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# Statement of Ownership:
# An Autoethnography of Living With HIV

*Gay men are disproportionately impacted by HIV/AIDS in the United States. There is a dearth of autoethnographies in communication literature about living with HIV/AIDS. In this project, the researcher presents an autoethnography about living with HIV/AIDS. The narrative has with three points: HIV diagnosis, disease progression to AIDS, and AIDS mortality. By analyzing these areas, this project presents stages of identity development and summarizes how these have changed over time. This project looks at how societal symbols around HIV/AIDS evolve due to changes in technology, science and policy. This study works against the distance presented in most social science studies of living with HIV/AIDS; instead it presents an intimate view of current HIV/AIDS discourse and public health.*

*Keywords*: HIV/AIDS, autoethnography, gay men, health narrative, communication studies

Human Immunodeficiency Virus (HIV)—the virus that leads to Acquired Immune Deficiency Syndrome (AIDS)—has disproportionately impacted gay men in the United States. According to the federal Centers for Disease Control & Prevention (CDC), gay and bisexual men—or men who have sex with men (MSM)—constituted 58% of all new infections in the United States in 2010 while being only an estimated 2% of the country's population (CDC, 2010). In the history of the HIV epidemic, gay men have been closely affiliated with the public view of the disease—including being stigmatized along with people living with HIV/AIDS (Gere, 2004; Herek & Glunt, 1988).

AIDS social stigma can be viewed as a discrediting of identity based on presumed HIV infection (Herek & Glunt, 1988). AIDS stigma has been identified as a barrier to HIV testing, HIV services and procuring social support (CDC, 2006). In addition to those living with HIV/AIDS, AIDS stigma has affected those populations considered connected to the disease: gay men, drug users, commercial sex workers, and caretakers of people living with

HIV/AIDS (Cohen, 1999; Herek & Glunt, 1988). While AIDS stigma is well documented in the research, there remains a dearth of knowledge on AIDS stigma interventions (Trapence et al., 2012).

Social science on HIV and gay men has focused on intervention, risk knowledge, behavior, community resilience, and vulnerability (Dieffenback & Fauci, 2011; Emmers-Sommer & Allen, 2001; Trapence et al., 2012). These studies have explored dimensions of AIDS stigma, racism and homophobia (Ayala et al., 2012; Cohen, 1999; Diaz et al., 2001; Dowsett, 1996; Spieldenner & Castro, 2010). In addition, they have advanced knowledge about disease management, patient empowerment, community mobilization, and public health practice (Brashers et al., 2000; CDC, 2006; Epstein, 1995; Gere, 2004; Vega, 2009). These studies have been productive in promoting scholarship and academic interest in gay men and gay health. The current shift in the HIV epidemic is to focus on biomedical solutions and policies (Dieffenback & Fauci, 2011). I posit that utilizing autoethnography and HIV/AIDS can help to situate the epidemic within its biomedical, personal and social contexts.

## LOCATING AIDS

Researchers have explored HIV/AIDS within its personal, social, historical and medical dimensions. The medical and biological reality of HIV as a disease exists alongside a multitude of social, cultural and symbolic meanings. These transform our understanding of the disease, its pathology, its infectiousness, the transmission routes and associated risks, and even the people who catch the disease. Due to the political agendas and concurrent social ills associated with AIDS, cultural critic Paula Treichler (1999) asserts, "our social construction of AIDS (in terms of global devastation, the threat to civil rights, the emblem of sex and death, the 'gay plague,' the postmodern condition, whatever) are based not on objective, scientifically determined 'reality' but on what we are told about this reality: that is, on *prior* social constructions routinely produced within the discourses of medical science" (ital. original author, p. 15).

Over time, the meaning of the disease has changed. Treichler (1999) points out "this transition from a concept of AIDS as a classic epidemic of acute infectious disease to that of AIDS as a chronic, potentially manageable disease represents one of the pervasive, influential, yet still contested shifts in meaning in the course of the 1980s and 1990s, one debated through personal observation and testimony, epidemiology, laboratory studies, clinical trials, and actuarial statistics" (p. 325).

The cultural critic and AIDS activist Douglas Crimp pushes for a dynamic relationship to the disease. Meaning changes over time, as do politics, personal and social conditions and medicine. Crimp (2004) acknowledges, "that world is the world of well-informed but nevertheless recently infected gay men who find it hard to explain, even to ourselves, how we allowed the worst to happen to us" (p. 11). The biological status of being HIV-negative is not assured with an infectious disease. The institutions built in the HIV/AIDS epidemic do not necessarily have space for this conversion: one is either HIV-negative or HIV-positive.

This world—where those who know about the disease but still become infected—fills more and more of the gay community in the United States. Treichler (1999) comments, "whatever else it may be, AIDS is a story, or multiple stories, and read to a surprising extent from a text that does not exist: the body of the male homosexual" (p. 19). There remains

an urgent to find new ways to explore the disease beyond medical research and treatment, to continue the process of uncovering the multiple stories that comprise HIV.

## AUTOETHNOGRAPHY AND HEALTH NARRATIVES

Autoethnography combines the researcher's self within a particular cultural context (Ellis & Bochner, 2000). In recent years, communication scholars have used autoethnography to explore intersectional identities including Asian gay masculinity (Eguchi, 2011), Black women's identity performance within academia (Griffin, 2012), and coming out within academia (Howard, 2012). Autoethnography can be problematic, as it relies on personal perception and memory (Tullis Owens et al., 2009). The method is useful in exploring a particular phenomenon from an intimate perspective (Holman-Jones, 2008). Richards (2008) notes that "the lived experience of illness and disability is their reality and those who must live with this reality are those who live it, not those who study it from a distance" (p. 1720). In this way, the social sciences have presented the researcher or clinician view of HIV/AIDS—the disease from the external and distant point of view, rather than an internal and personal one (Richards, 2008). Autoethnography provides the opportunity to examine the experience of HIV from another vantage point—one that can illuminate an insider's view.

Autoethnography can be implemented in multiple ways. It differs from traditional social science research where there is often a set path of collecting and writing up data (Tullis Owens et al., 2009). The autoethnographer sets up the project in a way that best suits the exploration of the phenomenon. Some autoethnography is explicitly political and emancipatory (Holman-Jones, 2008). Researchers have utilized a variety of formats in setting up autoethnography, including narrative ethnography (Tedlock, 1991), co-constructed narratives (Vende Berg & Trujillo, 2008), dyadic interviews (Ellis, 2004), and layered accounts (Ronai, 1992). Eguchi (2011) utilizes a layered account in his examination of femme gender identity in an Asian gay male body.

Like all stories, health narratives are a way of making sense of things—in this case, health and illness (Babrow, Kline & Rawlins, 2005). These narratives often present with culturally embedded symbols that reveal personal and social beliefs about sickness. They indicate how health and illness are both socially constructed (Sharf & Vanderford, 2003). Often health narratives are used to make meaning out of sickness—in terms of the individual's attempts within his or her own life, in terms of the context in which the illness occurs, and the temporal component of dealing with disease (Babrow, Kline & Rawlins, 2005). As with any use of symbols, health narratives can be problematic, as individuals can use symbols in error or have difficulty in telling their story (Harter et al, 2005). These tensions and concerns are central to presenting the narratives. For the researcher, the conflict is a key to illuminating the challenges inherent in disease.

Within the context of HIV, I see my own narrative as having three major points: the diagnosis, progression to AIDS, and AIDS mortality. This project is what Richards (2008) describes as an emancipatory discourse, an autoethnography of living with the disease as a way of breaking silences. As such, this is "more deeply imbued with context" (Richards, 2008, p. 1722) and involves my social network of colleagues, friends and family; my experience with the gay community; as well as interactions with the institutions that provide public health services (government and non-profit). Through this layered account, I will

present notes from a journal I kept at these various stages, and then analyze the text by asking key questions: 1) what does this say about HIV within the personal context of friends, family and work; 2) what does this say about the community context such as the gay community or graduate school; and 3) how does this connect to other relevant HIV literature? These three questions will take the autoethnography of the health narrative: individual context, the social context in which the illness occurs, and the various ways that time affects coping with HIV.

### Notes from the Journal: The Diagnosis

Today I am picking up the results of an HIV test. It's been a hard week, where every conversation is the wrong one and takes too much time and energy to clear up. I'm glad it's Wednesday. The weekend is full of the promise of relax and love with a wonderful man, if it works out.

I am 26 years old and have had seven, maybe eight HIV tests in my life. Before, I assumed I had HIV so it was a shock when the test came back negative. It's been three years since the last; my life has changed so much I would be stunned to have the disease. Even my motivation for the test was new—not out of a bizarre sense of duty because somewhere a voice insists gay men *should*, but because with this man, for this relationship, I want all the information possible so I can plan.

Another event frames the drawing of blood—the death of a colleague. Actually it was the way he died that got to me. I've been working for HIV groups for six years. This colleague—Black, gay, in his fifties—worked at the health department for ten years. He owned his home, had a huge circle of friends and was famous for his charm. He had a fabulous smile. He quietly entered into the hospital sometime in the early fall. He contacted a couple people. After two months he died from AIDS-related complications. Only a few knew he had AIDS; even though he worked in public health, he remained silent about his disease. His goodbye note, read at his funeral, was an apology for inconveniencing people. His family loudly proclaimed him another victim of cancer. AIDS was not said anywhere at his funeral, just in hushed conversations as we left the service. It is 1998 and still this man died in this painful, lonely way. There was rage in people's tears, shaking their voices. His shame covered everyone like feces.

Earlier that year, I broke off with a man in Atlanta. We had been involved long distance for eight months. It did not end well. Some time after the break he calls, hinting about hospitalizations and the cold that wouldn't go away. Finally he reveals he has AIDS and pneumocystis carinnii pneumonia; he's just gotten out of a serious hospitalization. He was diagnosed in 1992 and told no one but his parents. Even though I could have found him a case manager and doctor, could have brought him to resources that prevent deadly pneumocystis, he didn't say a word.

HIV is not a simple thing to discuss. Neither is sex, pain, intimacy, power, getting high or forgiveness. At least not in meaningful ways. There are jokes, euphemisms, after-school special sentimentality, moral positions and silence. This is part of the problem.

When Wilson died of AIDS a few years back, I was more than a little crazy. Somehow, I tested negative for HIV. I had always been one for pushing it, for meeting as many men as possible. There were whole years where I judged a night out by whether or not I went home with a man. It seemed, for a long time, that every man I met had HIV, that every friend I had

already caught it. As Wilson was dying, my 'cool' aunt pulled me aside to lecture me about risk. Apparently, my parents expressed concern and she chose to intervene. Without asking about my life, she spoke about responsibility, comparing her personal sex life with mine. I wasn't listening, thinking as I was of other people and places I could be. Desperate for a response, she concluded by telling me *not enough* of my friends had died of AIDS because then I would not put myself at risk.

I never spoke to her again. Not beyond polite hellos and goodbyes. Did she understand when I pointed that she is a White heterosexual married woman, and that we have very little in common when we go to bed? I didn't even bother to tell her that at the time of our "conversation" my boyfriend was dying and I had stopped counting the dead the year before. Condoms are not some ultimate solution in HIV prevention. Sex is hard. AIDS is not easy—neither is grief or frustration, poverty or hunger, loneliness or silence, pleasure or desire. There are no simple answers.

A close friend asks to meet over the summer. We've been friends for years, fought with and for the other, seen our lines of men, begun to recognize the patterns, reflected rage and passion between us. He also has worked in the AIDS field almost ten years. "It's me, I'm the positive one," he confesses. He hasn't told many; he found out three years ago. Why is this so hard for him? Where are the words for him to work through a relationship to his disease unmarked by shame and secrecy? When did even the gay community stop accepting HIV-positive people?

In the last six months, a colleague in HIV prevention said to me, "If someone got HIV now, they'd have to be stupid." In the last six months, this same person, with a background in HIV counseling and testing, explained to me, "Giving someone an HIV-positive test result is a death sentence." I believe all people with AIDS are innocent. I know that pleasure and desire are two tools we have to be whole, to heal, to understand the world and to be free. I believe the smallest human unit is two, not one. I take back nothing.

My family treats HIV like a storm on the horizon and they are waiting landfall. They've been like that since I came out as a gay man. My sister volunteered with an HIV support organization to get used to the disease. Another relative comments over dinner, "I don't see how anyone could date someone with HIV; it's risking your life." I believe—in his head—that he's trying to express concern, but it emerges from his mouth like a slap in the face. I stay quiet, suddenly finding the most interesting pattern in the food on my plate.

Truth is a troubling event. There is power in the truth. Often, being honest means admitting to conflicting sensations, feelings, perceptions and motivations in a single moment. How something can feel pleasurable and shameful; how much rage can lay behind lust; how crying releases pain, joy and loss; how relieved and horrified we can be at someone else's tragedy. There is a cost in denying the truth: in withholding history and in refusing language and words. It's strange to think- if we don't tell people what we really think and believe, what really happened between the two of us: we may never get the chance again.

In the waiting room, my number is called.

### REFLECTION: IN THE QUIET

Anticipating the test results becomes a moment of reflection. Every sexual act and every binge comes to the fore as if there is a judgment in the balance (rather than a diagnosis). HIV

testing and its associated counseling have been an important part of the disease prevention efforts (CDC, 2006). It is common to think about the kinds of support available amongst family and friends, and at work (Fesko, 2001; Zea et al, 2004). Conversations and actions are called up in memory and analyzed. Each word is cast in a suspicious light; every act has a potentially sinister motivation. The prospect of testing positive makes for a particular vulnerability. HIV is another level of "coming out" and, like with sexuality, it can alter an individual's support network, professional life, dating, and goals (Collins, 1998; Zea et al., 2005).

Access to healthcare is a critical concern at the point of diagnosis (Dieffenback & Fauci, 2011). Culturally competent healthcare can have significant impact on an HIV-positive person's health outcomes by encouraging beneficial choices, monitoring disease progression, identifying any potential opportunistic infections, and building a rapport with the patient so they remain in care. The sooner that the person finds this quality of clinical care, the more likely they are to maintain it through the course of the disease (Gardner et al., 2011). Insurance and public assistance programs can ameliorate anxiety around cost, but raises apprehension about identity in other ways. Individuals who are afraid of disclosing their HIV status may be cautious about utilizing work-based insurance plans. If the individual needs public assistance programs, the process of signing up for and using these services may constitute a new identity—as an HIV-positive person and a beneficiary of public assistance (Kinsler et al., 2007).

I have been in and out of public assistance programs, depending on my employment and insurance. While a graduate student, I found out the hard way that routine diagnostic tests were not covered by the university health insurance for pre-existing conditions. No one explained that to me; none of the faculty had been aware of this clause when they recruited me. While between jobs, I have had to use public benefits. Throughout, I have come to appreciate the stern compassion of those who provide medical and health care, like the client services director who explained the technical definition of "homeless" when I was living on a friend's couch but too proud to call the situation by name or the many nurses, doctors, physician assistants and receptionists who shared some warmth and a smile when I felt like a diseased pariah. I also became familiar with the contempt of some people in the healing professions: the receptionists who gossiped too loudly about the "AIDS patient" in the waiting room, the case manager who refused to refer me to services because I "didn't look sick," the HIV prevention staff across the city who felt the need to call and tell me to be ashamed and leave the field because I was a "failure of prevention."

The diagnosis is the moment where AIDS stigma becomes a practical concern. In this case, AIDS stigma is a moment where the person living with HIV/AIDS is discredited due to social values about the condition (Goffman, 1963; Herek & Glunt, 1988). After the diagnosis, each conversation and interactions reveals how people value being HIV-positive. In this case, the professional and familial network proved stigmatizing for this person with HIV. The lack of support and the expressed value given that health condition is illustrative: that being HIV-positive presents a threat to the personal and communal identities. In the former, having HIV means that you can transmit it. In the latter, having HIV shows that not all gay men are successful and accepted in mainstream society.

### NOTES FROM THE JOURNAL: HIV TO AIDS—STARTING MEDICATION

Ten years since the diagnosis: I've traveled and changed jobs. The love of my life—at the time—left me. Wandering the world—living in Los Angeles, Fort Lauderdale, Bangkok and Saigon—I've left most of my life behind with a series of e-mails like breadcrumbs dropped along a twisted path. New journeys open up: across sex, the gay life, and travelling. I feel lucky to be healthy after a series of torrid escapades.

Adventuring across borders allows for some anonymity. For the first time since the diagnosis, I'm free from HIV; I have options besides being a diagnosis. In Viet Nam, I am mostly a stranger in a strange land; in Thailand, I play multiracial Asian party boy. No one knows me or my past. But even in this liminal state, I can feel my history catching up to me like a bad smell. The world isn't big enough anymore. People start remembering me; Americans travel through Bangkok and recognize me from other parties, other jobs, other social protests, other conferences. I can't escape.

A group of gay Vietnamese Americans are vacationing in Saigon when I'm there. One recognizes me from some gay Vietnamese or gay Asian conference in San Francisco or San Jose (I can't remember exactly what or where). When I go back to his friend's hotel room, he calls the mobile phone all night, leaving messages warning him about my HIV status. I find out later that he's done this in the small gay scene in Saigon and I no longer feel welcome in the bars or coffee shops. Time to return home.

A few years pass, I get a job at a national organization focused on people living with HIV/AIDS. We develop national and regional initiatives, actively participate on federal scientific and community panels, and try to pull together a cohesive new voice for people living with HIV/AIDS—twenty-five years after the first case emerged in the United States. Typical of non-profits, no matter how much you accomplish, there's always more that needs to be done. In this position, I meet a lot of other people with HIV/AIDS. I meet: teenagers who were recently told from their parents that they were born with HIV; gay men who remain closeted about their status; people who refuse treatment because of fear of side effects; men and women who do not want to be reduced to a label of HIV. I meet people who were diagnosed in the past week, and others who have lived with the disease so long they act like they own it. It's a weird world to represent, an impossible feat to actually synthesize all these concerns into one coherent voice. Instead I try to build platforms big enough for everyone to have a place.

I do not realize how "out" my HIV status is until my first date with a man who would remain in my life. We meet at a national conference about AIDS. He was coming up in the HIV non-profit world, strikingly handsome and brilliant. One night he approaches me with, "I've always wanted to date you. Let's go out." My response is a nervous "yes." On our date, I tell him I have HIV—scared that this will ruin an otherwise lovely time with a beautiful man. He laughs at me, pinches my cheek and explains, "I think everyone knows that." I smile. Then realize what he means: this information about my personal health will always be public information.

My body gets erratic: I'm in and out of being sick and run down. I feel weak, diminished. My doctor tells me it's time for medication. The irony is not lost—I joke to my friends that working in HIV gave me AIDS. I would laugh it off, but my frustration, anger and fear rise up like bile—at my poor health; at the loss of face; at the thought of an AIDS identity. Yes,

even amongst those living with the disease, there is a hierarchy of social and health status. Taking medication is a clear sign of downward mobility. Over a decade of publicity on the side effects of medication has encouraged a fear of the pills: I have no desire for uncontrollable diarrhea or lypodystrophy (a condition that causes fat to shift in the body, leaving unsightly lumps on the face, back and gut). There has to be more than this disease.

"Before I die, I want a PhD" is my mantra. Graduate school brings new challenges. The accepted part of the struggle in academia—justifying a research area, coming out as a gay man, resisting the infantilizing force of the bureaucracy—is complicated by HIV disclosure. Do I tell my faculty? Do I tell my students? My colleagues? This is not a common thought among my cohort. I do not know how to say it until I put it within my dissertation.

### REFLECTION: OUT OF THE QUIET

Living with HIV is not as simple as taking a pill. It is also not as much a death sentence as it once was, as long as medication is accessible and affordable (CDC, 2006; Gardner et al., 2011). Healthcare is difficult to incorporate into a regular routine, especially if the individual is not accustomed to medical visits, clinic staff, blood draws and adherence to daily medication regimens (Campo et al., 2007; Kinsler et al., 2007; Penniman et al., 2007). People living with HIV have better health outcomes when they take ownership of the medical part of their disease (Tsarenko & Polonsky, 2011). When people living with HIV assert themselves in clinical situations, they are more likely to be retained in care (Brashers et al, 2000). Lack of social support and feelings of stigmatization can hinder healthcare utilization (Wohl et al., 2011).

Part of coming to terms with HIV is learning whether support will be positive or negative from established social networks (Baumgartner & David, 2009). My own pattern—disclosing arbitrarily for the first year, learning to be more strategic, finding support systems, avoiding and minimizing stigmatizing situations—seems to be echoed across other racial/ethnic minority gay men (Choi et al., 2011). Fear of rejection from prospective lovers, community institutions, co-workers and/or family remains a concern, even amongst gay men after thirty years of the AIDS epidemic (Harding & Molloy, 2008; Wohl et al., 2011). This can even impact willingness to disclose HIV-status (Fesko, 2001; Waddell & Messeri, 2006; Wohl et al., 2011; Zea et al., 2005). While I had told my family in 1990 that I was gay: I would wait until graduation from my Masters program to admit I was HIV-positive, ten years after the diagnosis.

I returned to working in HIV/AIDS, doing some small part to building an organization and providing a leadership voice. This is not uncommon amongst gay men (Trapence et al., 2012). Taking part in service provision and representing the community publicly is one way to take control of the disease and become comfortable with the diagnosis (Baumgartner & David, 2009). By choosing this strategy, I attempted to access an external source of support in the form of the community of service providers and advocates (Choi et al., 2011).

Ayala et al. (2012) have documented relationships between HIV risk behaviors and social discrimination and financial hardship in the lives of racial/ethnic minority gay men. Economics and social discrimination are a driving force in being able to access healthcare and finding out benefits when needed. These are underlying determinants in seeking out social support and in pursuing intimate relationships with other men. I moved away from

the future, and the investments that would infer a future (Harding & Molloy, 2008). I would remain in this chaos for years until other matters—a long-term relationship, a tenure-track position, and a stable physical health—began to shift my focus away from the moment.

## NOTES FROM THE JOURNAL: BEING MORTAL

Death can sneak in anywhere. At the park, in the bar, reading social media, going through my contacts on my mobile phone, filling out paperwork at the new job. Life insurance, healthcare plans, health care proxy, beneficiaries, emergency contacts—such simple words take on new meaning after living with HIV longer than I expected. Thinking about the rest of my life, even after it's over.

Most of my past is buried or scattered to the ashes. Memories before Facebook, the tumultuous days and nights of being newly gay in the clubs, the running of streets in hopes of finding something amazing that will make it all worthwhile, that young boy: so few around me have seen him, can remember him past the body and cantankerous man that's emerged. By twenty-three, I had grown inured to a funeral's awkward tension. By forty, I am—apparently—one of those people that you call when there's a drug emergency or someone dies. Years stamped on me like a passport. At some point along the way, I lost my door pass to the clubs.

I have not planned for a beneficiary. I have a dog but no children. My brothers' kids are comfortably ensconced in financial security. I have yet to put aside money for my cremation and funeral. Most of my friends also have HIV. We do not know how to frame our endings or our legacies. We only know what it's like when someone is gone, when their number is still in our phone, when their birthday still appears in our reminders—years after they died. I am afraid of disappearing. Of being that person haunting someone's cell. Of an unfinished life. Maybe we all are. But it's inside me. I have the diagnosis.

What about my friend from college and her daughter? No matter how troubled or sketchy I've been, this friend has insisted that I stay part of her life, through her graduate degrees, marriage, tenure, child birthing, divorce, and child-rearing. I'm unsure how she will take this conversation. Am I saying that she can't raise her child? Am I intruding on her private life? Do I deserve a place in this circle? When she thanks me and laughs at my nervousness, the anxiety lessens. If nothing else, this little girl will receive my retirement when I pass; one life is improved by my living. So many tantrums, so much drama—all with the intent of being remembered, of marking this world. I haven't been the easiest person to date, I'm sure.

At the new job, I am confronted by disclosure again. Do I admit to my HIV status amongst faculty or students? I know a few others that have both a doctorate and HIV. Most are closeted, afraid of what people will think about them. They consider HIV a reflection of their own intrinsic value apparently. One other is out and he works as an administrator on campus. Would he fare so well in the research arena? Will I? These are the questions that I must come to grips with in order to join the university faculty, so I know where I stand within their rules and boundaries.

Is it too late to be a partner? After the last fight, the final blow, can we find each other again? My friends tease that I keep in touch with all my ex-boyfriends. Not true. It's just the serious ones. My friends don't understand what I have put these men through, the parts of

me reserved only for intimate moments—the season of insecurities and the need to be whole. But I want him, that one where everything is unfinished. Where he's seen my worst and still comes back. No matter what everyone says. This moment is a love letter between men.

## REFLECTION: BEING QUIET

Past research has shown that gay men living with HIV/AIDS in the United States go through various points of identity formation. Often there is a point where one has to decide how to live and how to die (Baumgartner & David, 2009; Tsarenko & Polonsky, 2011). These are neither oppositional nor in some direct linear progression: rather, like with most identity, they present directions that people move towards (or away) constantly. I came to terms with the future at the point where I had to manage an institutionalized benefits package—something that has only recently become part of my family story.

For a gay man, being "out" about an HIV-positive status brings your sex life into focus. People understand that—for infection to occur—that the gay man probably had sex with another man. Without a condom. This flies against what Corey and Nakayama (2012) call the normative "tragic script, alone, sad and miserable, or the youth script, where growing old is tantamount to ritualized horror, or the marriage script, where the gay couple achieves happiness by emulating the joyous life of the married couple, children and all" (p. 20). By being "out," I am consciously working against narratives about growing old or being forever youthful; this status makes people uncomfortable asking about my life with my partner(s). In academia, discourse defining what is "appropriate" tends towards normative standards on sexuality, race, class and gender. Entering the university, for the first time in decades, I worry about my public history as an activist, as someone concerned with social change, as a person who believes that being "out" about my HIV-status is important. I understand that these actions, events and statements follow my digital footprint, that my politics about sexuality and health will follow me into the classroom (Corey & Nakayama, 2012). I understand my friends living with HIV who have doctorate degrees who choose to not come "out" and avoid academic placements.

Romantic and intimate relationships are a concern for people living with HIV/AIDS (Waddell & Messeri, 2006; Zea et al., 2005). Fear of rejection can result in not disclosing HIV-status to prospective sex partners (Baumgartner & David, 2009; Tsarenko & Polonsky, 2011; Zea et al., 2005). This level of stigma is pervasive and exists in multiple countries and contexts (Trapence et al., 2012). When I was first diagnosed, my brother commented, "Why would anyone date someone with HIV? It's a death sentence." Over the years, I have employed various ways to disclose: sometimes arbitrarily to everyone in hearing range, sometimes nuanced such as leaving my medication out or explaining to my sexual partner "If someone wants to use a condom in sex, you should just let them." While some do develop strategies at managing the social stigma, there are others with far less success in their tactics (Choi et al., 2011). In addition, stigma is a phenomenon at the structural and social level, so there are some limits to an individual's capacity to mitigate the entire social structure (Ayala et al., 2012). I do not know if the receptionists at the dentists office were talking about me as I waited for my appointment, I only know that I was alone in the reception area, that I had completed my patient intake form honestly (including admitting I had HIV), and they called each other out and pointed at me. To this day, I resist going to the dentist.

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Understanding the social and interpersonal dynamics is key to moving forward, although some researchers would limit their view of the epidemic to the biomedical and not mention social stigma as a barrier to ending the AIDS epidemic (Dieffenback & Fauci, 2011). Yet research continues to show that social support in intimate relationships helps with treatment adherence (Campo et al., 2007; Waddell & Messeri, 2006). Those closest to me remind me to take my pill, even when we are out partying.

While people living with HIV/AIDS have always been able to—and indeed have—procreated, changes in policy and medical care have made this process more accessible (CDC, 2006; Dieffenback & Fauci, 2011). These advances do focus attention on the notion of legacy—a consideration that I am finally able to entertain. Estate planning, including identifying and negotiating beneficiaries, has to become part of the HIV social service industry. After the diagnosis, I was still haunted by the specter (real or perceived) of death (Baumgartner, 2012; Harding & Molloy, 2008).

The growing population of people living with HIV/AIDS getting older is a concern in the health literature (CDC, 2010). There is still a dearth of research on the impact of HAART over time (Tsarenko & Polonsky, 2011). While I feel comfortable today with my medication, I recently had a scare and had to switch medications. The incident left me cautious about treatment. I understand now that HAART and other treatment is not a static process, that I am part of a dynamic partnership with my doctor and pharmaceutical companies, that I have to pay attention to little changes in my body. Identifying current social frames and meanings within their temporal context is important in HIV, as people living with HIV/AIDS make choices and develop identities within these frames (Baumgartner, 2012). Recognizing the impact on personal and community identity, on the individual body and the larger health outcomes, requires consistent and ongoing research projects.

## FINDINGS

There is a social meaning to disease beyond the biological health condition, and these values and assigned meanings can change over time. In the United Sates, HIV/AIDS has been associated with substance use, homosexuality, sex and immigrant groups (Triechler, 1999). These connections have encouraged a moral judgment against those living with HIV/AIDS (Herek & Glunt, 1988). Even within the gay community, the terms "clean" and "dirty" have emerged in online dating profiles to indicate HIV-status where being HIV-negative is "clean" and HIV-positive is "dirty," assignations that are obviously value-laden. Stigma has been so pervasive in the United States that even caregivers feel the impact, that even those working within AIDS organizations may express and/or possess stigmatizing attitudes about people living with HIV/AIDS (Herek & Glunt, 1988; Kinsler et al., 2007).

HIV/AIDS and the associated symbols have changed over time (Treichler, 1999; Gostin, 2004). Prior to the widespread availability of treatment, HIV/AIDS was considered a death sentence, and therefore people living with HIV/AIDS constructed meaning out of dying. With the advent of HAART, people living with HIV/AIDS are living longer—and therefore the social meaning of having the disease has changed (Tsarenko & Polonsky, 2011). Amongst the gay community, this has spawned a sense of shame about those of us living with HIV/AIDS, casting us as a problem that embarrasses the overall community. We are inconvenient and messy, revealing vulnerabilities that the gay community still possesses.

This identity is ratified within interactions with other gay men, community groups, families and institutions. The changing symbol system is embedded within these interactions. While HIV/AIDS is no longer a death sentence, it remains a potent stigmatizing identity (Tsarenko & Polonsky, 2011). Public health institutions problematize the identity by mandating HIV disclosure. Gay community organizers, in this project, have gone further and disclosed on behalf of the researcher. These compulsory methods ignore the social and legal constructions that discriminate against people living with HIV (McArthur, 2009), and they selectively sidestep the psychological theory on disclosure (Jourard, 1971). Disclosure is contingent on multiple personal and social factors, including the value of the relationship and the amount of disclosure exchange that occurs (Jourard, 1971; Zea et al., 2004).

The social interactions presented in this project point towards a shifting identity for those living with HIV (Baumgartner, 2012). Where there was a moment where "AIDS victims" were presented in a sympathetic light, the ongoing epidemic has undermined these efforts as "AIDS fatigue" erodes community mobilization efforts and social capital about working in HIV/AIDS (Gostin, 2004). A public HIV identity is no longer considered "heroic," a phenomenon that perhaps discourages people to disclose their HIV-status.

Within this frame about HIV/AIDS, the body becomes the enemy. When a diagnosis occurs, the body changes beyond previous expectations (Tsarenko & Polonsky, 2011). In the gay community, the body becomes the point of vulnerability and the infectious agent (Baumgartner, 2012; Collins, 1998). This narrative places HIV/AIDS as part of an irreconcilable difference between gay men and mainstream society—as if homophobia and heteronormativity were not present and problematic (Choi et al., 2011; Cohen, 1999; Dowsett, 1996; Gostin, 2004).

The science of HIV treatment has advanced: we know more about various ways to intervene in transmission (Dieffenback & Fauci, 2011). This should promulgate new conceptions of the identity of living with HIV. The current state of public health has yet to acknowledge and incorporate these shifting identities. Since HAART, organizations that promote the voices of people living with HIV have seemed to be under more strenuous challenges and have, in fact, begun fading (Ward, 2000). Where these limits present challenges to AIDS service organizations, the success of HIV science advancements are contingent on the uptake and understanding of the tools within the community of people living with HIV (Vallely et al., 2007).

## Conclusions

I found three primary points in living with HIV: the diagnosis, the progression to AIDS, and mortality. Other research has documented that people living with HIV have: resituated themselves from passive patients to health advocates (Brashers et al., 2000; Epstein, 1995); built organizations, community groups, and leadership positions (Trapence et al., 2012); used social networks to help with treatment adherence and mental health (Waddell & Messeri, 2006; Zea et al., 2005); continued to seek out intimate partners as well as other people living with HIV/AIDS (Baumgartner & David, 2009; Tsarenko & Polonsky, 2011); and recognized that medical care is a critical part of moving forward (Harding & Molloy, 2008, Campo et al., 2007; Tsarenko & Polonsky, 2011). I have yet to be comfortable with all of these facets of my life: since the diagnosis, I am consistently surprised at changes in my body, and my own understanding and feelings about these transformations.

HIV and other health issues benefit when explored through autoethnography. Richards (2008) posits that the internal understanding of disease is important in the context of clinical interactions, that autoethnography works against a "medicalized narrative" and builds subjectivity rather than relegating people to being "objects of study" (p. 1719). This narrative deepens understanding of the personal impact of stigma, treatment and social support. While autoethnography has not been focused in the health literature, it remains a viable exploration of health and disease in society (Richards, 2008). Autoethnography removes the distance that social science research can unintentionally encourage about the phenomenon, and—in the case of potentially stigmatizing conditions—the proximity of autoethnographic methods can provide a more intimate and personal sense of what the patient undergoes at the clinic, in society and amongst family (Vande Berg & Trujillo, 2008).

This project recognizes that memory can be a problematic tool. Tullis et al. (2009) assert "memory—or the accuracy of the memory—affects the authenticity of the story" (p. 190). The researcher has worked to situate memory within the personal, and referenced within other areas from that time (the journal entries). I have purposefully looked at these moments within multiple studies that could explicate these moments beyond the personal. I have not attempted to clean up the voice to discern a more stable trajectory; rather I have included the fragmentary style of these memories and journal entries. It follows the conflicted, back and forth, evolving positionality that is living with HIV today. For autoethnography to be productive, the researcher has to be able to critique the experience, the memory and the possible interpretations.

Butler (1993) points out, "One does not stand at an instrumental distance from the terms by which one experiences violation. Occupied by such terms and yet occupying them oneself risks a complicity, a repetition, a relapse into injury, but it is also the occasion to work the mobilizing power of injury…. The compulsion to repeat an injury is not necessarily the compulsion to repeat the injury in the same way or to stay fully within the traumatic orbit of that injury" (p. 124). In this way, my journey in this project is not meant to stay within the confines of victimization, the trauma of confronting stigma, or the vulnerability present in illness; it is to move this discussion beyond those frames while understanding the limits inherent in these settings. I do not put this project forth as a means of claiming the HIV position as my sole property, and even within that, that this one analysis of these series of memories are my only experience of HIV. It is a way of organizing information in a way that makes sense to those who do not live with HIV, as well as a lighthouse for those who do have HIV—to discern the meaning of having HIV in these times of biomedical advancement and shifting policy and funding. This project stakes out a claim for voice in HIV and communication studies, one situated within being gay and being a racial minority, one that promotes visibility in public health (Trapence et al., 2012) and advances an external source that can provide a source of strength for others facing similar challenges (Choi et al., 2011).

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