. Normal.

The machinery fully assembled, staff—I count four—begin to trickle in. Soon, an anesthesiologist arrives. He takes up a position near my right shoulder in my peripheral view. The doctor enters thereafter with a flipchart in hand.

“Hi Steve,” he says. “We’ll start in a few minutes to get this bronchoscopy out of the way for you. First, I want to review your file with you and go through some of the risks before we go ahead. Ok?”

I simply say, “Sure.”

I cough. Surrounded by instruments and people, I feel ill-prepared to say anything that reads as contrary to moving ahead, whatever the risks. *Is this by design? I do not feel in control. Can I now dissent and, further, what might the implications be in the context of a busy and highly*



*specialized ICU? The gaze upon my ill body of six people now in my room feels difficult to countermand. In my weakened state, I must choose my battles carefully.* I recall the anesthetist asking me to count backward from ten. My compliance with the countdown dismisses any remaining dissent about the procedure now beginning. I make it to eight before I fade into unconsciousness.

When I wake up, the room is empty aside from the two side chairs, the gurney, and me. A nurse notices that I have begun to stir. I ask her about when the bronchoscopy will take place.

“An hour ago,” she says with a chuckle. Her rapid exhalation briefly fogs the glass of her protective headgear. “It’s not uncommon to feel a little disoriented after sedation.”

“Oh!” I respond.

“We should have results for you in an hour or two. In the meantime, would you like something to eat? ... Are you hungry?”

I notice that my glass of water has disappeared. It likely was removed as a matter of protocol, given the number of people who had been milling about recently in my room.

“I am not sure how much of anything I can eat. I can try. Maybe some soup?”

Ordering hospital soup feels like a strong indicator that the sedation lingers still. Maybe it will be kind enough to blunt my taste buds a while longer.

I feel relief once the bronchoscopy is over. Though I continue to feel weak, I feel as though I turn a mental corner. Assenting to the procedure and its few though significant risks is meaningful. I take baby steps but steps nonetheless to control illness. Andrew arrives with my Mum, Stella, for a visit. They are both clad, head-to-toe, in the same hazmat gear that staff continue to wear when they are in my presence. I am thankful but nervous for their visit. *How fearless my Mum is. I know she does not want to be here, in this untenable situation, and yet this is her son.*

*She cannot not be here.* I try to reassure them both, but especially Stella, that all is ok. She seems transfixed, as they both sit in the chairs beside the entrance to my ensuite washroom. I notice her looking beneath the gurney at my feet, which is now at eye-level for her. Then I realize that the catheter inserted earlier into my bladder continues to fill a collection bag now hanging beneath my feet but in clear view for them.

“I guess I shouldn’t have had all that beet juice,” I say wryly.

“Looks more like apple,” Andrew quickly jabs.

I am thankful that he remains dauntingly with me in humour and in life. I am sad for Mum who, for the first time since I was a wee lad, has to contend with the gravitas of my piss pooling uncontrollably and unceremoniously.

When they leave after a brief but light-hearted chat, I know that Stella is in good hands with Andrew. *He is one of the kindest and most sensitive people I know.* This comforts me.

When I arrived at the ICU, I was one chilling draft away from expiry. Now, three days later, with the abundant attention and compassion of a team of people looking out for me, I feel as though I have a fighting chance.

## **Back to Hospital One**

Slipping off the endangered list merits a transfer from the ICU to my doctor’s hospital across town, the place where my medical ordeal began to climax three days earlier. Again, the familiar wheelchair does its part to ensure that I make it there without falling due to my weakness. The room is decrepit in comparison to the stark ICU from which I have just come. High ceilings and sizable windows provide little relief from exposed pipes, cracked and flaking paint, and well-worn tile floors. Two small bedside tables, each topped with a reading lamp and telephone separate two single cots. After the orderly leaves the room and takes the wheelchair with him, I sit at the

foot of the one closest to the window peering out in the direction of our home. My adumbrated reflection upon the glass, as the sun begins to set, floats eerily between my perch atop the bed and my gaze homeward. Although I cannot see it beneath the verdant canopy of treetops, I long to be there. *How close it is and yet how far away it psychically feels from this place.*

Andrew and his Mum, Erika, arrive shortly after my arrival for a brief visit and to help me to get settled.

Noticing the television, Andrew asks, “Does it work?”

“I won’t need it. The shows are mostly trash, anyway.”

“What about the phone? Can we call you? Let me write down the number.”

Erika sits next to me at the foot of the bed. My thin frame cannot hide how ill I am. Conscious that the hospital gown into which I have changed is likely gaping in the rear, I adjust my position to face her. She says little, but her face speaks volumes.

I know she cares. She has become a second mother to me over the course of the fifteen or sixteen years I have known her. She has accepted me as family despite no explicit mention from Andrew or me of our relational status. It seems good enough to her that I be accepted on the merits that I am her son’s best friend. In hindsight, I wish that Andrew could have found a way to “come out” to her before her death. The tremendous relief that coming out provided me biases this view. I wish only for a similar outcome for him and his family. The experience of coming out reminds me now of the need to reveal illness and, despite the complexity, how wonderful that outcome might be. Not being out makes navigating some subjects difficult. For instance, I cannot tell her that my illness is HIV-related. *How much might she even know about HIV?* Talk of one thing necessitates engaging a myriad of others, across varying states of disclosure. It seems too much for the immediate moment in the context of a hospital visit. *If I were selfish about disclosure, I*

*would just say what I wanted, and in unfiltered ways. My reticence is, at least in part, a reflection of my concern for the feelings of and my relationships with others.*

Erika notices how scratchy the bedspread is.

“I bet it’s wool,” I say.

She strokes it with her hand outstretched and nods.

“It’s probably 100 degrees outside and I have an orange, wool bedspread!” I lament in an attempt to make my inner desire to leave more palpable.

Dinner arrives, looks inedible, and smells even worse. It is some kind of beef smothered in ersatz sauce. Neither the colour nor shape of its components make the meal identifiable. I wonder if the equally questionable-looking side dish of corn will facilitate surveillance of my consumption, or the lack thereof, later when I poop. I pick at the offering with the tip of a fork, half expecting it to dissolve in the chemical slop, then return the utensil to its place beside the entrée plate. Erika inspects the platter and agrees with my assessment of it being unpalatable. She seems ready to insist upon cooking me a real, a proper German meal, when Andrew sticks a finger in the sauce and summarily licks it clean.

“It’s not bad,” he says.

“Then you eat it,” I say while inching the tray gingerly toward him with the tips of my fingers.

He does. Andrew rarely misses a meal. I laugh to veil my disgust and ask Erika if she would smuggle something in for me when next she visits. She nods overwhelmingly in support. *How willingly might she continue to be my accomplice if she knew my illness to be HIV? It doesn’t seem like the right time to tell her. When will that time (ever) be?* After Andrew finishes my dinner, they take their leave to allow me to rest.

It is seven o'clock. I toss and turn. It is too early for me to sleep and too hot to get into bed. The scratchy wool cover continues to vex me further. Unable to find comfort, I move about the hospital room from bed, to chair, to window. Annoyed, I conclude that I need to leave. The slop they call food. The inhospitable mood of this room. The proximity and allure of home on the other side of the window. I summon the nurse by using one of the buttons on the wall at the head of the bed. By the time she arrives, I have tossed the hospital gown into a disheveled heap upon the woolly bed-topper and stand fully dressed and ready to go. My ill-fitting clothes disguise neither my weight loss nor a need to stay. However, my directness and unwavering tone with the nurse convinces her of my resolve as I hasten to depart.

"You can't leave without first speaking with your doctor," she sternly warns.

"Can I take the call in the hallway outside this room?" I motion the black rotary dial phone glued to the wall in the corridor just beyond the room's doorframe. It looks like an antique piece. I wonder if they built the hospital around it.

"You'll need to sign some paperwork if your doctor says it's ok to leave. I'll get him on the phone and let you know when," she says as she turns in a huff into the corridor and left toward the nurse's station.

It feels like a long wait. It takes considerable effort to continue to sit upon the bed. Yet, I am adamant against laying down as it might signal a desire to stay.

Restless to remain seated, I shuttle to the doorway and prop myself against its cool metal frame from where I can see the nurse. She is on the phone having an animated conversation. Her hands flail. She risks dropping the clipboard from which a ream of loosely attached pages swings precariously in the breeze. I cannot hear what she's saying from this distance. Finally, she motions to the phone on the wall. As I move slowly toward it, the phone begins to ring.

“Hello?”

“You have some concerns, Steve?” my doctor asks calmly.

“I can’t stay here. It’s not conducive to my health. I need to be at home.”

“That’s not a good idea right now. You should stay a few more days until you get your strength back. Besides, the drugs that you need to take right now are complicated. It’s best to have an experienced medical team nearby to take care of you.”

Across town at St. Mary’s, the ICU staff were angelic. Although I failed to get much uninterrupted sleep over the course of three days, I felt their presence around me constantly and their concern for me unrelenting. Now, here, at Grand River, I feel unimportant and isolated—more so than I had felt as the sole occupant of an isolation room in ICU.

“I need to leave,” I say again with more certainty.

“I do not agree, Steve, but it’s up to you. If you leave now, though, you’ll be doing so against my orders, and I cannot be responsible for any consequences.”

“I understand.”

We end our conversation. I sign the discharge paperwork that the nurse has prepared for me and guide myself along walls to the elevator, then down toward the main entrance. Along the way, I stop at the pharmacy to pick up the medications that I am expected to take. One of the medications is a prophylaxis to ward against opportunistic infection because my CD4 count is so low. My count is around 54. AIDS, the third and most advanced stage of HIV, begins when the count drops below 200. Still, I feel that I am able to manage my health better outside the hospital, despite the quantifiable metrics through which I am characterized. I am not only ill but also acutely so. *Numbers don’t lie!*

I pour myself into a taxi just outside the main entrance and ten minutes later I am home. I sit on a couch in the living room. Andrew is still dropping off Erika at her house after their visiting me. When he arrives a few minutes later, he is stunned to see me in the living room, sitting quietly in the soft glow of a table lamp. Then he becomes angry.

“What are you doing here? You were just in ICU for the last three days. Are you nuts?”

“No. I am not,” I say quietly. “I just could not stay in that hospital. It didn’t feel right. I am not going to get well there.”

“And you are here? You’re such a stubborn fuck!”

“Yes. I am. But I feel better already. I just *need* to be home. Ok?”

Because Andrew is not one to fight, I interpret his anger as being expressive of his deep concern for my, and our, well-being. My sincere insistence appeases him, for now. He kneels at my feet and rests his head gently on my thigh. I pet his head with my hand and lean forward to kiss it. Measuring life breath by breath, I know I will get better. Home is where our hearts belong. My life, post-diagnosis, begins anew.

### **The Pragmatics of HIV Status Self-Disclosure**

The regime of medication that I must take after leaving the hospital is not complicated, despite what my doctor told me. I am scheduled to take some pills every three hours, which is the trickiest piece when sleep intervenes. Yet, I am committed to getting better and able to manage. Day by day I begin to feel stronger and more like my old self. Follow-up visits to my doctor confirm that I am making good progress. We both laugh at the events of my discharge and how quickly I have managed to distance myself from my near-death moments in the ICU just two months earlier. My breathing is much better. The coughing is gone. Over the past three months, I have even managed to regain all of the twenty-five pounds that I lost since last fall. Most

importantly, I look well. However, looking well and being well pose a conundrum for HIV. *How will I account with others for any of the ways—especially, my weight loss—in which illness made me appear differently? Will I reveal to others, in general conversation, my HIV status? How will I continue to act in terms of my moral responsibility, especially when the greater social expectation is for me to remain silent?*

Although the process is similar to that of disclosing of my sexual orientation, I continue to feel that coming out as HIV+ feels riskier and a disclosure that induces vulnerability. In addition to the psychic and physical labour required to maintain good health, revealing my status may compel me to need to help them in certain ways. For instance, I will need to help others understand and thereafter cope with the changes to my social reality once my disclosure occurs. This is, at least in part, because disclosure can call others to pore over previous interactions and decisions to assess their potential exposure. Sharing a drink, a straw, or eating utensils are among the most obvious of these. In a general context, none are unduly questioned practices. In the context of HIV, having participated in one of these sharing moments may result in a re-evaluation of risk, whether it is real or perceived, for contracting HIV. Thus, disclosure imposes a measure of work to be done. In dire cases, that labour shifts almost exclusively toward PLHIV and to matters of our personal safety when the potential failure of someone coping may result in threats of harm, violence, or mortal injury to us.

For example, anger may arise when someone feels that they have not been told soon enough. The reality is, however, that self-disclosure of HIV status remains difficult when silence is expected, even when asked directly about HIV. When anger is not sufficiently satisfied, it may lead to psychological violence, as in the case of “DIE FAGGOT,” “FAGS deserve AIDS,” or “AIDS is God’s punishment.” Words I’ve heard many times, directed at me and others, when



understanding and compassion are fleeting. The goal of physical violence is to remove the perceived threat rather than attempting to understand it. Unfortunately, intimate partner violence, especially as it intersects with HIV self-disclosure, remains an area of growing concern (Ramachandran, Yonas, Silvestre, & Burke, 2010). Violent interactions and the continued uncertainty that self-disclosure will garner acceptance make the HIV closet difficult to breach.

Nevertheless, disclosing that I am gay has become an integrated practice of being mindful and authentic in everyday life. The script, so to speak, that I use to reveal this information improves year after year and across contexts—whether this disclosure occurs with friends, at the office, in front of students that I teach, or in general public settings. I have had plenty of opportunities to practice disclosing and only a few occasions when concerns for personal safety because of sexual orientation encourage silence. For HIV, however, disclosure still remains new and uncharted territory. The risk of disclosing and uncertainty over responses feels too great. *I didn't understand HIV the way I do now until well after I became HIV+*. Unloading HIV status feels different than does confirming sexual orientation. “AIDS [*sic*] is understood in a premodern way, as a disease incurred by people both as individuals and as members of a 'risk group'—that neutral-sounding, bureaucratic category which also revives the archaic idea of a tainted community that illness has judged” (Sontag, 1989, p. 46). *How will I share the enlightening news of my virus on board? How will I mitigate the potential to be harmed, both now with the immediacy of disclosure and in the wake of its effects over the longer term? How can I articulate this illness is not a punishment but rather a gift?* Lifting the veil of secrecy imposed upon HIV too often feels threatening to my personal safety.

**CHAPTER FIVE:**  
**BIOTOXIC HAZZARD—A (B)ROMANCE**

In the previous chapters, I disclosed experiences tied to my sexual orientation and HIV status, focusing on the personal stakes and meaning for each. These disclosure processes feel less awkward with practice. However, the choice to disclose always feels consequential and with often direct and immediate impact upon the direction and quality of my life.

In this chapter, I turn my attention from my past to the present. Expanding on my emphasis on friendship, I continue the exploration of sexual orientation and HIV status and the tensions that often arise when discussing these topics with longstanding friends.

**You Are Here**

As I mentioned earlier in this dissertation, “self-disclosure is the act of making yourself manifest, showing yourself so others can perceive you” (Jourard, 1971a, p.19). Through disclosure I seek to be visible, to be understood, and ideally to negate my being disposable.

Disclosure is many things, including a weapon. My disclosures reveal the truth of who I am. Like the peeling of an onion, I make myself visible to others, layer by layer, over time, and across relational contexts. Piece by piece, I systematically disclose to dismantle the Master’s house (Lorde, 1983). For example, the revelations I include in the dissertation draw on my lived experience from several decades to situate self-disclosure in the specific context of HIV. I make these disclosures to challenge the prevailing tales which circulate about what HIV is and is not, who it affects and does not. The direct benefit to readers, I think, is a nuanced understanding of

HIV without the need to experience it firsthand. I write about (non-)disclosure of my HIV status in everyday life experience to long-standing friends and the forces that constrain “difficult” or “impossible” conversations about HIV. These conversations and their impact are never certain, and the work of self-disclosure is never finite. This cannot be overstated. Simultaneously, I attend to the myriad ways that identity is implicated in the act of (non-)disclosure and how disclosure, in turn, affects who I am and who I am allowed to be.

The conversations with Andrew and Mum took place before this study began. These mark the first times I had to disclose my HIV status. Saying the words “I’m HIV positive” for the first time was simultaneously stressful and a relief. Being in the company of two people I love, and who love me, made it easier than I could have imagined it being. These first conversations inform the disclosures to friends, which follow.

### **Andrew**

I have found both a friend and a life partner in Andrew. He and I often revisit the moment when we met at *The Half and Half*, laughing at how dismissive I was of his overtures to get to know me. His *entrée* becomes a longstanding inside joke for us.

“Nice weather we’re having!”

The utterance brings into sharp contrast how much I avoided looking for love and how essential he has become in my everyday life. I tell him many times over that I would take a bullet for him. I would, without flinching. He means that much to me. His attention infuses the everyday moments we share together, big and small; they add up over the course of our thirty-plus-year-history. He walks his talk. When the diagnosis of HIV arrives in my life, he is there *with* me.

“We’ll get through this ... together.” He quickly strides from the kitchen to the living room where I am sitting, the wireless phone still in hand after I received the news of my status. He reaches out to embrace me.

His touch means the world to me during these first few moments after diagnosis. It penetrates so deeply and means more than words could express. His touch reminds me and makes me feel that I am not alone. I reconnect with the humanity that has just been stripped from me with the diagnosis of illness. His touch bolsters my spirit and blocks my devolution into yet another clinical statistic, bereft of life. He makes the difference between giving in and fighting on. It is a pivotal moment that lingers still. His belief in me, in us, is restorative. I trust that we will, indeed, get through this unexpected turn in the road, together. We have.

Andrew’s bearing witness to the arrival of this news might seem to downplay that much disclosure occurred.

“I’m HIV positive,” is all that I say as I hang up on the call with the doctor though he has heard my half of the telephone conversation from the kitchen before rushing to my side. *I love that he stood by watching silently. It might be easy, looking in on our mise-en-scène, to misconstrue our openness and connectedness as an invasion of privacy.*

Our momentary embrace reminds me of the tendency with self-disclosure to elicit reciprocity among conversation partners (Jourard, 1971b; Cozby, 1973; Greene, Derlega, & Mathews, 2006), and how reciprocation is needed for relationships to grow (Hargie & Hargie, 2010).

“How do you feel?” he asks right after I heard the results.

“I’m ok. I’m *ok*. I had hoped that it wouldn’t be positive, ... but I was prepared for the eventuality that it could be. I’m ok. I’m relieved. I’m relieved to finally know what is responsible

for this fucking coughing, the weight loss, and my inability to walk more than ten feet without having to sit down to catch my breath.”

The confirmation of diagnosis brings Andrew to my aid. My acknowledgement of his question reveals the nuance of disclosure in that I simultaneously affirm where I am while offering a template for his response. It offers an invitation to journey with me and illness while also granting permission to walk away. I think of the times when I have disclosed my sexual orientation. I don't make apologies for who I am. I seek no permission to be who I am. At least one of the implications in the nuance of such disclosures is that, if you don't like what I have shared about who I authentically am, you are free to walk away. The relationship will be over. We're done. It's similar now with the news of being HIV+. If you can't be with me on this path, Andrew, feel free to walk away.

It might seem difficult when looking in from the outside to live with this philosophy of letting someone go, especially someone who I claim means so much. Indeed, it took me a while to become relatively comfortable, to reach a place where jealousy and possessiveness inside the relationship is minimized while being socially pervasive outside it. However, I solemnly believe that we ought to hold others with only the lightest of touch. *We cannot own other beings*. They should be present in our lives because they choose rather than feel obligated to be there because we somewhere learned it.

As life changing as a diagnosis is, it is not all bad. *HIV has been a gift to me*. A diagnosis also brings less uncertainty and relief. Now that he and I knew the root cause of my chronic coughing and weight loss, we can make plans. Certainty restores a modicum of predictability to an otherwise tenuous existence predicated by waiting, waiting for what will happen next, for the inevitable decline to nothingness. Bodies with HIV like mine can vanish into thinness and then

extinction rapidly. I've seen it far too often. *Will this be my last breath? Will I die in his arms? What will it be like for him to awake next to me, motionless and cold? Will he ever outlive that experience, that image, the coldness void of lips that no longer move not only to meet but that magnify his embrace? How could I ever do such a heartless thing to the man that I profess to love so totally?* I cannot.

Coping with illness means coming to terms with the loss of control and a body's diminished capacity because of illness (Frank, 2013). Yet, there are also many things now that are within my control. A diagnosis delivers bad news but it also brings something good. For me, it offers a different point of view that compels me to stand on the liminal precipice between life and death and to choose, instead, to turn back. By turning back, I begin to see the world in subtle, different, and nuanced ways. For instance, the thought of my own mortality flashed before me many times as I lay in the ICU. It periodically haunts me, still. To give in to it feels like a betrayal of the love that I feel from, and for, Andrew. This betrayal feels like I am effectively refusing the tremendous gift (and burden) that life and love is. Indeed, I fight on because of him. I fight because we remind each other what it is to be alive. And like any good story, I want to know, and experience, what happens next.

Andrew and I both learn of my illness at the same time. I hear it on the telephone; he reads it in the tone of my voice and facial expression when looking on. I consider myself lucky, to have found a friend and life partner who wants to show up for and share in everyday experiences, whether bad or good. Andrew is no fair-weather friend. His presence and being there make disclosing to others easier. I know, but do not take for granted, that he will be there for me if my disclosure to others doesn't go as well. *Exhale.*

## Mum

Sometimes self-disclosure is not initiated but rather encouraged by others. Shortly after returning from the hospital, Stella comes for a visit. We sit in the sun room of my house, looking out at our summer garden. A flock of starlings pecks noisily at the grass as they forage for food on their migration across the lawn. As we stare quietly at the birds, I clear my throat nervously and tell her that I have something to say. Before I can begin, she is already scanning my more-emaciated-than-usual body. *I am thankful not to be in a hospital gown, this once.*

“It’s HIV, isn’t it?” she asks, trembling.

“Yes,” I say, leaning in to place a calming hand upon her knee. “I found out a few weeks ago in March from the doctor that I am HIV-positive.”

“Will Andrew leave you now?” she asks with the loving concern that many mothers do and Mum, in particular, always exudes. She places her hand on top of mine, still resting upon her knee.

Her physical connection, skin upon skin, is an exemplar of a mother’s love. *Despite what she may or may not know about HIV, I remain her boy. For me, her touch confirms this.* Yet, I am stunned by her sudden candour. Since coming out as gay to her in 1987, she seldom raises questions that suss out the intimacies of relationship. Both Andrew and I are implicitly accepted. Now, for the first time in decades, she wants to know about our relationship and, in particular, if I am soon to be alone.

“No. We have an open relationship. Andrew has no plans to leave, but you can ask him about it if you like.”

“It’s ok. I love you, Steve.”

We quietly return to watching the birds, our hands still stacked upon her knee with our fingers now intertwined. She made disclosing easy because she took initiative to open the

conversation for me/us. My ill body does not hide much, but nonetheless she connected the dots and asked bluntly about what is ailing me. I didn't want to disclose my HIV+ status to her. I didn't want her to worry. No parent should have to watch their child die and I don't want to be that exception. I appreciate the connection I feel because of her willingness to engage me in this way. I appreciate her. *Mum loves to pleasantly surprise me. Why can't disclosure always be this effortless?*

Often, though, disclosure isn't the topic of "polite" conversation. Sometimes, fucking with the notion of polite conversation means turning rules of decorum on their edge to unlearn and to unravel social convention that condition what private information should or can be shared publicly. Yet this work to "unlearn" is often difficult work (Berry, Gillotti, & Adams, 2020). It takes hard work to dismantle the Master's house (Lorde, 1983) while it's continually being reinforced. I faced complicated decisions. *How much can I tell Mum? How much will she want to know? How much of a right to know does she have? Which of the competing voices in my head will win the day? How has she instructed me to be in the world? What will disappoint her?*

These are the thoughts that flood into the microseconds that it takes to mentally struggle and decide—because I *really* wanted to be authentic with her. I needed to be fully present with her like she did and continues to do for me. Mum has always been there through poopy diapers, first teeth, skinned knees, falling from bicycles, high school graduation ... the whole works, front row seats, every time. I am thankful, before I speak, to feel her fingers moving on top of mine. They expressed more than words ever could. My eyes met hers in silence. A tacit knowing imbued the glances of our exchange. A son. A mother's love. She made it easier to disclose.

Mum manages to broach the subject of HIV because my outward appearance makes illness difficult to hide. I labour to breathe. I can walk only a few feet before needing, again, to sit and



compose myself. *Sometimes that means reaching unceremoniously for the floor because who has furniture every six feet in their house?* It takes ten minutes to complete the trip across the house to the bathroom and back to the comfortable couch from which I look out onto a backyard. In it I watch the many small birds and animals continually mill about and interact and I long to be as animated as once I was and they are now. I may as well be wearing a blanket when I slump back into the sofa, my clothes filled with air from their being several sizes too big. *I once filled these clothes. They fit snugly. I'm physically just a sliver of what I used to be.* It makes my health an obvious target of inquiry. I feel utterly vulnerable. Yet, disclosure is still my choice.

Mum is kind-hearted. She asked me directly about my illness, reinforcing my experience with and of her during the course of my life. She is also selfless. She often puts others first. Before I entered the working world as a teenager, I saw her more than once cut food from her supper plate to pad the portions of other family members, Dad's in particular. We had some lean years as a family in the early 1980s. *If you have ever cut your own portion or skipped a meal entirely so that another could eat, you likely know how this feels somatically, both for yourself, your benefactor, and anyone sitting silently by in witness (as I did).* Putting others first is not only effortless and routine for her but it is also something she genuinely believes in doing. Born during the Second World War, she understands adversity. I once took heat from a group of feminist peers at school for suggesting that Mum had found her niche. I relented. Niche is too reductive and stereotypical a word to fully embrace what Mum does and who she is to me. She does not easily surrender to a category. *How? How could I not disclose to her?* She is so important in my life. Thanks, Mum. I feel your love daily. It softens the impact that HIV has on everyday life. In those dark moments that randomly and occasionally punctuate life, I need only conjure your spirit to tip the scales toward balance once more.

Mum often keeps things to herself. She's "wired" (read: programmed by others, as each of us is socially and culturally conditioned to do throughout our interactions with others) to put herself second in the equation. That means that she routinely lets others speak before she chimes in herself. Often, she offers agreement. *I wonder how frequently she might inwardly disagree but outwardly assents, nonetheless, to keep the peace.* Her hand on top of mine felt tremendously important. She doesn't have to understand what it means to be gay, to be sexually adventurous, or to live with illness. Her hand on top of mine affirmed her willingness to be present. It helps me to think how my disclosures to others is an example of me being present.

### **Arwyn**

In review, my diagnosis comes in March 2005, toward the end of my first year back in university. My illness throws studies into disarray. I am taking five rather than the recommended four courses on my schedule. I can't keep up with all of them. Something will have to give. In one of my courses, *Speech Writing*, I accept a final grade of "D." I've come up short on a few of the assignments and don't feel like arguing or explaining the context of my health circumstances that have limited my performance in the class. Another of my courses, *Theatre History*, is offered only once every other year. I miss a final exam and the instructor wants to offer me a grade of incomplete rather than to work with me into the summer months to conclude what has, to date, been good progress. I'm too tired and, frankly, too ill to contest. It's a blessing in disguise. I'll take his course again in two years. In the meantime, I can explore a joint major by picking up classes in Speech Communication instead of Drama. *More Drama is less drama. I chuckle.*

I take time over the summer to recuperate. I've started and respond well to medication. I reach an undetectable viral load (see Glossary) within the first month and my CD4 count continues to climb, the admonition from my doctor that it will never be "normal" notwithstanding. I take it

slowly. Rest. Sleep. My appetite returns, as does the weight. In the span of two months, July and August, I return to my typical adult weight of 145 pounds, which feels healthy but still reads as “skinny” to everyone else. The summer is hot. Sitting by the pool, I manage to tan, deeply. When I return to school in September, many of my classmates are shocked by how “good” I look in comparison to how I had looked at the end of the last semester and the last time many of them had seen me. It has been quite a physical transformation, from the brink until now. I’m lucky. I’m resolved to live. Yet, my appearance is but the veneer atop the chronic, lifelong battle waging on inside. HIV is invisible to them.

I take courses in *Interpersonal Communication*, *Leadership*, *Crisis Communication*, and *Small Group Communication*. By the winter of 2009, I am ready for a capstone course, with Arwyn called *Performative Inquiry*. I write using autoethnography for the first time. My topic calls attention to the disjunction between what I make public and what I keep private. *It’s the spark that led to this in-depth dissertation*. My illness may be top of mind, but it is far from the page. I share myself in other, more guarded ways, to the extent that one can curate snippets of lived experience for a 40-something-year-old-body and shoehorn them (neatly) into a 20-page publication limit. My choices to keep sensitive information hidden magnify the chasm between private and public. I am proud of the work. Yet, when I look at it now in the current moment, as I am near the completion of my doctoral adventure, I wish I could have disclosed more. I wish I could have been more vulnerable. I wish I could have been as authentic, on the page, as I feel I am now being in this dissertation. I wish I could have been candid and gritty. *This is someone’s life*. It’s my life.

I recall being petrified in the first class with Arwyn. I’m not sure what I will learn from her. Most of all, I’m not sure what I will learn about myself. I have just recovered from illness, and am now managing a chronic condition. Do I want to use my illness as the focus of a class

project? Coming out about being gay feels old, familiar, and tested. HIV? That's less certain territory. I proceed cautiously.

Arwyn asks our class to sit facing a partner. The boy nearest me looks my way. I turn to face him. Both of us sit cross-legged upon the apron of the stage in theatre classroom. The floor is cold. I fight off an urge to shiver against the need to find focus.

"Who is your partner?" Arwyn asks. "Don't speak. Just observe."

I notice a few students in my peripheral vision have begun to write notes about their observations. I'm still trying to make sense of the boy I'm facing. *Where should I start? Can I say he's attractive? What will that admission say about me? Will it make him feel uncomfortable? What will he say about me? Will he be accurate? What am I giving away? What am I hiding?* I struggle to begin, to make sense of this simple exercise which feels so deep. I'm overthinking, I think. *I chuckle.*

"Notice where your attention goes," Arwyn says to us, seeming to sense the discomfort around the room. "Write down whatever comes to you."

Her voice is warm and personal. It connects me to the exercise, allows me to be present, and calms my inner thoughts. Words flow on to the page.

Arwyn is similar in frame to Mum, but to describe either of them as being small would be a colossal error. She sits upon the edge of the stage a few feet above us looking out on the apron. Her legs hang comfortably and rest upon the heels of black, knee-high leather boots. A black leather coat, open, drapes stylishly from her shoulders. I feel such warmth exuding from her. I feel drawn to know her.

I feel torn as the first class progresses and a "fight or flight" sort of response promptly kicks in. I am filled with dread and want desperately to drop the course. I don't have any qualms about

my sexuality, or disclosing that I'm queer. But as I peruse the syllabus, look at assignments, I feel that the type of personal introspection and revelation that this course will require aren't superficial. It feels too risky to disclose aspects of myself that have to this point remained hidden, especially to my student peers. *What do they need to know and why? Why challenge the privilege of being able to pass ... as healthy? Will disclosure of my HIV status lead to rejection?* I also feel called to stay. *What if I could disclose my HIV status, as easily as it had been with Andrew or Mum?* I decide to stay and see where this path leads.

As it turns out, staying is one of the best academic and personal decisions I've ever made. Arwyn is a brilliant teacher and mentor, and in the years since I took her class, has become a dear friend. Yet, despite her knowledge of my being gravely ill early in my tenure at UW, my revelations through writing and during the many conversations we have had since, I have chosen not to disclose my HIV status to her.

Instead, I talk about illness from the standpoint of a distanced and objective observer. I choose my words carefully. I don't lie, yet, I also don't reveal what I feel I ought to. Our conversations about illness are like so many of the conversations I've had about sexual orientation. I walk to the brink relationally, peer over the edge, but I never quite get to the point of describing myself in ways that look back from the other side of the chasm.

One night when I am having dinner out at a restaurant with Arwyn, I cross the line. I lie to her.

"I'm not HIV positive, but I know so many people who have or who have died from AIDS," I say.

She accepts what I have to say. I guess that, among many things, I'm a charming dinner guest. The conversation continues as we eat, choose dessert, then sip coffee.

My lie gnaws at my insides. I've done it before. I told my doctor that I wasn't gay. Somehow, I believed that being gay would consign me to some lesser status of service, or worse. Affirming my gay identity would lead to denied access. In the conversation with my doctor, and now with Arwyn, I don't stop to think that the access I am denying might be to me.

I apologize to my doctor. Soon after dinner with Arwyn, I feel an overwhelming need to set the record straight, as it were. Owning my truth feels important, affirming, and morally correct. Denying myself feels like the choice others would have me make, others who themselves take issue with homosexuality, HIV/AIDS, or other shades of deviance. It takes a lot to say "fuck that nonsense!" In my gut, I feel the difference between living a life that others prescribe and the freedom that being authentic invokes. In a virtual video call with Arwyn, I correct the record.

"I haven't been truthful about my health," I say.

Over the last few years, Arwyn has related a few of her own health experiences. A diagnosis with fibromyalgia, the dismissiveness of (often white) male doctors regarding her female body in pain, and the unfortunate severing of a renal artery during surgery to remove a tumour on her adrenal gland. The intimate details she has disclosed to me more than set the stage for me to reciprocate.

"I am HIV-positive," I tell her, not wanting to dance around the issue any longer. "I lied to you during our last dinner. I didn't want to be known as "Steve with AIDS." This illness isn't central to who I am. At least, I don't want it to be. Also, I know . . . and feel . . . that you have the capacity to understand, to appreciate me as *ME* and not me with illness."

"I've always thought of you as just Steve, and I don't mean just in a diminutive sense. You're so much more to me. I cherish our friendship and that you 'get' me. Thanks for sharing this with me. Thanks for trusting me."

That's it. In a world in which acceptance is often tenuous (Herek, 1996), I do trust her.

That trust also means holding myself to account, especially when I don't feel I can perform as authentically with and for others. Her guidance from years earlier still resonates with me. Honour where your attention goes. Over the years this sentiment has become a calling for me. The things that draw our attention are important. I think about HIV. I think how it affects my body. I think of my resilience. I think about the close, personal, and intimate relationships I have forged with others. It would not have been possible to feel connected to others as deeply and essentially as I do without the experience of HIV. For the gift of HIV, I am thankful. As Adams (2011) points out, it's the things that oppress and challenge that give us something to push back against. In not wanting to be known primarily as someone who is "suffering" with a chronic illness, I strive to disclose myself as openly as possible and in ways that I wish. *This is my narrative*. The path forward, however, isn't always linear (Howard, 2013; Wallace, 2014) and that is sometimes a difficult tension to navigate.

### **My Angels—Argentia, Isis, and Constance**

When graduate students aren't in class, teaching, or trying to find time to sleep amid the burgeoning workload and hazing rituals designed to shape us into professional academics, we eat and we drink. It is July 2016 and I am off to a lunch date at *Sake House* with my angels! I have returned to the USA to pack up my apartment and return to Canada, where I will remotely complete my dissertation writing. Our meeting is a goodbye, for now.

As I pull into the restaurant's parking lot, I see Isis walking into the restaurant. I hurry to find a parking spot and hustle to catch up to her, noticing Argentia's car already in the lot as I rush toward the front door of the restaurant. She and Isis are both in my cohort; Constance is one year behind us. We're what many people politely refer to as "mature" students; however, we prefer to

identify through our lived experience than the auspices of age. As I enter, my eyes adjust to the dimly lit interior in contrast to the bright Florida sunshine outside. Argentia springs to her feet upon noticing me.

“Steeeeeeeeeeeeve!!!” her arms wrapping around my waist and pulling me in, tightly.

Isis follows suit, pecking my cheek then using her thumb to clear the affectionate red lipstick left in the wake of her embrace.

I adore these beings. I shall miss their physical presence and sagacity, their profound impact upon my everyday life when I return to Canada. As I take up a seat facing the front entrance, Isis catches me up.

“I’m having a sake and Isis is having a glass of red wine. What’ll ya have?”

“Maybe a beer?” I muse. “A beer. But don’t wait for ...,” I raise my hand as if already holding the glass to cheer. We laugh. Isis laughs into her sake, the first sip of which is already half-swallowed.

### *Argentia*

In August 2014, Argentia sits at the head of the table in my first class at USF, a doctoral seminar led by Arthur P. Bochner called *Narrative Inquiry*. Through the stories that each of us shares around that table over the next four months, I learn that she is also Canadian and has connections to Toronto. She has two kids, both now in their twenties, and she loves to sing, especially at the local Karaoke bars of which Tampa has many. She also has a challenging relationship with cars and Tampa Bay traffic. I commiserate. The frequency of accidents that I witness on the road when commuting to USF on I-275 and on East Fowler Avenue, in particular, infuses my otherwise love for driving with an abundance of caution. After a particularly tear-filled



class with Art, which includes several stories that my fellow students share detailing deeply intimate, somatic trauma, Argentia hugs me in the parking lot as I walk her to her car.

“Ouch!” she shrieks. “I’m missing a few vertebrae in my lower spine.”

I relax the hand that has nestled into the small of her back. “Oh! Sorry! I didn’t know ...”  
(*maybe I just forgot*).

“Canadians and their sorry,” she quips.

We laugh at our cultural connection through citizenship and become tearful again about the stories we’ve just heard around that table (see Ellis, 2004).

“If that table could talk,” I say, “fuck! I can’t imagine the stories it’s heard over the years.”

We shake our heads in agreement and deep contemplation.

“I remember reading about that table in Ellis’s (2004) *The Ethnographic I: A Methodological Novel about Autoethnography*. It’s amazing, and perhaps a little intimidating, that we’re here, now sharing in the rich legacy of this department,” I add.

I feel that I know quite a bit about Argentia but that I haven’t been as forthcoming. *Am I waiting to be asked?* Despite the many intimate disclosures other students make in class, I don’t raise anything related to my HIV. *How can anyone ask about something that’s likely not on their radar?* I can’t wait for people to ask. I need to tell. *But I’d rather people just ask. Sigh.*

I also wonder if I have made disclosing my HIV status more difficult. I tell myself that it’s not that important. I don’t want to be defined by illness. That’s not who I am. In actuality, that’s who I am, but illness is not all that I am. I need to find ways to make the path to disclosing shorter. Why are there so many small “d” disclosures that I feel a need to complete before getting to the big “D” disclosure that is HIV?

Over the course of the next two years, Argentia and I hang out often. We grab coffee. Linger on campus after class. Attend karaoke. Venture all over Tampa and points nearby in search of good food and evenings of conversation. Go to Ybor where we “fight” over the muscular bartender who distracts us from the drag show at Hamburger Mary’s with his heavy pours of vodka. And even when plied by alcohol, I keep my HIV a secret. She doesn’t ask. I don’t tell.

### *Isis*

Isis is the most stylish friend in our group and the one who most overflows with love and life. When I see her walking into the restaurant as I arrive, I chuckle. For once, she is on time. She’s definitely a fan of making a fashionably-late entrance. She also has a knack for making the room pause long enough to notice her ingress. As I walk toward the table, she hops to her feet and pecks me on the cheek before enveloping me with the warmest of embraces.

I meet Isis in April 2014, a few months before relocating to Tampa to begin my doctoral adventure. She agrees, through the orienting kindness of then Graduate Director, Jane Jorgenson, to offer me a campus tour. I am to meet Isis in the reception area of the department at noon. It’s now 12:25pm. I check the time on my phone against the clock on the wall. She’s late or not coming at all. As I stand to leave, Isis appears in the doorway.

I’m drawn to her. There’s something about her energy, presence, and immediate magnetism.

Our tour begins with gusto but stops after only fifteen minutes. We find a bench to sit upon right outside the Marshall Student Center, where we have just exited with oversized smoothies that we bought at Jamba Juice, the perfect accessory for the hot and humid Tampa Bay weather. The sun beams. A waft of jasmine fills the air. The wind tussles palm fronds, making their shadows dance on the white concrete pathway at our feet. Our conversation starts innocently enough: we

talk about the USF campus, the doctoral program, and the department's people present and past. Quickly, we turn to our own lived experience. I've never thought of myself as an old soul, as I think of Isis in this moment, but how would I recognize her as such without being one myself? It feels as though we've met before and have known each other for a long, long time. Our conversation and overall relating comes easily. The tears come, too, as we both have *lived*.

"I remember getting my breast cancer diagnosis," she says, tugging at and reorienting what she often refers to as the "chicken cutlet" that stands in for her left breast. "I came home from the clinic, told my husband, and watched him pack a bag to leave me and our five kids that same day."

In early 2018, she reaches out to me in Toronto from Tampa by telephone.

"Hey. Can I ask you something?"

Right to the point. I like her.

"I'm worried about someone who just tested positive for HIV and I know you work on this stuff. Do you have time to talk to them? I think they really could use an ear ... well, really, I'd feel better knowing that they talked with you. Would you?"

"Of course. Give them my number. I'm happy to chat."

"Thanks, Steve. It's ... it's my son."

A half hour later, I spend an hour on the phone with him. I disclose my HIV-status, thinking it important that he not feel alone in this. After the telephone call, we briefly communicate a few times online. He and I do not talk again, by phone or in person, for some time.

I call Isis shortly after I last chat with her son, to give her an update and try to reassure her.

"Don't worry about your son. He's bright, asked intelligent questions ... I think he'll be ok."

"Thanks, Steve. I love you."

I think about this call often. Also, I think about meeting Isis for the first time and our conversation on that bench, the scent of jasmine heavy on the breeze. *I've walked by this bench many times since, as I cross the campus, and the memory of my conversation with her always leaves me warm inside and smiling.* I never explicitly disclosed my HIV status to her. Somehow, it felt unnecessary. I think back to that moment when Andrew had let his hand linger longer than it ought to have on my ankle while his mother bore witness. Our being in that moment, Andrew and I, and my being in this moment with Isis feels so right. As much as disclosure is vital, there is also something to be said for letting disclosure happen, or not, in its own time. Isis never asked me to explicitly disclose. She dropped no clues that she “knew” my secret. It felt, through our conversations and connection, that my HIV status was no issue. There was something in her eyes, that twinkle, that spark.

Isis will forever remain dear.

### ***Constance***

Constance joins the program in the fall of 2015, a year after Argentina, Isis, and me. She reluctantly agrees to meet for lunch but insists that she can only come for takeout because she's too busy. Her husband, Hardin, is faculty in another department at USF. They have two school-aged boys, one with a disability that requires their near constant attention. She's a dotting mom with a huge heart. She wears it on her sleeve. As she finds us seated, she puts a hand on my shoulder and smiles widely.

Everyone is delighted when she arrives. We immediately pull out a chair to make space for her at the table. She plops her bag down into the chair, relieved by the brief unloading of its weight from her shoulder but emphasizes that she only has time to chat briefly while awaiting her takeout order. *She's always carrying this huge bag of things. Why has her burgeoning bag previously*

*escaped notice? The metaphor is too much. Constance would carry the world before looking after her own needs. Mothers. Selfless, like mine. A tale for another time.*

I love my cohort and their willingness to adopt Constance. They are all truly wonderful people. Smart. Interested. Warm. Open. All of them.

I flashback to a conversation with Constance from the day before. She's been struggling with her Plan of Study, the document that is required of doctoral students after we each finish coursework.

"Aside from listing the courses I've taken, and explaining why, I'm stuck with what else to write," she explains.

"I can send you mine, if that helps" (see Appendix C).

As soon as those words leave my lips, I catch myself ruminating about my Plan's contents. I list courses and provide a rationale for their relevance to this dissertation. But it's the narrative I include to contextualize my dissertation's importance that concerns me the most. I disclose personal information about my HIV status. I have yet to disclose these details to Constance, any of my doctoral cohort, or to anyone at USF. I hadn't really planned to do so. As I mentioned above, I don't want to be known for my illness before she gets a chance to know me as a person.

"Sure. If you don't mind. That'd be great," she says beaming, and somewhat relieved.

I hedge.

"Happy to share. There's some stuff in it though that's not in general circulation. You'll know when you get to it."

"Oh. That sounds ominous!"

"Nah, it's not that ominous. Happy to share. If you have questions after reading, let me know."

I send my Plan to Constance via my USF email account. Of course, doing so now also means that anyone who knows it exists and wants to read it can request a copy of it by using the provisions of Florida's "Sunshine Law." Institutional email isn't considered to be private. It's one of the reasons we're not permitted as instructors to discuss grades with our students over email. It makes me nervous about what I share and with whom. I want to control my illness narrative. I wonder, now, if this deep-seated need for control also forecloses on productive and open conversations about HIV. I feel a need to do better. Especially in light of this dissertation, I need to find ways to make the *process* of disclosure feel less arduous and precarious. I trust that in time, I will become as accomplished at speaking about HIV as I have about my sexual orientation, without thinking first about permission to disclose. I don't apologize for being queer. I need to start thinking about HIV in that way, too.

Constance has had the chance to get to know me, so disclosing to her feels right. It feels supportive. It feels safe. Her hand on my shoulder now confirms that my trust is not misplaced.

"Thank you for sharing," she says, squeezing my shoulder lovingly. "I read it. I love you."

There's something about touch that always gets me, especially after sharing my HIV+ status. I recall too many stories from the 1980s in which people recoil, withdraw from intimacy, and otherwise withhold connection in the wake of disclosure about HIV. If you haven't heard tales of families disowning children, or hospitals refusing to bury bodies because of HIV, I can confirm that these stories are real. I recall visiting Jeff as he lay dying in the hospital, gently holding his forearm as we spoke. Constance's hand on my shoulder, in the here and now, means a lot.

The disclosure of HIV status always comes with some risk. Sometimes it is violence and sometimes it is death. It seems opportune to remind that in some countries even the suspicion of

being gay, and the longstanding inference that HIV is a gay disease, can result in being killed. This potential outcome is stigma writ large.

### **Constance and Hardin**

I haven't seen Constance in some time. Grad school and daily life have kept us both busy. Finally, we find some free time to get together at her house to kibitz over a glass of wine about grad student life. Hardin joins us. We sit around a circular table on their patio, despite it being yet another humid and warm Tampa evening. Our conversation starts innocuously enough with shop talk: grad school success and angst, the ever-present feeling of inadequacy that stalks us from the moment we decide we want to expand our respective consciousness, and not having enough hours in the day to tackle the work as well as we'd like, nor sufficient enough hours in a day to have restorative sleep. The lamentations over grad school feels like routine small talk. It's the same each time I meet with any of my student peers to chat, Isis being the exception. In my group we usually move beyond it quickly enough and begin to talk about more intimate things. This get together with Constance and Hardin is one or two months after sharing my Plan with her. I'm keen to address issues that will broaden the context of my HIV disclosure to her in the proposal. I jump in.

“Despite being HIV-positive for over a decade, there's one thing that no one has ever asked me, which I find curious,” I say. “No medical professionals, no social workers, no friends, no family, and not even my partner. I suppose I should just be thankful that I have such abundant acceptance of me ... and I am. But I cannot help but wonder why no one asks.”

“What don't they ask?” says Constance. Hardin remains silent, sips from his beverage, and looks on. He seems curious, no doubt imagining what I'm about to share. “No one has ever asked me how I got HIV.”

“Oh. Can I ... ask now?” she equivocates. “How did you?”

“I think it’s likely the result of having so many sex partners.”

“How many have you had?”

“I’ve lost count, but the number is well over a thousand.”

“A thousand? Why?” Constance replies in puzzlement. Hardin leans in but remains silent. His curiosity seems to intensify, but I feel no judgement from either of them.

“Yeah. It seems like a lot, I guess. But I’ve been sexually active since I was nineteen years old and I’m now fifty-two. That’s thirty-three years. Even a conservative estimate of three men a month, over almost four hundred months ... that’s well over a thousand.”

“But you and Andrew are...”

“We have an open relationship.” I can tell that these circumstances feel unfamiliar and beyond what either of them are accustomed to hearing in the context of what a committed relationship is expected to be. *Who gets to decide what constitutes openness, commitments, and relationships?* More importantly, Constance and Hardin seem keen to understand how such relationships function, especially over the long term. It seems different than what they experience together.

“A thousand, though?” she smiles, impishly.

“I think that the number of guys I have slept with has increased my risk, definitely of exposure. Also, not all of them discuss their HIV status. Both Andrew and I have agreed that we will use condoms, both within our relationship and with the men we meet. We feel that this is sufficient to keep us safe.”

“But it didn’t?” she asks.

“I guess not. I can think of one time ... and I’ve never told anyone this ... when I visited a bathhouse, and I was getting fucked. I made sure he wore a condom. After he was done, he quickly



put on his towel and left. When I went to take a shower, I found the condom hanging out of my ass. The fucker slipped it off, perhaps when he pulled out .... I didn't think too much of it at the time, but it's the only time when I question my safety. That moment comes back to me repeatedly. I picture the room, the darkened hallway outside, an adumbration of his appearance, and how I feel in the moment. It's a lot to remember. Anyway, there's nothing I can do now to change what happened."

Constance leans in and reaches out to place her hand upon the table in front of me. She smiles. Her eyes look directly into mine. She is the epitome of empathy and warmth. Hardin has remained silent through much of the conversation. He nods occasionally, and offers periodic, guttural agreement with my disclosure. It's a lot to take in. Sometimes words and meanings take time to arrive. I sense that Hardin has things to add, but in this instance, he defers to Constance.

Although words feel unnecessary, a gift when they do arrive, their absence often punctuates the gravity and solemnity of becoming and being HIV+. I reflect upon a moment when I disclosed my status in a paper for class. When I next saw the instructor, she carried on like nothing had happened. Maybe it hadn't. Maybe she didn't read my disclosure. Maybe it didn't register. Maybe it was too awkward to bring up, in the company of other students. Not bringing it up amplifies the heaviness of silence in ways that mirror trying to hide sexual orientation when one cannot and does not pass (Fox, 2013). An important part of disclosure is acknowledgement.

### **What Happens at Brunch, Lingers**

In July 2016, Constance, Isis, Argentia and I, together with another graduate student member of our USF family, go to brunch. We sit at a circular table at Oystercatchers, a local favourite at the Grand Hyatt that offers an equally grand assortment of fare, even for a buffet, and

panoramic views of the [Tampa] Bay, just beyond the mangroves. As mimosas arrive, I'm eager to share details of the dissertation proposal draft that I'm working on. We lift our glasses and toast.

"I can't believe that the first sentence of my dissertation proposal announces my HIV status."

Mimosa-sipping. Silence. Extended mimosa-sipping.

It doesn't occur to me that their silence is a signal for me to continue. I mean, I just finished a course in discourse analysis in the fall. This is how discursive turn taking is supposed to work. Why am I not recognizing in this silence a need to say more? *More?* I just told them I'm HIV+. When actually, in hindsight, all I said was that I started off my proposal with my HIV status. I failed to disclose if it was negative or positive. *Oops!*

When the conversation starts up again, I don't really notice. I'm too busy analyzing what went wrong. It's like watching an instant-replay, the scenario plays again and again in my head. After a few minutes of introspection, I make sense of where the conversation has meandered and jump in. We talk a lot about what we learn from courses, instructors, administration, and the good and bad of USF in general. Even after the meal, as we walk slowly along the sidewalk toward the parking lot, no one raises my disclosure. It lingers. I should address it. However, I feel like everyone knows, or should know. Disclosure in written form seems easier, as with the sexual orientation revelation in my letter home (Appendix A) or HIV in the Plan of Study (Appendix C) shared with Constance. When I have to speak it aloud, I seem to choke. I need more practice.

### **"Coming Out" as HIV+ at an International Conference**

During May 2017, in Urbana-Champaign, Illinois, at the International Conference of Qualitative Inquiry (ICQI), I prepare to "come out" as HIV+ for the first time. The setting for my disclosure is not only public but also professional. As I finish tweaking my paper and practice

aloud its presentation the night before, I try to reassure myself that disclosing like this is the right thing to do, that all will be ok. In the back of my head, I hear the voice of doubt which is quiet at first but then is gradually louder. It is like hearing a tap drip water in the middle of the night. *Drip. DRIP!* It refuses to be silent.

The next day about a half hour before my presentation begins, I begin to make my way to the room where we'll have the panel session. On the way there, I run into Sarah J. Tracy, a professor who teaches at Arizona State University. She's bubbly and smiles effervescently when she spots me walking toward her in the busy hallway. I met her in 2008 while attending the annual conference of the National Communication Association, our discipline's largest organization at a business meeting for the Ethnography Division. In subsequent years, I've attended panel sessions where she's presented and we've had pleasant conversations, often at business meetings. More recently, in 2015, she delivers the Department's Grazier Lecture, which I attend. I also join her, a faculty member, and a small group of other graduate students for dinner at Frenchy's Rockway Grille on the beach in nearby Clearwater, FL. Sarah is like many of the women to whom I feel drawn: intelligent, outgoing, and playful with a vivacious *esprit de corps* for social issues and a genuine curiosity about people, in general.

"Steve!" she beams at seeing me again. A warm hug follows.

"Hi Sarah. Great to see you."

"You, too. Where are you heading?"

"I'm off to present."

"Fabulous. What's your paper?"

I hedge. I fully expected to see people whom I know. I didn't anticipate I would have to go into detail about my research focus and plans so fully or so urgently. No amount of rehearsal prepares me for moments like this.

"I'm going to talk about illness and narratives of disclosure."

"Oh, that sounds interesting. What's the disclosure?"

"HIV. The disclosure is my HIV status. I'm HIV-positive."

"Steve! That's so brave. Wonderful. I wish I could be there."

"Thanks. I don't know how brave I feel. I mean, I don't think it's brave to disclose. I mean, ... I'm not sure what disclosing means. I'm really hoping I can just do my thing and perhaps some of the people who might attend the session can tell me what it means to them. That feels right. Disclosure is the tip of the iceberg. *Just the tip, honey.* I'm there for whatever comes next, including the exploration of what's presently hidden."

She and I stand talking in the hallway for what feels like being in a bubble for eternity. The busy hallway feels empty. I am transfixed by her sincerity and the totality of her engagement. *Perhaps her response will be echoed by the audience at my presentation. I hope.*

"I don't know what to expect. I mean, deep down, I think it'll be ok. Well, more than ok. Maybe even affirming? But, you know, "reviewer number 2" might be in attendance ..."

Sarah laughs out loud.

"I think I need to get going to my presentation. I need to settle for a few minutes. Take a deep breath, you know?"

"Wonderful." She rests her hand on my forearm then leans in to hug me again to show that she understands and cares. "Your presentation is going to be amazing. I want to hear all about it later." I nod.

Promise?

I nod, smiling widely as I turn to walk away and begin digesting the significance of our unexpected interaction. My hand clutches tightly at the manila file folder with a printed copy of my presentation hidden inside. I feel more confident that I am doing the right thing.

The presentation is, indeed, as wonderful as Sarah predicted. I am thankful for the many great questions and the warmth with which my disclosure is received, by new-colleague presenters and audience members alike. It is the first time that people linger after a session ends to engage with me in discussions about the work I've presented.

"How wonderful that you're able to share so much," says a young woman near the front of the audience.

"You really reached me. I have never met anyone who is HIV+ before. Thank you for being so candid and vulnerable," another woman says as she clamours to pack up her papers and belongings from the desk at which she sat so that she can move closer to me.

As the audience begins to disperse from the room and move on to other sessions, several of the presenters remain to continue the conversation. Their engagement and feedback feel personally and professionally validating. What resonates most are the personal stories and anecdotes they share with me. Sharing my story kindles their desire to reciprocate. It is a beautiful moment of disclosure and awakening.

### **Eamon and Milan**

I have known Eamon for almost forty years. He and I met in early 1986 at *The Half and Half* (see Chapter 4). We both attend the same university, although we are in different programs. We come together through the weekly coffeehouse that the LGBTQ+ student group runs on campus each Wednesday. We become fast friends and eventually roommates. We share a bed

platonically for over a year. Others rarely see us without each other in public. People speculate that we must be fucking. We aren't. We laugh that the friendship we develop overflows with laughter, is so unusual, and is so seemingly inexplicable to many of our friends. It is so much so that our bond only seems intelligible through the paradigm of being lovers. Let people talk. We giggle, defiantly. We're *sisters*.

Milan is another university friend who is a jovial bear. I don't think he has ever greeted me during the thirty-six-plus years I've known him without his having a smile upon his face or his breaking out soon after into full belly laughter. We become friends just as he is preparing to graduate and move from Waterloo back to Toronto. After his graduation, we stay in touch and find the time to go to bars in Toronto a few times a month through the summer and into the fall. For a few years after he graduates, I bring Andrew to participate in a ritual gathering of my university friends on New Year's Eve at *Chaps*, a popular gay cruising and dance bar in Toronto. Eventually, the anticipated annual routine wanes. Andrew and I miss one year due to food poisoning, and the next year passes without much fanfare. We're more content to stay at home with each other on this night, which is also our observed anniversary, than to venture out with former friends. Those relationships slowly fade.

When I return to live in Toronto from Tampa in the summer of 2016, I want to reconnect with Eamon and Milan. I am curious about our respective lives and what each of us has been up to over the course of the last twenty-five years. So, I reach out to them. We plan to have lunch, which I begin to dread attending on the day before. *What if this meeting is painful? Have we missed too much of each other's lives? What if our divergent journeys make reconciliation impossible? Will I like them both, still? Or might we now be strangers? Will they like me? I don't think I've changed much, but have I? If we are able to re-connect, what stories will we tell about our missing*

*years? Will any of those stories include HIV? Will I come out as HIV+?* When we get together, we spend ninety minutes laughing and carrying on over food and drink. Our conversation resumes as though we have never been apart.

When I see Eamon again it's his disarming laugh that I remember most. For Milan, it's his bearlike body, constant smile, and tendency to giggle irreverently at almost everything, whether it is funny or not. I remember them for bringing such joy and lightness into my world. They continue to do so on this occasion and pick up where we left off during our last meeting with seeming ease. Over the course of our lunch, we reminisce about many friends from our university days, and also lament the sobering number among us who have died. Illness and death are occupational hazards of being a *faggot* from the 1980s (see Chapters 2, 3, and 4). I get tired of hearing the phrase that entangles friends who have passed: "complications of AIDS."<sup>17</sup> That being said, HIV fails to complicate our rekindled friendship. If anything, it brings us together. We're among the luckier ones of our university cohort to survive. Our minds stay with those who did not. We toast to their absence and remind ourselves of their stories.

Over the course of lunch, we disclose our respective HIV statuses indirectly. *Are we so knowledgeable about HIV because we're fags, or is it that we're fags that the experience of HIV has come so close to home so frequently? Or both?* We are cut from similar cloth. A kind of mutual understanding exists as a result from what *is not said*. For instance, we each know too much about the drug cocktails used to treat HIV. The clinical conditions that manifest as HIV turns into AIDS. We know firsthand how HIV marks bodies, in part, because we have witnessed other bodies marked by weight loss, fat displacement, and visible lesions which are more than just freckles. We

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<sup>17</sup> HIV is not fatal. It is a virus that attacks the body's immune system, weakening it until it can no longer fight against opportunistic infection. Those infections become fatal in the body's weakened state. Whenever I hear the phrase "complications of AIDS," and I hear it often in the 1980s, I cringe at its lack of specificity and the utter inadequacy of it to bring a more humane closure to a life.

don't have to explicitly admit to being HIV positive to each other. The writing is on the wall. We don't have to name and explain HIV for each other. That feels right. Not naming it through our conversation loosens the grip it has on our lives. For these fleeting ninety minutes, we're just friends coming together like once we did before the spectre of HIV interrupted our music. In these moments, we channel the essence of our former selves again in unguarded and carefree ways. HIV cultivated these new senses, and we cultivate newer senses and selves within interactions based on what's said and isn't and, at the same time, what's here and isn't.

We have gotten together many times since that lunch. When we talk about HIV, it's often through a lens of an understanding: it's inside us but doesn't control us. *Why would we give it that kind of power?* We're each thankful to be alive and together. We're thankful also for being able to see the world through the standpoint of chronic illness. It's the little things in conversations with others that tell us how they orient themselves to bodies like our, queer, ill bodies, that make few if any excuses for being. There's something so freeing about being with other HIV+ men without having to spend every waking moment thinking about HIV. One of the pervasive messages that cast a pall upon gay life of the 1980s was the fear of contracting HIV. That same fear instilled in us no longer has relevance. I think of the HIV testing anxiety, slowly wasting away, and becoming unfuckable. HAART has helped us to live free of HIV's spectre. For us, members of a sizeable "poz" community, it's not about forgetting (Howard, 2013) the dreadful impact that HIV has had upon us and loved ones, but toward reclaiming a life where HIV isn't a death sentence. HIV won't kill us. It won't kill those we sleep with because we're undetectable. Rekindling this kind of hope, altogether snuffed from our nascent adult lives, feels like a victory.



## Milan's Shocking Provocation

In early October 2022, Milan and his partner come to visit Andrew and me for the weekend at the “cottage,” our house outside of the city that feels, for us, like an oasis from most things; it is a sacred space springing from its need to exist for queer bodies like ours. A quiet street, neighbours who are cordial but who keep to themselves, and music, often gay-themed, to complete the welcoming tapestry in lieu of the controlling, doom-and-gloom news cycle beyond these walls. We're careful about whom we invite to share in this space's queer sacrament. We all sit together in the living room before dinner. I dim the lights to set the stage for a meal of giving thanks that will soon follow. We sip wine, nibble, and kibitz. Then, Milan raises his glass. He looks directly into my eyes and drops a bombshell.

“How many men do you think you've killed with your HIV?” He laughs hysterically as soon as he finishes speaking. The impishness of it all.

*I love him for questions like this. Unfiltered. Unfettered. Meaningful and grounding.* The mouthful of wine I have just audibly slurped from my glass feels impossible to swallow. It balls up against my Adam's apple and gets stuck. I'm taken aback. Speechless. Milan's penchant for cutting through the shit catches me off-guard. It gets him into trouble, too often, but it's an attribute that I profoundly relish. *He's one of my longest, most endearing friends and comments like this are a reason why.* I had not thought about HIV before in the way he proposes ... and I should have.

His question cuts to the intersection of disclosure and social responsibility. It's possible that I could have infected others before my diagnosis. That old hoary chestnut about ignorance being bliss comes to mind. Bliss for whom? For Dexter? That didn't end well for him, or his friends. Guys fucking each other, whether protected or raw, in some global game of Russian

roulette ... the odds are not in our favour. For me? I became so ill that I almost died. I didn't want to go to the doctor because of the worst that I feared: HIV. That's worse than death? Let that sink in.

In the here and now as I move to conclude the writing of this dissertation, I reflect upon how difficult disclosures about myself to others have historically been and, yet, how relatively easy with the passage of time that they have become. *I haven't been taking stock as I write my dissertation, but wouldn't it be something to analyze this project, sentence by sentence, through the lens of disclosure. What is said, about whom, and what remains vested in shadow.* The shadows are important, just as the larger part of the iceberg looms beneath the water's surface.

When conversing with others, I pay attention to things not said. I lean in, wanting to know, not wanting to judge lest I create some psychic block to prevent someone else from knowing important things about themselves and their context. This predisposition feels important to being authentic, to myself and to others. It's an orientation in honour of the romantic vision of queer futurity that wrests possibility from contention. And while that queer utopia may never take shape upon the real-world-stage, it lives within and drives my hopes and dreams. Silence is just disclosure waiting to happen. Disclosure is world-building.

I think back to the years during which I avoided seeking a diagnosis for my illness. I avoided talking to friends more openly about their experiences with HIV. I waited in silence, hoping to be rescued by a language I didn't yet possess, and which might help to counter the harsh narratives being constructed *for* and *about* me. I was the villain, the little bundle of sticks, the worthless sack of disfigured skin.

“That fuckin homo right there gone [sic] give you AIDS if you sleep with it!”

The whispers linger, the scars have cut deep, but I no longer believe the lies. Waiting to be invited to disclose is the trap. *Tinkerbell, give me strength.*

“No. You’re mistaken. I can’t give you HIV. Since a month after beginning HAART, I’ve been undetectable. HIV stops with me.”

If only you knew your status, HIV might stop with you, too.

**CHAPTER SIX:**  
**CONCLUSION(S ARE ALSO A BEGINNING)**

**The Spark and its Promise**

I am thankful to Diana Denton, my mentor and muse, for nurturing that original spark of inquiry that has since led to this dissertation. During a first encounter with autoethnography in the winter of 2007, she guided her students to “honour where your attention goes.” These words have since become a personal calling, beckoning that I attune to and address the world about me, and especially its silence. I leaned into it. At first, I was curious about personal details that others so freely shared while keeping other details a secret: the public versus the private. Why? I thought. At that time, however, my lens pointed outward into the world, my gaze toward others rather than inward to myself. It was through autoethnography that I learned how to inquire more deeply within.

*What was I keeping a secret? Why?*

The story arc which spans the pages of this foregoing dissertation isn’t only about what happened to me. It’s about *how* and *why* these experiences happened and their ongoing significance. The inner monologue, what appears in italics through various moments of this project, grants insight into my most private realm. Many of these thoughts are so personal and private that I could never share them when they happened. I came back to them only through the power of writing in hindsight (Freeman, 2010). They represent a collection of moments that matter; they are the inner workings of sense-making, world-building, and Being (Heidegger, 2011). I have suggested in several places in the document that the stories I convey and explore on these pages,

or in conversations that erupt because of them, will only ever be partial. Disclosure as a process is ongoing and incomplete. That's important. I believe I am expected to produce research *conclusions*, such as these, which are *definite*, *exhaustive*, and *authoritative*. Yet, I can make no such promises about what HIV disclosure can yield, only that it is an important epistemological, ontological, and phenomenological process that favours the "texture" (Stewart, 2007, p. 129) rather than just the clarity of knowing. Through self-disclosure, I have given others an opportunity to experience my consciousness a little more. In doing so, I create possibilities for knowing them and further a reflexive understanding of myself (Jourard, 1971a).

In what follows, I further reflect on HIV disclosure along what I have come to believe are some of the more prominent and promising main ideas concerning this cultural issue which emerge within my lived experience. These moments are at the heart of what qualitative inquiry seeks to engage, challenge, cultivate, and celebrate. They are moments that give context to the research questions that have guided this study.

### **Responding to the Research Questions**

Two research questions have guided this project:

(RQ1) What does it mean relationally to disclose one's HIV status to people who are long-standing friends?

(RQ2) What do these conversations demonstrate about self-disclosure amid the tension of stigmatized identity, the perpetuation of silence, unhealthy rituals of relational communication, and diminished visibility for PLHIV and illness?

The narrative arc of this project is a direct response my first research question. In each scene, I provided details of interactions as well as nuanced thoughts and feelings that informed the experiences in these representations. I engage this question knowing that friendships hang in the

balance of whether or not disclosure happens and, when it does, how it occurred. I might disclose something that would foreclose on one, some, or all of these relationships. A simple question is what drove me forward: are friendships built around acts of omission, deception, or secrets worth having? That is, aren't such relationships just instrumental and superficial? Thus, the explicit goal of self-disclosure within the context of this project and my everyday is to live authentically.

In response to the second research question, I organize alphabetically by theme the main issues which emerge and give meaning. These are themes that illustrate how I have chosen to orient myself and perform in my life, especially as it relates to authenticity.

### *Anti-Oppression*

My inquiry is rooted in an anti-oppressive framework. I tell my story to mitigate socially and historically organized power that every day seeks to disempower, marginalize, silence, and otherwise threaten my existence, and the existence of people like me. I aim through this storytelling to be courageous and defiant. Yet, these stories are also risky, as I have been cautioned numerous times that my disclosures are irreversible and may have vocational consequences beyond the conclusion on my degree. Silence (neutrality) favours the oppressor (Wiesel, 1972). Being silent about HIV hasn't moved the conversation forward. It hasn't legitimized or carved out a space in which sharing can more easily happen. I must try to discourage the silence.

I also recognize that it is not possible to tell my story without "undoing" (Pearl, 2018, p. 201) many stories told about me which are either incomplete, misleading, and/or altogether false. Little stories like those espousing that boys don't play with dolls (when, in actuality, we do), and the hyper-masculine ones that call us to "man-up" in the face of hardship (I'd rather sissy my walk!) flow from the tributaries into canonical rivers that scream, fiercely and unrelentingly, "fags

deserve AIDS” (we don’t; no one does). Telling my story resists such cruel dehumanization. HIV doesn’t discriminate; that’s a human failing.

Finally, the undoing of oppression requires us to question its genesis, as Tillmann-Healy (2001) aims to do concerning the unconscionable murder of Matthew Shepard in 1998 in Laramie, Wyoming.

When something like this murder happens, “we”—the non-perpetrators—often are so shocked and disheartened that we distance ourselves from ‘them’—the perpetrators. We tell ourselves that they must be crazy or evil. Such explanations come quickly and easily. The hardest question to ask is this: what kinds of personal, familial, and cultural conditions have to exist for this act to make sense somehow, to seem almost *rational*? We don’t ask this because it implicates us in the problem; it forces us to identify with the killers, to bring them close and see them as part of us. (pp. 212-213)

The us/them dichotomy is a manufactured division that works in the service of creating binaries and reifying oppression. Republican versus Democrat. Man versus woman. White versus Black and other persons of colour. All, oppressor versus oppressed. The former should know better. The latter has their choice curtailed or removed. A first-person account like the one I’ve provided in this dissertation, seeks to redress the damage being done by the prevailing narrative that circulates about HIV and the people it most closely affects and offers a direct challenge to dismantle systems that create and sustain it. This is a collective responsibility and condition of our humanity. The burden of labour isn’t something that should be expected solely from HIV+ folks.

### ***Sincerity and Authenticity***

In telling my story, I used narrative, emotional, and “human truth” (Bochner & Ellis, 2016, p. 253) to underscore the ways in which the process of excavating the past is an intensely subjective

“reinterpreted or reexperienced” (Sacks, 2013, p. 11) re-telling of events that have long-since past (see Bochner, 2007). What remains important are the echoes and ripples that impact the present day. Many of these experiences are cultural and collective. I strive to write openly and honestly.

In October 2014, for example, David Purnell, a USF doctoral student colleague shares a manuscript in progress (see Purnell, 2016). I clutch the pages loosely, trying not to snarl their edges as I stride up a flight of wooden stairs to my bedroom and then close the door. I have homework to do but these pages feel urgent. I’m no more than a paragraph in before I weep openly. 14-year-old Purnell is in his bedroom and hears his father yell at HP, Purnell’s older brother.

“WHAT’S WRONG WITH YOU? WHAT DID I DO TO DESERVE A SON LIKE YOU?” my father screams. “I’M GAY!” my brother, HP, yells. “I have known that I was gay for as long as I can remember!” “YOU’RE A FAG, AND I WANT YOU OUT OF THIS HOUSE TONIGHT!” (Purnell, 2016, p. 501)

Being labelled a “fag” and being told to leave the house are nightmarish tales that I suspect any gay man would dread. I didn’t grow up in a house like that, have no father so inclined, but the scene is palpable and undeniable. *It could have happened ... to me. It continues to happen.* I’m drawn to the experience, its humanity, and its author. To present our experiences authentically, as most autoethnographers tend to do, our respective monologues are “imbued with the speech of others” (Taylor, 1991, p. 32-33; see also Bakhtin, 1981). The stories we tell may be unique to each of us, but their tropes and moral import we inherit from our cultural milieu. I understand coming out as gay and disclosing my HIV status differently because I did not have a traumatizing experience like Purnell when growing up. Yet, I think of the many everyday instances when the language others use has given me pause when on the cusp of a choice to disclose or not. The pursuit



of authenticity pushes me to disclose (my being gay and my HIV status) as often as I can, even when it might be challenging or dangerous to do so.

***(Spoiled and Stigmatized) Identity Work***

Identities are complex, interdependent, nuanced, layered, and overlapping (see Butler, 2014) performances within the context of relationships (see Kaufman, 2001, 2014; Kramer, 1978, 1985; Kushner, 1993; Ryder, 2010). That is, who I am and who you think me to be are constantly moving, fluid, and negotiable across their relational context. Despite the expansive social location that accompanies such fluidity, I also experience my identity as “spoiled” (Goffman, 1963) even when the impact upon me personally feels nominal. In part, this is because I witness how bodies like mine are treated. And while I do not wish to identify as someone who suffers with “full blown AIDS,” my reticence to disclose my HIV status more readily across contexts points to the discordance I often feel. *HIV is a gift*. Readers of this dissertation might disagree, and therein lies the beauty of identity as unfixed rather than static, negotiable rather than predetermined. A productive way to think about this is to conceive of the plurality and subjectivity of living beings as essential and their identities as always becoming.

Who might you become, Steve? If I could send a capsule from the future to younger Steve, it might read something like this.

Let me start by saying that your choice to be silent, Steve, was okay when those first few feelings of attraction toward boys arrived at age seven or eight. *Who could you have told anyway? Your parents or teachers were the closest to you but what sense could they have made of it, or helped you to make of it?* You didn’t fully understand those feelings at the time, however “real” or “natural” they felt to you. The risk you felt over being different was real. The choice you made to remain silent kept you safe. It also gave you time to live with your truth, to test it out for yourself,

to find its edges through play and conversation with your peers, and to wrestle with its dimensions before getting to the point when you would one day set it free. Perhaps schools and parents alike should have known that you, and perhaps others like you, had the potential to come of mental age with respect to sexuality years before reaching puberty, the biological maturation point during which those feelings of attraction could be realized as you became capable of reproduction.

Look back upon those early school days during 1971. The pop-up picture books about which you were so awestruck in first grade were about families just like the one you were growing up in. They were fantastic and memorable! But those stories were also patterned upon the bedrock of a past that is now escapable. Those stories did not look forward. They simply recreated familial relationships and arrangements that had already come before. Let go. Write new stories. *Like this one*. Yet, recognize that writing of this vulnerable sort will typically be risky, and for some, dangerous. The fight over the knowledge our stories showcase against attempts to censor them will be heartrending. This fight, three decades after your first experiences with magical pop-up books, will be neither atypical nor isolated. So, don't lament your choice to keep feelings about your sexual orientation to yourself a little while longer. That choice is indicative of the larger need for self-preservation. You'll know, you'll feel it in your bones when the time is right.

As you inch towards puberty, you'll have many more opportunities to test the edges of sexuality and the contradictions of relating, more generally. That play you wrote for Miss Bee in third grade is a prime example. You used it to manipulate a small group of hockey-playing-boys from your class getting them to touch you in ways that, for you, were more than platonic. It crossed a line. It disrespected their agency. None of those boys will ever talk about it with you. Nonetheless, you'll feel shame in the moment, shame that you'll carry with you many years later. Even now. However, that shame is instructive. It reminds you of the power you have and how

important it is to handle matters of sexual orientation. They are delicate and fragile but also potent, volatile, and potentially devastating if not handled with care and reverence. You'll never know the full impact of those interactions with those boys, and you hope that there are none. These are lessons about how non-disclosure operates to create a private and pervasive Hades and how precarious the fine line is between silence and telling. The irreversibility of interaction (Watzlawick, Bavelas, & Jackson, 2011) cautions you against revealing too much. Your need to live authentically underscores the importance of claiming identities and performing them in ways that align with your innermost desires. *Let that freak flag fly, gurl, as often you can.*

By the time you begin high school, you're still confused. Your body is growing, but not as much as have those of other boys you know. Remember the first week of being in ninth grade? Standing in the hallways with other boys you find yourself looking up more often than across to meet their eyes. You see the stubble and pimples pushing out of their faces while your hand traces the same, familiar, and smooth lines along your own cheeks and jaw. These changes exacerbate the feelings of difference that you continue to feel. To try to fit in, you feign sexual interest in girls.

These overtures, like those with the hockey-boys years earlier, are a violation of others and personally inauthentic. You can avoid behaving in these ways toward others. Would speaking out mean losing friends? Taking an occasional fist from one or several of the jocks to the face or gut? Having to explain to your dad, who was selected by the Special Forces, how you were beaten up at school for being a pussy ... or faggot. The cost of being authentic was unfathomably huge. Take some comfort in knowing that high school is, almost by design, a place of final testing before leaving the nest to stand on your own feet in the vast world beyond. Focus upon and excel at your studies. You'll be okay. Engage those teachers who seem most open and eager to work with you. If only one of them was out. You'd have at least one example of how to be in the world that

resembled more this notion of identity still forming about you. You should appreciate the lesson. If one of them had been visibly queer, you'd have a working model from which to cobble together your own framework toward understanding identity. They told you as much as they could, given the time period (1979-1984).

The constraints under which those teachers and administrators worked. You never had her as a teacher, but you saw her in the hallways, that one history teacher who was "suspected" of being a lesbian. So fierce was the grapevine with negative impressions of her that it made your sexual orientation disclosure impossible. You could only hint at it, in terms that could just as easily be explained away should challenges arise. If teachers and adults could not be openly out, what chance did you hope to have? Look for subtle clues. When you discover them, lean in openly. If you don't manage to say anything, at least let your body language affirm your willingness to share space.

These experiences prepare you well for the university years about to unfold. In your first semester of being away, when you meet Dorothea, she will be your catalyst. Her willingness to see and be with you where you are and her open responses to you are mature beyond her or your years. You won't know it at the time, but she's the one who sets you on the queer path forward. You'll confide in her. Your trust will not be misplaced. Unfortunately, because you're not straight, things between you two, including your friendship, will eventually begin to fade. These memories remind me that being open with others is profoundly important. The time with Dorothea is a watershed moment, a turning point during which the conversation about sexual orientation feels finally able to happen. You experience it first with her then test those feelings in your conversations, one by one, with others. Sometimes candid, sometimes couched in the well-

practiced, lightning-quick innuendo about which you'll become (eye-rolling) famous. You are Touchstone and the world is your stage (Shakespeare, 1623).

Dorothea makes possible the ability for you to come out to your parents the following year. Though she, herself, might not have written letters like you did (see Appendix A), preferring instead to sit face to face in disclosure with the people who are important to her, she respects and is supportive of the tempo and timbre of your plans. She makes you wish you were straight so that you could be with her, a way of paying back her kindness and love in the ways that she might want. But you both know such a thing is impossible. You are each wired differently; being gay is in your DNA, and not a choice. *When the fervent mob proclaims that being gay IS a choice, you'll want to remind them that it most certainly is not, unlike sleeping with their sons and daughters and thereafter spending every fucking Thanksgiving and Christmas dinner with the in-laws for the next fifty years debating this point!* The angst that you have for many years felt over being different seems so small and insignificant in this context. You feel in your bones, no matter what the outcome is, that coming out to your parents is the right thing to do. There is so much you want to share with them that you have kept hidden for so long: mundane moments in everyday life, the men you have met, the love you have discovered, and the great joy and happiness you continue to feel.

You also experience hardship, which you'll mostly take in stride. Thankfully, through much of it, you won't be alone. The first time you are called a "faggot" out loud, the words and that interaction will stir dread in you. You'll feel your pace quicken as your brain instinctively switches from fight to flight. You'll also feel Chase gently yet purposefully squeeze your hand tight. It is your holding of hands and walking stridently across campus in broad daylight that

prompted this oral assault. That hand now calms you. It connects you. Your queer family will be there for you.

Chase turns to you and says, “If you want to hold hands, don’t apologize for it by running away.”

It has taken me almost forty years since that (*perfect?*) moment with Chase, walking hand-in-hand on a cold spring day, to realize that the truth requires no apology. Consequently, when you disclose things about yourself now, you no longer squirm or hint that you need others’ permission. *Every time, you still mentally assess whether it is safe to reveal whatever it is that you plan to say. It’s always an organic dance, an unrelenting evaluation of context. Safety first, but principles often override the silences. Truths must out.* You resist telling others things about yourself so that they can be discounted. You disclose that you’re gay because you are proud, confident, and undeterred by the telling. When once you might have run from the threat of words hurled toward you, now you will turn to face them defiantly. It took a while to get here. And the funny thing is, it’s time to move on because identity work never ends.

### ***(In)Visibility and Representation***

When you look back upon your university years, you’ll wish you could hold the hands of the many boys you meet. You’ll reach for them, but they are no longer here in this world. Their absence is heartbreaking. It will remind you over and over how ephemeral and brief life is.

HIV is a bitch.

Simultaneously, it’s a blessing. Without HIV, you’ll struggle at tech jobs that occupy your professional time through most of the 1990s and the early years of the new millennium. Despite the love and intimate partnership with Andrew, you’ll feel that something purposeful is missing. A near death experience with HIV helps you see the world ... differently. Facing your own

mortality subtly alters your DNA, I think. At least, that's the sense I've been able to make of it for you.

Your illness will be visible to others, but they won't recognize that any bodily changes signal your being HIV+. You'll labour to breathe. You'll walk slowly, ten paces at a time before requiring a pause to catch your breath. Your weight loss will make your clothes hang like sacks draped across your bones. You'll be thankful for the invention of the leather belt and for one-size-fits-most shoes. Yet, despite the obviousness of your illness, only a few people in your inner circle will ask what illness you have. Others intrinsically know and therefore need not ask. *How could they know? In the straight world through which you move, few if any will know what HIV does to bodies and how it looks.* In short, they don't suspect. You assume that HIV is in their blind spot. It's in plain sight yet out of their minds. You'll have flashbacks to *The Normal Heart*, the acting project in which you participate during the spring and summer of 1987. You have none of the telltale Kaposi lesions that might connect my weight loss to HIV. HIV is invisible.<sup>18</sup> Your doctor knows. You'll disclose to your dental hygienist when next you go for a cleaning. Andrew knows, and you'll never forget his support and that embrace in the moments after you hear the news of your illness by telephone. Everyone else? They need an explicit disclosure that connects the dots. Don't lament its necessity. Just find a way to, unapologetically, tackle this task. Downplay it, if you must.

“Oh, this short of breath thing? Gah. It's just the H. I. V. [emphasis intended] Nothing serious.”

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<sup>18</sup> Soon after diagnosis in March 2005, I begin and respond well to medication that reduces my viral load and saves my life. Other than the initial and sudden weight loss and the cough that persisted for eight months, no one questions if my illness could be HIV.

But it is serious. This illness will almost take your life. As you lay on a hospital gurney, surrounded by machines and loved ones, with tubes and bags inserted and suspended about you, you'll need to get your shit together and decide to check out or hang on tight. You *would not be in the least bit surprised if this moment of decision should play out over and over and over again like some sick version of Groundhog Day. Why? Because HIV is a bitch.* If you choose life, and I hope that you will, HIV will warrant your being (more) candid with folks. You might think that you'll only want to tell those of your inner circle, the people who matter most to you. You think that's a mistake. Think back to high school. Think about how much could have been accomplished if only you'd had *ONE* teacher come out to you. Be that person with respect to HIV to as many people as you can and not just to those who are near and dear.

Don't think for a second that disclosure can't be difficult. It'll take years of practice. The more practice you put in, the more comfortable it will become. Okay. When Donald J. Trump gets elected to be President in the United States in November 2016, there's a hot second in which you might think the world is about to go to Hades. In these frightening times, find a way to be bold anyway. The right has long been a proponent of silence. Do not let the occasion of their ascension, whether in the United States of America, in Canada, or in other parts of the world, deter you from speaking your truth to power. Being visible will require you to fight. Being visible also won't be enough.

You'll need to tackle issues of representation. That is, who will you let speak for and about you rather than with you. Own your narrative. This will become important on matters of health. When you look back at the timeline of HIV with the hindsight afforded by writing in 2023, you'll be thankful for the activism of the queer community, especially through the 1980s and early 1990s, which demanded that the government take notice and provide aid. Many people will offer



exemplars of the importance of being in the line of fire and the stakes that accompany that quarrel. You will not make it to live in the new millennium without their acting up. Praise them when you can. You'll also be thankful for HAART. It'll arrive for you just in time. In 2004, the 2,000,000 deaths related to HIV signal its peak (WHO, 2020). You will narrowly avoid becoming one of those data points. Find ways to spend your time productively. Not many get second chances like this. If you can, use these experiences to leverage your credibility to speak with PLHIV. Always strive to speak with them rather than about or for them. Challenge others to follow this compassionate and respectful example. You'll learn how to tackle this over time but a communication class you will soon take plays a pivotal and orienting role.

In a small group communication class led by Dr. Diana Denton you'll learn about "I-statements" when developing feedback that you'll share with other group members. The format of the statement is as follows:

I <expression of emotion> when you <observed behaviour> and hope that you can <desired action> in future.

Through the I-statement you will become better at expressing your emotions and linking those to the behaviours of others. Your first few attempts will feel awkward, like Bambi trying to walk on ice for the first time. Practice. Practice. Practice. You're going to get better. Through these statements you'll help others to realize the impact of their actions upon you, and the interdependently nature of interaction and relationship generally. You will use this approach regularly. It will also bring you to another life changing experience that will put you on a path to this dissertation. The I-statement will help you to champion the kinds of change you would like to see enacted in the world. The I-statement is also a brilliant model for disclosure. Tell people about your HIV and provide a response framework. *I'm HIV+ ... and a whole lot more.* Don't lose sight

of the importance of revealing yourself to others. It will connect you meaningfully to the world around you. In a world that often forges ahead at a brisk pace, taking a stance to represent yourself emotionally and thoughtfully without waiting for others to ask is fundamentally important, especially in the fight against HIV and the silences it creates. Illness will provide you with a critical standpoint that others will lack. Use your illness wisely. Make sure others take notice. Act as though lives matter because in this instance, they do.

Now, wake up and look forward to a promising future.

***Friends, Allies, Queer Family, Oh My***

I undertook this project with the help of dear friends. Although disclosure is likely to encourage reciprocity from others (Goffman, 1963), this is not why I feel called to disclose that I am gay or that I live with HIV. *I hope that Milan's bombshell continues to ricochet in your head a while longer.* I choose to write this dissertation, a sizeable and ongoing disclosure itself, because I want to deepen my relationships with friends rather than run from them. Yet, I recognize that disclosure may also strain, and create distance between me in these friendships, especially when who I reveal myself to be differs from their assumptions and expectations. *That's ok. This underscores the nature of choice in membership of my extended queer family.* Let the world unfold as it needs to. Find a space to “be” in a world designed to exclude queer bodies, and in which disclosure is emotional labour that sometimes feels unnecessary and excessive. The labour of queer bodies to address issues of social injustice shouldn't be ours alone. Invite others to help with the heavy lifting whenever you can. Appreciate the choices and the responses that emerge.

Steve, as an introvert, you'll spend a lot of your time alone. You'll enjoy your own company. The stories that dance in your head, whether you are awake or dreaming, will always be writ large. You'll never truly be lonely, though at times even an introvert needs company. You'll

be fortunate to find Andrew. He'll be your forever guy. I cannot tell you how much adventure and love or sadness and heartache will fill your years together. You'll make it a habit not to keep things from each other. You'll share intimate details of your days, events, food, drink, people. Some of it will feel mundane yet utterly essential. Know that you will feel alive with him and want to stay alive for him. Call it love. Through your communication you'll realize so much reciprocity. Little taking. Mostly giving. When you write about your relationship, you'll also be careful not to be too prescriptive. What you share is glorious, but others must find for themselves what works for them best.

One of the things you'll remember is the first slow dance with Andrew. In the waning days of 1988, at a gritty, smoke-filled gay bar in the basement of a furniture store on the main street of Andrew's hometown. You'll dance to *True* by Spandau Ballet. You'll remember the clicking of soles from your beer-sticky-sneakers as you shuffle together on the decrepit, chessboard-black-and-white-tiles of the dancefloor. You'll remember his hands wrapped tightly around your waist, and yours cinched diagonally around his shoulder and upper back, your ear resting upon his free shoulder, and your lips caressing his neck. His cologne will flare your nostrils. His sweat will melt upon your tongue like candyfloss. Though your eyes will mostly be closed, you'll notice other couples dancing nearby. They, too, look blissful. The world outside these doors, beyond the reach and appeal of this music, is not ready for two men to embrace in this way. In here, though, you'll feel at home. These people are your queer family.

You'll be reminded of a similar moment that occurred years earlier with Chase. How you lusted after him. How his aroma never fully left your clothing or skin after the first time you had sex. How you didn't want it to go away, so you left the clothes that you wore that night unwashed in a laundry basket and avoided showering.

You'll recall these moments with Chase and Andrew because of the feelings they encompass and still preserve in your heart. They are moments upon which you annotate profound feelings of rapture and fulfilment. This is what it feels like to be with your queer family. You feel seen and vulnerable. At ease and in peace. Somatic boundaries delineated by skin yield to the greater connectedness of Beings. You won't feel this way often which is one of the reasons it'll be so special. You may try to kindle it with varying success. Make no mistake though, when you find your queer family ... you'll feel it.

Your friend Milan will host a Christmas party in late November 2018. His partner, who you know quite well, will be there, and most of the other guests will be of their circle of friends. Andrew will attend with you. Kitschy music from the 1980s will play on the stereo as people sit around or mill about, hopping in and out of conversations, while snacking and drinking. You'll tingle. You look around the room and the reasons aren't immediately obvious. You scan faces and watch lips move without hearing what's being said against the dull thud of the music's bass track. Your friend Eamon is there, too. He walks in from the patio where he had disappeared for a smoke break. He beams as you notice him and begins walking toward you. He crystalizes the reason for your tingle during his approach. All these folks, with the exception of Andrew, are HIV+. It hadn't hit you quite like this, not even during those visits to *Hassle Free*, when so many of the men in the waiting room were definitely gay and could have been HIV+. I see you, my *poz* brothers, Eamon and Milan the dearest among them. Being in your presence is affirming. They are my queer family. I feel awakened.

Being with so many HIV+ people in one room takes my breath away. *It is the heaviest of pauses.* We survived. We're full of life. In a few days, on World AIDS Day (Dec 1), a photograph taken in 1993 of the San Francisco Gay Men's Chorus will circulate again on Facebook. Most of

the nearly one hundred men depicted appear in ghostlike silhouette, purposely rendered to match the photograph's background. Only seven of the original Chorus members remain. Those seven are survivors. *The gravity and enormity of what surviving means seeps into every moment of my being. Another heavy pause.* Places like San Francisco, New York, and other urban centers were ground zero in the early years of the epidemic. To be alive now, we have much for which to be thankful. We also have much sorrow and grief to express. These expressions are possible without taking ownership of the virus which courses, now, through our veins. However, interpretations change when we disclose our status. There's an opportunity to connect with others, to talk frankly with them about their fears and their hopes through these moments of momentous heartache. In these moments, we are not solely ill or healthy, queer or straight. We're *human* beings. Sometimes it takes moments of profound sadness to reveal our unbounded potential to be and do good in the world. Sometimes, we just need to summon that strength through being vulnerable.

I feel empowered through my queer family to explore self-disclosure as a complex and nuanced process. How do we disclose? How do we fight to remain visible? How do we embrace vulnerability through illness to reclaim humanity? How ought we to engage others? In part, Steve, I need to remind you that we can never disclose once, across all contexts, and to everyone. The process of disclosure has no end. Thus, disclosure might best be described as a practice that is constrained by social constraints (e.g., power) and a demand for repetition, all of which is subject to routine scrutiny and evaluation that perpetually asks deviant bodies to explain and to satisfy the conditions for their continued existence and tolerance/acceptance. In 2023, in this current moment of writing, acceptance still comes with a price, and sometimes a hefty cost. Self-disclosure of HIV continues to be risky. However, I have some practice and renewed hope. It took a near death experience and the loss of many loved ones to kindle hope inside me. To see the good in the world.

But that light cannot go out. Revealing ourselves to others, little by little, relentlessly and over time, will help us to combat the perils and kindle the possibilities being in the world, sometimes with illness, but never alone.

Across these moments of lived experience, if I must single out one thing as being most vital, then it would be this idea: coming out, fighting for space in which to be visible, being an exemplar for others, these are all signposts that ought to remind us that even when we think we're alone, feeling like we're the only one who can possibly imagine or be experiencing the things that we are, there is always someone else. Reveal yourself, often, realistically, and deeply. When you do, others will find you. You'll find each other. This is crucial to why I tell my story.

### **Meta-Disclosure(s)**

I didn't expect to be here, writing this conclusion. For years, the completion of this dissertation project has felt (and has been) elusive. The writing, not good enough. The stories, incomplete. Another plague, unleashed upon the world. The point of this study, too small in a dystopian and cacophonous sea of cultural events seeking to shape the world in ways I could not have imagined as this project began. *Deep breath.* Only recently did a dinner I had with Eamon bring my senses into focus. The epiphany that his provocation encouraged is that HIV won't go away without our help. Not knowing our HIV status and refusing to talk openly about HIV only tighten its profound and decades-long grip upon our lives. Refuse to be silent. Actively reveal yourself through your lived experience so that others may find you and thereby find themselves.

I wish an account like this dissertation had existed for me, especially through years in which I felt racked by anxiety about being gay in a hostile world, grief and loss, HIV testing, living with HIV, and the prospect of connecting. I needed not only to know that things could be okay, but also that exemplars for how they could be existed to guide me. If I hadn't taken that leap of faith and

entered the coffeehouse at my university so many nights ago, where would I be now? I can't imagine. Finding my queer family, as I did that night, has made all the difference.

Leaps of faith can be difficult. That night, I felt it in my bones, in my DNA. I was stuck on a path that others had taken the lead in authoring. I wasn't a character in that play. I knew I was different. I knew that there was more to life than pretending to be straight. Daring to live a more authentic life started with those few small steps into and through the darkness. And though the years since have not all been kind, I cannot imagine a more fulfilling path.

### **The Road Ahead**

First-person writing from the standpoint of an HIV+ person allows the sort of research on this topic that both validates the lives of PLHIV and simultaneously re-imagines us as more than “abject others” (Scheman, 1996, 2016). Instead, we are trailblazers. We are worthy of inclusion. We are not just a means of understanding enumerated ways of Being in the world, but to the enormous possibilities and uncertainty inherent that result from how we relate and live. We are *autoethnographic* trailblazers whose stories should be told, acknowledged, and respected. To cut off such a limb, so to speak, of research is to fail to understand the full nature of its functioning and worth, historically, now, and into the future. Nonetheless, to undertake a first-person account of PLHIV identity is risky because it entertains the possibility that such an identity might be rendered incoherent (Butler, 2014), if not worse, with respect to the normative social order. However, writing through a lens of friendship (Tillmann-Healy, 2003), as I have done in conveying my story, will foreground the relational tenets of identity and its negotiated, constitutive reality to help mitigate this outcome. Related, it is also important to clarify that I make no apologies about PLHIV identities, including any assurances that there exists a unified, singular identity. My hope is that this project, through its multi-faceted moments or episodes, results in something that

resonates with and piques the curiosity of readers. However, should the outcome be incoherent identity(ies), then there also exists the possibility to march to a new drummer, and to encourage others, including those who live with social advantage or privilege to take notice and embrace these stories and storytellers.

I am completing this dissertation at a time when we are on the cusp of medical research that “can confidently say that when a person taking antiretroviral treatment maintains an undetectable viral load, they do not transmit HIV to their sex partners” (CATIE, 2017a).<sup>19</sup> This is ground-breaking news with significant potential to combat the decades of pervasive stigma, ignorance, and fear that continues to complicate the fight for control of HIV. Unfortunately, the relational prospects for PLHIV, understandable in terms of quality of life with an emphasis on stigma, continue to lag medical advances (see Speakman, 2017; Joachim & Acorn, 2000; Barrow, 2017; Sippel, 2016; Coleman, 2017; Catalan, Tuffrey, & Ridge, 2017; Slater, Moneyham, Vance, et al., 2015; Vincent, et al., 2017; Ferlatte, Salway, Oliffe, & Trussler, 2017). As such, I hope that this project helps to raise awareness about the everyday and mundane relational issues that PLHIV face, and to create opportunities that will help to improve our quality of life.

How might you join in?

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<sup>19</sup> For HIV- folks, PrEP (see Glossary) provides significant protection against HIV infection.



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doi: 10.4324/9781315419930

APPENDICES

Appendix A: Letter Home

WATERLOO  
N2J



MR. & MRS. T. F. RYDER

COLLINGWOOD  
L9Y



Steve Ryder

Waterloo

Ontario, N2J

Sunday, June 28<sup>th</sup>, 1987

Dear Mum & Dad;

Hope this letter finds you both well and in good spirits. I've thought long and hard on what I'm about to say and the bottom line is that it frustrates me all to hell to have to deal with it in this way. I'd wanted to talk to you both when I was home two weeks ago but everytime I come home, I have felt progressively more and more alienated to what used to be our "family" unit.

Being away from home has allowed me to develop into what I would call a young man, in a positive light. I feel good about myself and what I'm doing and where I'm headed. I have many friends, good, intelligent friends, and I can't wait to finish school and become a little more "adult-ish".

But this being away has not allowed me to share in much of the life I knew in Collingwood on the farm with you both. It was a very simple existence and I now look on it with great value, though the thought of living in a "small town", bores the hell out of me. There's nothing there for me. I am, at present, too much of a city dweller.

I could go on and on but I'd like to be concise.

You've always told me I could come to you with anything. This is going to be a test of that more than anything. I count on acceptance, or at least, the opportunity to educate you about myself and the lifestyle I have discovered. Any decisions you make, I will accept. I can't tell you how many scenarios of your actions I have enacted in my dreams over the past year or so. I am well prepared for you. You have raised me all too well!

Anyway, now that the stage is set, so to speak, I can say what I have to say.

I've felt different for most of my life. If I wasn't being alienated at school for being "smart" I was being picked on for being "socially"



different. What I'm getting to, is that I'm a homosexual.

Phew! I've said the god awful "H" word. Do you still love me? Do you still think of me as your son? I hope that both these questions gain "YES" answers. I suppose I should know but I've changed so much in the past few years that I guess I have forgotten much about the way you two handle problems and deal with issues.

You know, for the longest time I was convinced, 98%+, that you'd accept me for who and what I am... but then I come home and there is something about AIDS on the news. I forget what the leading conversation was but what I remember most vividly is a quote along the lines of "as long as you're not one of them homos". And how do I tell you I'm gay after hearing something like that? Perhaps you were trying to let me know something? I must be extremely naive.

Disparaging comments don't bother me in the least. Call me queer. Call me a fag. They are only words. If anything, I know damn well what it feels like to be a minority, but you would be surprised just how accepted a minority the "gays" are. Or would you? I dunno anymore.

What I am seeking in telling you this is more of a sharing thing. I wouldn't call my life secretive but do you know what I have been doing with myself? Do you really? What have I been doing at university these past 3 years? I don't mean sexually. I mean, as a person, interacting with others. For a whole year I was one of the most prominent figures in politics on campus. In fact, I headed several successful fund-raising benefits, profit going to AIDS research.

With respect to AIDS: DON'T WORRY ABOUT ME! It's a scary disease, I know, and I realize that I am human and could possibly get it if I am not careful, BUT careful is exactly what I am. I'm not exactly what I would call promiscuous.

It has been rather difficult for me to cover many issues and still remain concise here. I've tried to state my position. I LOVE YOU BOTH IN AN EXTREME AMOUNT. You are wonderful parents. My only desire at this moment is that we can share more than we have. I am asking for a chance to "LIVE". Isn't it experiences like this that make up our lives anyway?

I hope to hear from you soon.

LOTS OF LOVE, Steve XOXO

## Appendix B: IRB Exempt

**From:** rsch-arc@usf.edu  
**Sent:** Tuesday, February 27, 2018 12:05 PM  
**To:** ryders@mail.usf.edu  
**Subject:** eIRB: Study Processing Complete



### IRB Study Processing Completed

**To:** Steven Ryder  
**RE:** Self-disclosure  
**PI:** [Steven Ryder](#)  
**Link:** [Pro00033677](#)

You are receiving this notification because processing has been completed on the above-listed study. For more information, please navigate to the project workspace by clicking the Link above.

Please note, as per USF IRB Policy 303, "Once the Exempt determination is made, the application is closed in eIRB. Any proposed or anticipated changes to the study design that was previously declared exempt from IRB review must be submitted to the IRB as a new study prior to initiation of the change."

If alterations are made to the study design that change the review category from Exempt (i.e., adding a focus group, access to identifying information, adding a vulnerable population, or an intervention), these changes require a new application. However, administrative changes, including changes in research personnel, do not warrant an amendment or new application.

Given the determination of exemption, this application is being closed in ARC. This does not limit your ability to conduct your research project. Again, your research may continue as planned; only a change in the study design that would affect the exempt determination requires a new submission to the IRB.

***DO NOT REPLY:** To ensure a timely response, please direct correspondence to **Research Integrity & Compliance** either through your project's workspace or the contact information below.*

***Research Integrity & Compliance***

*University of South Florida - Research and Innovation ARC Help Desk (eIRB, eIACUC, eCOI): (813) 974-2880*

*Email: [rsch-arc@usf.edu](mailto:rsch-arc@usf.edu)*

*Mail: 12901 Bruce B. Downs Blvd, MDC 35, Tampa, FL 33612-4799*

*Template: \_000 - IRB Study: Certified Exempt*

## **Appendix C: Plan of Study (Abbreviated)**

Stigma is insistent. It marks bodies, habitually and indefinitely. A consequence of ignorance and fear, it ruptures the social order and perpetuates oppression that unduly yokes those people who are most vulnerable. I am a relational communication researcher and teacher who is passionately committed to better understanding this social problem, primarily as it relates to experiences and consequences of illness, namely HIV/AIDS. I seek through my work to disrupt and challenge taken-for-granted assumptions, expectations, and practices that people enact together within interaction and relationship. The relational communication approach helps to shine a light on stories of illness and its impact upon bodies that might help to dispel ignorance and assuage fears in the lives into which such stigma so wantonly, irrationally, and inhospitably creeps. Stories may originate within the experience of but a single being, but their influence, though occasionally subtle, can propagate like a ripple on a pond. The stories authored by those with less power are often not fully heard or are silenced. Such stories must be told.

I plan to write my comprehensive examinations in late summer 2016 and defend my exams in early fall. In this dissertation, I plan to focus on stigma's stories, drawing on and further expanding the conceptual areas described above. I am already beginning to research and to plan fieldwork in which I will hear, collect, and re-tell through narrative, ethnographic and autoethnographic renderings what emerges through, around, and about relational processes of stigma. Stigma is raw, potent, and meaningful. The distinct ways that stigma's stories are performed in the unique contexts of storytellers' lived experience have tremendous potential to improve the human condition. While extant research has uncovered helpful knowledge on the ongoing problem of omission, my ethnographic and autoethnographic approach will provide both tangible results and an organic framework. At first, stigma's stories are important and need to be

told in order to render the often-silent effects of stigma visible. Also, the telling of stories ought to be invitational, in ways that encourage the silent to feel and be included and to perpetuate a means by which they can participate. I am currently deliberating possibilities for sites of fieldwork and will have this decision made in time for the submission of my dissertation proposal.

Throughout my coursework (see below) I have worked to develop an expertise in several domains essential to my planned research: relational communication, health communication – with a particular emphasis on HIV/AIDS and current ethical concerns in health – and the application of narrative and autoethnographic methodology. Queering Communication will be especially useful in identifying and reshaping the existing shorelines of knowledge; challenging assumptions and tried-and-true rationales of who is allowed to participate and to what extent, especially as these define processes of healthcare, public discourse, and policy. Methodologically, I will draw from explorations in both Critical (e.g., the on-going conversation in feminist, gender, and queer theories) and Qualitative (e.g., techniques and strategies of meaningful scholarship, writing the literature review, qualitative research design) Methods courses. My learning through courses in Autoethnography, Narrative, and Writing Workshop helped me to develop an equally productive framework upon which to define, enter, and traverse the field, and equipped me to gather and to make visible the stories of the marginal. My out of department courses in anthropology have provided complementary insights from a worldview beyond communication. For instance, coursework in HIV/AIDS and the current course on Legal/Ethical Aspects Applied to Anthropology have introduced me to key and complex concerns and problems for which single solutions are not possible. These have emphasized the highly uncertain, provisional, and dynamic engagement required to negotiate successfully this field.

To this point, I have not been entirely transparent about the personal effects of stigma in my everyday life. Goffman (1963) defines three types of barriers (stigma) that control individuals against full social acceptance into *normal* discourse: character trait, physical difference, and group (e.g., race, religion, nationality, etc.) identity. Stigma can arise when one is not – or is perceived or labelled to be not – what one performs when one is unable to *pass* for what one represents oneself to be, thus incurring what Goffman labels a *spoiled identity*. Such branding of bodies creates difference, a difference I have attempted to date to shirk because of the negative effects of stigma that I have witnessed over the last twenty-five years. I have experienced its direct effect upon people that I have loved, people who were marginalized, who suffered ill health, and who are no longer here to tell their stories. Most were gay identified. Many, if not all, were members of a community of men who had sex with men (MSM). This community has an elevated and historically disproportionate risk for HIV infection and the effects of stigma. To be transparent, I must disclose that I am implicated intimately in this field: as a member of the community, as a gay man, as a man who has sex with men, and as a body, since its diagnosis in the spring of 2004 but likely for many years prior, imperceptibly marked not only by HIV but AIDS. I will be an active participant in this research, autoethnographically when speaking to, and sometimes for, issues of health and stigma. The telling of my story is inseparable from the larger story conveyed through this dissertation.

## **Appendix D: Glossary**

The consistent application of terms within (health) communication research, as well as across other disciplines in which research into self-disclosure intersects, merits attention. In this section, I include working definitions and applications of some key terms that are important to elaborating contextual factors which have either a direct or peripheral relationship to this project.

### **90-90-90**

People who do not know their HIV status may unknowingly pass HIV to others. In January 2017, the Joint United Nations Programme on HIV and AIDS (UNAIDS) announced a new treatment target guideline in the fight to end the HIV epidemic that suggests the following:

By 2020, 90% of all people living with HIV will know their HIV status. By 2020, 90% of all people with diagnosed HIV infection will receive sustained antiretroviral therapy. By 2020, 90% of all people receiving antiretroviral therapy will have viral suppression.  
(UNAIDS, 2017)

### **Bareback/Barebacking**

While euphemistically accurate, barebacking—unprotected sexual intercourse—is one of the mater’s tools (Lorde, 1983) used pejoratively from a heteronormative standpoint to exert control over expressions of intimacy between MSM. Of course, HIV ought to and does play a role in the decision-making process of whether to have unprotected intercourse, or not. However, barebacking continues to be demonized. It matters not that only 33.7% of men and 23.8% of women aged 11-44 in the United States used a condom during sexual intercourse (Copen, 2017). It matters not that HIV is not exclusive to MSM. It matters not that for MSM, unprotected intercourse will not result in an unwanted child. It matters not that MSM can be monogamous. It matters not that some seroconcordant couples prefer the intimacy of bareback sex. What seems

disproportionately to matter is that barebacking is a vector of illness, the psychological burden of which is unfairly yoked to MSM.

### **CD4 / CD8**

CD4 is a glycoprotein found on the surface of immune cells. CD4+ T helper cells are lymphocytes, a special kind of white blood cells, which are considered essential to the human immune system's ability to fight infection. While the absolute number of CD4 cells present in routine blood testing offers a measure of how well a body is, more recent measures rely on the ratio between CD4 and similar CD8 cells as a more stable measure of overall health. A normal range for CD4 is between 500 and 1500. In adults, when CD4 drops below 200 or in the presence of an opportunistic infection, HIV is considered to be advanced (stage 3) (CDC, 2016).

### **Erasure / (in)Visibility**

Visibility frames "how illnesses such as HIV/AIDS are experienced, perceived, and imagined" (Persson, 2005, p. 239). That is, the physical manifestation of HIV as it alters bodily appearance, and its social and political dimension largely as the result of stigma and policy enacted through fear and ignorance. Today, with advances in medical treatment, HIV marks bodies in imperceptible ways. Yet, the effects of stigma, fear, and ignorance as enacted through policy or law continue to marginalize MSM and PLHIV. Pushing to the margin, as a means of social exclusion, is a dehumanizing step toward limiting agency, responsibility, and accountability of speech as a precursor to outright erasure (Alcoff, 1991; Butler, 1993). A common example of erasure in literature or discourse is to use terms like man, fireman, or policeman that subordinate other identities, such as female (see for example, Cixious, 1970; Pelias, 2007). Exclusion is not only a function of the normative social order; within the gay community, behaviours which

marginalize others occurs across race, age, bodily ability, appearance, and any number of other discernable ways of marking difference as a means of exercising power or control.

### **HAART/ART**

Highly active antiretroviral therapy, now more commonly referred to as ART (antiretroviral therapy), is the umbrella term used to identify a milestone approach to treating HIV that emerged in 1996 when the protease inhibitor, Indinavir, was approved. Although significant side effects continued to accompany many HIV drugs, taking a triple combination of drugs, a “cocktail,” to treat HIV rendered it a chronic rather than fatal illness (see Vella, et al., 2012).

### **HIV and AIDS**

A critical distinction exists between HIV and AIDS. HIV is an illness and AIDS—Stage 3 HIV—is the clinical progression of infection wherein a measure of blood’s infection-fighting CD4+ T-lymphocyte cells/ $\mu$ L falls below 200 in persons six years of age or older *OR* a complicating health condition is diagnosed (CDC, 2016; Verville, 2016). That is, a person might have a CD4+ count well above 200 cells/  $\mu$ L but their illness is considered to have reached Stage 3 upon diagnosis of an opportunistic infection (OI)—any pathogen which takes advantage of a condition which would not otherwise exist. In my own case, I developed a persistent cough. Over the course of several months, the cough worsened. It was not until a blood test confirmed the presence of HIV antibodies that further tests were recommended to ferret out the root cause of the coughing. It could have been tuberculosis, for instance. After admittance to intensive care, and the performance of a bronchoscopy, I was diagnosed with the OI pneumocystis pneumonia (PCP) which is caused by a yeast-like fungus. Notwithstanding that my CD4 count was 45 at the time, well below the determining threshold of Stage 3 HIV, the OI itself provides sufficient evidence of illness progression without a blood test.



Much of this project focuses on the liminal environment surrounding the event of self-disclosure. That is, the moments closest to the occurrence of disclosure. Heightened uncertainty permeates these moments. As such, it may be neither possible nor practical to deploy terminology of the definite. Through these moments, the distinction between persons having a negative, positive, or unknown viral status may be in indeterminate or in flux. Because this project focuses acutely on self-disclosure, the HIV-status of friends is not central to this inquiry. However, I mention the distinction here as a reminder that the ground upon which disclosure operates is always in motion.

Clarifying these terms is important, at least in part, because “AIDS” often incorrectly appears as a synonym for “HIV” in the extant research literature (Humble, et. al., 2012; Adam, et al., 2015; Adelman & Frey, 1994). In popular discourse, I have often witnessed AIDS being used in disparaging ways, as in “I hope you get AIDS and die”. However, the unfortunate ignorance—a major focus throughout this research—expressed through such slurs does not warrant immunity to its speaker. Neither is AIDS a cause of death. To the contrary, in the presence of good health combined with a failure to begin treatment, the development of AIDS can routinely take eight to ten years (Morris & Cilliers, 2010). As one might surmise, to live with an undiagnosed and untreated infectious illness for a decade is likely to have significant health consequences, both for the person and for those who may come into intimate contact. (Intimate contact and sexual contact are distinct but both importantly implicated. For example, the sharing of a drug injection apparatus does not necessarily involve sexual contact, but it is intimate.) HIV acts to weaken a host immune system until it can no longer ward against OIs. As such, death related to HIV is often reported as due to complications of HIV rather than from the virus itself. If I read that someone is dying or has died of AIDS, I am curious about underlying circumstances that require further probing (see Ellis

& Bochner, 2001, p.91). Therefore, the consistent and accurate use of terminology helps to clarify what may be happening in emergent situations, which may be rapidly in flux and occur across varying contexts.

Additionally important is the distinction between disease and illness. As public health researcher Laws (2016) points out:

‘Disease’ refers to the biomedical perspective, which historically in the US and Europe has been characterized by mind–body dualism, and biological reductionism. Diseases are abstract entities—biological processes or states—which are thought of as similar regardless of the psychosocial setting or the afflicted individual. ‘Illness’ refers to the patient’s experience. It is broader, particular to the individual, and patterned by psychological, social and cultural factors. (p. 2120)

Therefore, throughout this project, I will refer to HIV as an illness. While the term illness often refers to its bodily effects, a relational communication approach to illness primarily attends to bodies in interaction. Whereas a body may be marked in various ways by illness, the chief concern of this research not of illness, but rather people’s behaviours that arise with respect to illness.

### **Incidence and Prevalence**

Incidence is the measure of new cases (of illness) within a target population. Prevalence is the measure of actual cases within a target population.

### **PEP / PrEP**

“Post-exposure prophylaxis, also known as post-exposure prevention (PEP), is any preventive medical treatment started after exposure to a pathogen (such as a disease-causing virus), in order to prevent the infection from occurring” (Wikipedia, 2017b). PEP is often indicated when an accidental risk event occurs, such as a condom breaking during intercourse or a needle-stick

injury in a clinical setting. Alternately, “PrEP (pre-exposure prophylaxis) is only for people who are at ongoing very high risk of HIV infection” (CDC, 2017a). PrEP is indicated for those who are HIV negative and wish to maintain that status across risk events. That is, they may be in routine intimate contact with someone who is either serodiscordant or of unknown serostatus. PrEP remains controversial, in that some argue it increases risky behaviour (Guest, et al., 2008; Mimiaga, et al., 2009; Brooks, et al., 2012); has been slowly adopted (Kirby & Thornber-Dunwell, 2014); and, by some accounts, is not yet widely understood (Hicks, 2017). Important, too, is what MSM express as their needs with respect to risk reduction interventions, especially when faced with HIV prevention fatigue (Vanable, et al., 2012).

### **Serostatus / Serodiscordance**

Serostatus refers to the presence of HIV antibodies in the blood. A seropositive outcome indicates the presence of HIV. In couples, serodiscordance is an indication that one partner is HIV+ and the other HIV-. Until recently in sexually active couples, the risk to the seronegative partner was considered elevated. However, an HIV+ partner who is undetectable and is medically adherent—takes medication as prescribed, without interruption to treatment—cannot transmit HIV (CDC, 2017a; CATIE, 2017a). While ground-breaking, how will such news translate into the everyday experiences of HIV?

### **Superinfection / Coinfection**

Superinfection is the theoretical possibility which exists for someone who is already HIV positive to contract another strain of the virus. However, “A study in the *New England Journal of Medicine* titled *Inhibition of HIV-1 Disease Progression by Contemporaneous HIV-2 Infection* revealed that people who are HIV+ with the two major subtypes have a slower progression towards

AIDS than people with only HIV-1 or HIV-2. This challenges the notion of superinfection by illustrating that contemporaneous infection can offset itself” (Wikipedia, 2017a).

Co-infection occurs whenever someone who is HIV+ becomes infected with another illness (CATIE, 2017b). Co-infection may be bacterial or viral (Golub, Grov, & Tomassilli, 2009) and can elevate the risk of contracting or transmitting HIV. Common examples of coinfection are sexually transmitted illness (STI) such as syphilis, gonorrhea, chlamydia, or other communicable forms of illness that may impact the immune system such as hepatitis, the human papilloma virus (HPV), or tuberculosis (TB) (CDC, 2017b).

**Undetectable = Untransmittable / U=U**

“The evidence is in: If you are HIV+, take treatment and maintain an undetectable viral load, you can have sex knowing that you won’t pass HIV to your sex partner. In short, when HIV is undetectable, it’s untransmittable” (CATIE, 2017a; Collins, 2017). This news has significant implications for PLHIV and the ongoing stigma they face. From personal experience, reaching undetectable viral load remains a primary goal of treatment. Blood testing, routinely performed at intervals of 3-6 months, is a diagnostic tool used to help maintain undetectable status.

### **Vertical / Horizontal Transmission**

HIV is transmitted in two main ways: vertically, from mother to child; and, horizontally (or behaviourally) through activities such as unprotected intercourse, transactional sex (Himmelgreen, Romero-Daza, et al., 2009), the sharing of intravenous drug paraphernalia, or, more generally, through participation in activities which carry an elevated risk for infection through direct contact with (potentially infected) “blood, semen (cum), pre-seminal fluid (pre-cum), rectal fluids, vaginal fluids, and breast milk” (CDC, 2017c).

## **Viral Load**

“Viral load [VL] is the amount of HIV in the blood of someone who is HIV-positive” (CDC, 2017h). The primary goal of HIV treatment is to lower viral load, to low or undetectable levels, in order to achieve viral suppression. Once suppressed, the virus is now considered to be untransmittable (CATIE, 2017a; Collins, 2017).