

THE FIRST FIVE: NARRATIVES ON THRIVING WITH HIV

by

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This is dedicated to the people in my life I am fortunate enough to call *family*.

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ABSTRACT

The current study seeks to provide insight into the lives of newly diagnosed HIV-positive gay men living in the southern United States. This work investigates how six gay men with HIV navigate healthcare and social service infrastructures, negotiate disclosures, manage stigma, and work to maintain a healthy sense of themselves by engaging in adaptive coping mechanisms within the first five years post diagnosis. Data were collected through semi-structured interviews. Interviews were organized to excavate descriptive information on three dimensions particularly salient to overall wellness: Access to Care, Social Support, and Well-Being. Narratives from these men describe an intersectional positioning where people with access and ability to utilize resources can expect minimal issues achieving and maintaining viral suppression. Data also show that social support from close friends and community integration in the form of activism and education help the men overcome expected and enacted stigma concerning HIV infection. Further ethnographic research can seek to investigate these dimensions of wellness over the life course or utilize similar methodology to investigate other demographic cohorts.

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INTRODUCTION

Nineteen eighty-one is considered the first year of the AIDS epidemic in the United States (Gould 2009; Padgug 1989). The earliest reports of infection came from gay and immigrant communities (Cran 2006). It was in this milieu that HIV/AIDS was stigmatized and conflated with sin, immorality, and deviance. HIV, like any other virus or bacteria, has no moral agenda. However, because of the confluence of social, geographic, and demographic factors which intersected in 1981 in America, this *virus* has a social identity which burdens those infected in ways beyond those simply associated with the physical health of the body. Judith Lorber (1997:86) predicted that, “even when AIDS is ‘conquered’ ... it will not be socially acceptable or culturally neutralized. AIDS has entered the world’s mental landscape, and we can’t get away from it.” Lorber’s prediction would come to be a prophecy. In an era when Highly Active Antiretroviral Therapy (HAART) can increase the lifespan of those infected to levels congruent with societal averages (Lancet 2008; Samji et al. 2013) and Pre- and Post-Exposure Prophylaxis (PrEP/PEP) reduces transmission rates to nearly zero (CDC 2015), HIV is still a stigmatized illness.

HIV as an illness is different from other chronic conditions such as diabetes or other so-called self-inflicted illnesses like lung cancer from smoking or cirrhosis from alcohol abuse (Padgug 1989). In the United States HIV/AIDS was framed as an illness of immorality, only affecting the dregs of society, homosexuals mostly, but also intravenous (IV) drug users and Haitian immigrants

(Gould 2009; Padgug 1989). This framing was unique to America, because in European and African countries HIV diagnoses were not endemic to gay communities (Cran 2006). The linkage between gay men and HIV/AIDS was so durable that women could not be diagnosed with AIDS (based on syndrome symptomology) until feminist advocates in the AIDS movement lobbied the Centers for Disease Control (CDC) to update diagnosing guidelines to include ailments unique to women (Cran 2006; Gould 2009; Lorber 1997).

There are currently more than 1.1 million HIV-infected persons in America, with an estimated 1 in 6 unaware of their status (Kaiser 2014). Far from the early days of HIV/AIDS, infected persons are not trying to simply stay alive, but many have the added goal of living *well*. Because of the introduction of combination therapy and HAART, HIV has become a manageable, chronic illness akin to diabetes (HHS 2009). In contrast to the multiple pill cocktails which symbolized AIDS treatment in the 1990's, many modern treatment modalities call for oncedaily pills. Although efficacious treatments are available, access to care is a significant barrier to health maintenance for many HIV-positive persons. A recent release from the CDC (2014) reports that as of 2010 nearly half of HIV-positive gay and bisexual men were not adhering to prescribed treatment regimes. HIV/AIDS scholars have documented how the illness disproportionately impacts minorities and impoverished people, because of the high cost of treatments and issues with the American healthcare system (Crawford et al. 2013; Gould 2009; Harris 2010; Nunn et al. 2014).

Fear of the negative consequences of disclosure drives some HIV-positive people into what Berg and Ross (2013) call *the second closet*. The continued stigma associated with HIV/AIDS has been documented as a cause for the persistent infection rates (Benotsch et al. 2011; Moore, Kalanzi, and Amey 2006). Some people choose to avoid disclosing to sexual partners for fear of rejection. For others, stigma avoidance manifests as outright avoidance of HIV testing (Zhao et al. 2012). In their qualitative study of HIV-positive gay men, Berg and Ross (2013) found that stigma not only manifested in social isolation but also in direct threats, harassment, and job loss. Stigma avoidance then becomes a way of shielding one's self from the social and emotional troubles which come along with an HIV diagnosis.

Much of the existing qualitative literature on HIV/AIDS does not consider length of time since diagnosis in their data analysis (Moore, Kalanzi, and Amey 2006; Berg and Ross 2013; Bird and Voisin 2013; Sandstrom 1990). This distinction may not have mattered much when people with HIV were expected to experience a truncated lifespan; however, the prognosis for persons diagnosed is much different today. Thus how people negotiate HIV/AIDS over the life course is important to current and future coping research, because the illness may manifest itself differently during various periods in a person's life.

For this study I worked with a sample of gay men, all of whom live in Middle Tennessee and have been HIV-positive for less than five years. The purpose of the research was to explore the lived experiences of these men as

they negotiate various social and institutional systems (family, friends, healthcare providers, social services agencies, etc.). Utilizing existing research and my own experiences as an HIV-positive gay man living in Tennessee, I decided to focus on three dimensions of negotiation: 1) gaining and maintaining access to treatment, 2) disclosure of the diagnosis to others and social support networks, and 3) the maintenance of emotional and mental health or well-being as participants learn to live with HIV. To date researchers have yet to investigate how these areas are managed in the first years of diagnosis, although some studies do suggest that utilization of various coping mechanisms change over time (Hays et al. 1990; Ueno and Adams 2001). In this way my goal was to help “unpack” the intersections of physical, social, and emotional health and wellbeing as people with HIV acclimate to the diagnosis and seek support for maintaining overall health and well-being.

METHODS & JUSTIFICATIONS

As I began mapping of what this research would look like I had very definite expectations. I have spent the past six years of my life experiencing HIV both as an HIV-positive person, but also as part of a community. I have observed friends of mine diagnosed with HIV and experienced with them their struggles ranging from coping with their initial diagnosis, accessing healthcare and maintaining insurance coverage, having negative reactions to medications, experiencing issues with service providers, negotiating how, when, and whom to disclose their status. I have witnessed people thrive with HIV. But I have also observed people struggling with the daily challenges of the infection and illness. Often those who thrive and those who struggle are one and the same.

I was diagnosed with HIV in 2009 and my involvement in the community includes being a consumer and client of HIV care services in Nashville as well as taking on a role as an advocate. This role ranges from being an educator on issues regarding HIV formally and in my day-to-day life to providing instrumental support in the form of volunteering and fund raising. Because of my own experiences with HIV I knew there were certain segments of experience not being represented in the existing literature. Most of the literature concerning HIV/AIDS focuses, with good reason, on the myriad difficulties HIV-positive individuals face ranging from coping with stigma (Earnshaw et al. 2014) to poverty (Crawford et al. 2013), and racial disparity (Garafalo, Mutanski, and William 2013).

The intersectional approach is used in purposeful effect to target high-risk HIV-positive individuals and groups (Garafalo, Mutanski, and William 2013; Nunn et al. 2014). We know from existing research that poor people of color living in inner cities are sequestered in HIV *microepidemics* (Nunn et al. 2014) where their infection and survival rates are much lower than those even in historically gay communities. The *geography* of the epidemic has as much to do with who survives past the first five years of being diagnosed with HIV as does the introduction of new antiretroviral treatments. Intersectionality is a great tool for targeting specific demographic traits and determining who is most in need of support, but I have found that it is also a useful tool in discovering how to successfully manage HIV. By applying research resources to those who are doing well despite their HIV status, we can begin to construct a paradigm in which we can account for the factors which lead to successful health and wellbeing as an HIV-positive person.

The use of qualitative methodology is by no means novel in HIV research. However, since coping strategies and experiences may change over the life course (Hays et al. 1990; Ueno and Adams 2001), my intent was to focus on a specific temporal period in the lives of the men I researched. Selection criteria dictated that all participants be at least eighteen years of age, self-identify as gay, and be HIV-positive for less than five years. While there is need for research to focus on the experiences of other populations such as women or heterosexual men, I chose to limit selection to gay men. I would argue that given the social

context of this particular disease different types of people will experience the illness in very different ways. So instead of trying to tie together stories from otherwise disparate people I chose to focus exclusively on gay men. The fiveyear cut off was as arbitrary as it was loosely associated with a common period used to measure mortality for recently infected persons (Reif et al. 2014). This ethnographic approach supplements extant data on how many people are living and dying, with rich information about how people live *well*.

I interviewed six men during the Spring and Summer of 2015, all living in and around the greater Nashville area. I utilized various methods to access potential participants. As a member of the community of which I intended to research I had entrée to a handful of people and resources. Recruiting through interpersonal contacts proved to be a hit and miss technique. Two personal friends agreed to be interviewed while others declined speaking with me. I secured an arrangement with a contact who works for a local HIV/AIDS outreach agency. We agreed that I would come as a guest speaker and give a presentation to one of their monthly client groups and I would be allowed to recruit from clients in the audience. This proved fruitless since only two clients attended my presentation, and neither of them fit the selection criteria. I secured one contact through snowball sampling after discussing my thesis work with a coworker. The remainder of the participants were respondents to recruitment fliers posted online or passed out at Nashville's gay pride event.

Interviews were conducted at a place of the person's choosing, typically happening at a restaurant or coffee shop. The formal consent documentation which I sent via e-mail to the men to review prior to the interview states that there is no financial incentive to participation, but where meals or drinks were involved I covered the cost as a courtesy. I was able to secure from IRB a waiver of the signed consent requirement, and instead had the participants acknowledge via audio recording that they received, reviewed, and understood the informed consent materials. The interviews ranged in length from around 45 minute to well over two hours. They were structured around the three themes I chose as the dimensions of wellness: access to care, social support, and overall well-being. I utilized an interview protocol to provide a general outline for questioning, but allowed for the interviews to progress according to their own trajectory. The interview protocol is located in Appendix A.

My data collection and analysis approaches are both heavily focused on a feminist methodology in which I position my data in a social justice frame and allow for my own subjective experiences to inform my data analysis. Much of the analysis is framed in terms which consider the privileges of the men I spoke with, and acknowledges inequity in care and treatment. I made my role as a researcher *and* as a stakeholder clear to all the men I interviewed. In analyzing the data I attempted to focus on the narratives I received and letting them speak to the true nature of the men with whom I worked. I found my literature review to be an ongoing and evolving process as I had to constantly return to existing work

to help explain the emergence of unexpected themes and ideas. I found this technique well-suited to the narrative approach I took to presenting these data, because I could integrate new information into the narrative where it became needed.

What I have compiled are the stories of six HIV-positive gay men living in the south who have been positive for less than five years. I was fortunate enough to work with men who were as enthusiastic about participating in my work as I was (I discuss this further in the section on *Well-Being*). Ethnographic work utilizing interviews suffers from lacking a direct observation of the “actual empirical social world,” but as Blumer (1969:48) remarks, “the nature of the empirical social world is to be discovered, to be dug out by a direct, careful, and probing examination of the world.” The process of self-disclosure and rapport building with a cohort of which I am native allowed me to *dig* deeply into the lives of the men I worked with and excavate from their stories a commentary on the social meanings of HIV in the current era. The illness of HIV is ever changing as a social object, and these stories show a glimpse of the current stage of illness evolution for a small group of men in middle Tennessee.

ACCESS TO CARE

“My doctor even tells me all the time that he would rather have HIV than diabetes.” – Kevin, HIV-positive since 2013

Nashville’s gay pride celebration in 2015 was historic, because it was held the day after the Supreme Court ruled that marriage equality was the law of the land. Fueled by the excitement of the latest civil rights victory LGBTQ people and their allies turned out in record numbers and far exceeded the fifteen to eighteen thousand estimated attendees (Langston 2015). Access to this huge pool of possible participants was the perfect opportunity for me to show up with recruitment flyers. Wading my way through the crowd I approached groups of men and pitched my research. Most people I spoke to politely smiled, took the flyer, and committed with little enthusiasm to get back to me if they should know anyone willing to speak with me. This is where I met Kevin. He disclosed his HIV status to me immediately upon hearing details of my research. He was at the festival with a group of four or five friends, and spoke candidly about his status and his interest in participating in my research. I got a good vibe from Kevin, and was pleasantly surprised when I got home several hours later and already had an e-mail in my inbox from him. Kevin and I met a week later to have dinner and conduct the interview.

Kevin was diagnosed with HIV in December of 2013, “it was two days before my birthday,” he told me. A few months prior to receiving his diagnosis Kevin had a “two week stretch” where he exhibited some symptoms of

seroconversion. Seroconversion refers to the initial phase of infection when people experience, and often dismiss as a benign infection, flulike symptoms such as fever, nausea, fatigue, and diarrhea (Mayo 2015). Kevin decided to go in for a sexually transmitted infection (STI) screening a month or so after he recovered from his illness. Kevin's initial test results were negative for HIV, but his doctor suggested he be tested again after a few weeks to allow time for antibodies to build up to the level that they would be detectable. "I kinda already knew that it was going to come back positive, because it was just something in me saying that it's, it's, something's not right. Like it's just my body saying internally that something wasn't right." Kevin's suspicions were confirmed with the second test.

Kevin's primary care doctor in Clarksville directed him to a specialized clinic in Nashville. The Vanderbilt Comprehensive Care Clinic (CCC) is where Kevin receives his HIV-related care although he remains a client for general care with his doctor where he lives. During his first visit at the CCC Kevin had his initial assessment and blood tests run. Three months later he was prescribed the HIV drug Stribild. Stribild is part of one of several classes of drugs which is highly effective in halting the replication HIV in an infected person's body: "When I first got my viral load, it was ... maybe 100,000 (copies per mL of blood), my CD4 was still in the normal range, but after maybe a month or two of being on Stribild it had already gone down to undetectable." When copies of the virus in the blood are less than 40 copies per mL the person is considered *undetectable*. Thanks to

the efficacy of modern HIV treatments Kevin quickly regained his health. But getting drugs represents only part of the story of managing HIV care.

Getting Drugs into Bodies

Prior to the introduction of HAART in 1996, having HIV was considered a death sentence which killed most infected within a decade of transmission. Images of the wasted faces of dying young men came to characterize AIDS in the 1980s and 1990s. The physical manifestation of sarcoma lesions on the skin of infected men came to be the scarlet letter which symbolized the sinful nature of the homosexual. Much of the early history of the AIDS epidemic in the United States was framed as comeuppance for disobeying the laws of God and nature (Padgug 1989). The conflation of sin and sexuality, scholars claim (Cran 2006; Gould 2009), contributed to the slow governmental response to the epidemic which by 1987, the year President Reagan made his first speech devoted to the topic, had claimed 20,798 lives (Boffey 1987).

AIDS activist groups like the AIDS Coalition to Unleash Power (Act Up) took the fight against AIDS directly to the government agencies and elected representatives they deemed to be negligent and adversarial in their response to the epidemic. Act Up's version of direct-action activism is credited with directing a social movement which brought AIDS into the lives of all Americans through campaigns of civil unrest and governmental lobbying (France 2012; Gould 2009; Harris 2010). Splinter groups like the Treatment Action Group (TAG) worked

directly with the Food & Drug Administration (FDA) and National Institutes of Health (NIH) in finding effective HIV drugs and making them available and affordable to the public. The mantra of “getting drugs into bodies” was part of an effort to remove institutional barriers which were delaying the process of getting drugs to those who desperately needed them, even if those drugs were untested (France 2012; Gould 2009). Due in part to the efforts of the early AIDS movement activists an HIV diagnosis has gone from being a death sentence to becoming a potentially manageable, chronic illness (HHS 2009). Key components to the survivability of the HIV infected are early detection and treatment. Studies on mortality find that infected persons who begin a treatment regimen before their white blood cell count falls below a particular threshold can expect to have a lifespan comparable to an uninfected person (Lancet 2008; Samji et al. 2013).

On the other side of the treatment breakthroughs is the intersection of class and race (Watkins-Hayes 2014). An HIV positive person can only expect to benefit from HAART if they have the proper availability of and access to care. This access to care, and even routine testing, is often more difficult for people of color and those living in poverty (Crawford et al. 2013; Garafalo, Mutanski, and William 2013). The class disparity is so entrenched that despite popular belief, most HIV/AIDS hotspots are centered in poor neighborhoods and communities and not those which are historically inhabited by a large population of gay men (Nunn et al. 2014). Even within the gay community white, middle class gay men

have historically had the greatest access to care (Gould 2009). The CDC (2014) reports that nearly half of HIV-positive men who sleep with men (MSM) are not adhering to prescribed treatment regimes. Additionally, a pilot program for routine HIV testing conducted in a predominantly black community in Georgia found that nearly half of the visitors to the Emergency Room not only tested positive for HIV, but also had viral progression to the points of an AIDS diagnosis (Hagen 2015). The ability to adhere to treatment relies heavily on a person's ability to access potentially life-saving drugs. Consistent adherence to prescribed medications is also important to protect against viral mutation which can impact the efficacy of certain classes of antiretroviral drugs (NIH 2015). For the men I interviewed accessing and maintaining care involves more than just *getting drugs into their bodies*, but they learn to navigate a web of service providers to ensure there are no lapses or issues in coverage.

Testing and Navigating Healthcare

The Vanderbilt clinic is the primary source for HIV-related care for all the men I interviewed. Fear of discrimination from medical providers has been documented as an inhibitor to seeking care (Vaswani and Vaswani 2014). Kevin, Jeremy, and Xander in particular describe having overwhelmingly positive experiences with the staff and physicians at the CCC. The luxury of accessing quality medical care for HIV is not a privilege however afforded to many infected people in the state. The southern region of the United States accounts for a

disproportionate number of new HIV infections as well as a higher than average five-year mortality rate (Reif et al. 2014). Much of the disparity is linked to increased rates of unemployment and poverty, low rates of health insurance coverage, poor sex education, and gay-related stigma (TNDOH 2010). Additionally the HIV/AIDS care infrastructure is described as a “patchwork” of services, nationally and locally, which leaves large gaps in care availability for certain populations. Access to a devoted facility like the Vanderbilt clinic provides the men I spoke with, “regular access to continuous care” which is vital to successful disease management (Martin, Strach, and Schackman 2013).

Having health insurance or access to supplemental coverage is a source of help and anxiety for some of the men. Sean, 29 and diagnosed in 2011, has worked as a server in restaurants for most of his adult life. Most restaurants do not offer health insurance to their wait staff; although mandates in the Affordable Care Act makes changes to this for some restaurant employees. At the time of his diagnosis Sean was working at an Italian-style pasta and steak restaurant in downtown Nashville which did not offer health insurance coverage, nor provide enough of an income for him to be able to afford to purchase coverage on the individual market. “I knew from having friends who are HIV positive that getting diagnosed wasn’t a death sentence the way that it used to be, but I was still really scared and upset. So the fact that I didn’t have health insurance, it uh, it really freaked me out.”

Sean was familiar with Nashville CARES, a local HIV/AIDS outreach and social service organization, which he visited shortly after receiving his initial diagnosis. A social worker there introduced him to the insurance assistance options available to him, namely Ryan White. This assistance program, named after the teenager who died of AIDS in 1990 provides Sean with coverage of his HIV-related medical expenses. Despite having access to the coverage afforded by the Ryan White program, during our time together Sean discussed having had some difficulty with navigating the bureaucracy of the program.

See, the thing with Ryan White is that you have to requalify every so often otherwise you get kicked off of the rolls. A lot of the time there might be a wait list to get the coverage, so if you're kicked off you could be without your medication for who knows how long, you know? Over the past few years that I have been using the program I have had issues where my coverage was dropped and I was without medication for a couple of weeks. Another time I actually got my medication, but got a bill in the mail of out the blue a couple of months later for over a thousand dollars!

Jeremy has been in a relationship with an HIV-positive partner, so when he was diagnosed he was well aware of the options available to him in Nashville. Like Kevin, Jeremy was prescribed Stribild by his specialist at the CCC and his viral load dissipated to an undetectable level within a couple of months. But like Sean, unstable employment and health coverage was a cause for concern as to how to maintain adherence to treatment. There are myriad reasons why people have difficulties maintaining a steady treatment regimen. Issues associated with cost can be highly prohibitive, but even when financial barriers are removed issues with untreated depression, homelessness, stigma, or having had a

negative experience with a healthcare provider all may impact whether or not someone chooses to consistently adhere to treatment recommendations (Tobias et al. 2010). Fortunately for the men I spoke with Nashville CARES does provide mental health and other services to help ameliorate some of the other issues clients may have as barriers to maintaining care. Xander shared his feelings about the agency: “I went to Nashville CARES. I love that place ... They actually took me to get my labs done the first time and get me in care. They got all my information. They told me everything that was available. I have taken advantage of a lot of those opportunities, a lot of that stuff. They really helped me a lot.”

When I spoke with Jeremy he had recently broken up with his partner and moved back home to Ohio. Jeremy was able to sign up for Ryan White coverage just as his employer-sponsored coverage lapsed so he was able to maintain his medication regimen. Had he not been able to get on Ryan White promptly he would have been faced with prescription costs of \$2,400.00 a month. What the move meant for Jeremy however was long commutes to see his HIV specialist.

Part of this moving process means now I've got to actually start getting my healthcare established in Ohio, which apparently is going to be a lot more difficult because my pharmacy specialist is telling me that I need to get into what they call a 'Center of Excellence for HIV Treatment' and, so for me that's like UK which is two hours away in Kentucky.

For Jeremy, who is in the midst of starting his own business, he still travels to Nashville periodically to meet with clients and to see his children. Since he established his treatment in Nashville and lacks a qualifying clinic near his

new residence, Jeremy tailors his schedule around doctor's visits and client meetings. He states: "I kept all my healthcare here, and organized my visits around when I'd be in for that training and visiting my kids." Kevin also commutes from his residence forty-five minutes north of Nashville to see his specialist. Kevin was advised by his primary care physician that there was no specialist in his city who he could see specifically for HIV-related issues. He says he does not mind the commute and it gives him a reason to visit Nashville every few months.

Jeremy and Kevin both have stable transportation and the means to afford the commute to seek aid from a specialist in Nashville, but this is a luxury that many do not have. Outside major metropolitan cities in Tennessee, like Nashville and Memphis, HIV-positive individuals face seeking treatment from general practitioners or making the commute to HIV specialty clinics in those two cities. While a general practitioner may be able to provide adequate care to treat HIV, many positive men hesitate seeking care for fear of stigmatization, especially in smaller communities (Arya et al. 2014; Berg and Ross 2014; Gillard and Roark 2013). Justin expressed having a certain level of comfort getting treatment at a renowned clinic which caters specifically to people with HIV. This comfort level not only manifested in a willingness to travel for doctor appointments, but for Justin it served as a type of anchor keeping him living in Smyrna, a small town south of Nashville.

Justin was diagnosed in 2012. He has been working as a nurse since he graduated with his bachelor's degree in nursing science a few years earlier.

Justin was born and raised in Clarksville, the same town north of Nashville where both Kevin and Sean are from. He has had issues with potential lapses in medical coverage, so despite a desire to move away he feels like he will “probably never leave” his current position working as a nurse for Veteran’s Affairs. Justin feels overall satisfied with the level of care he receives in Nashville, and is concerned not only with finding a specialized care provider if he did move, but with being “equally as satisfied with them.”

For Justin his serostatus acts as a tether which keeps him committed to maintain treatment with a service provider he is satisfied with. Disparities in access to quality care are attributed to the lower numbers (19%-25%) of HIVpositive individuals in the US who are virally suppressed (Kim et al. 2014). For those who live locally this is not much of a concern since the existing infrastructure appears to provide adequate care and services, but for those who have moved away or are considering moving away, leaving an established medical situation may seem a daunting task. The concern is not only in the ability to transfer care, but to receive the same level of quality of.

Charles, Kevin, Sean, and Xander do not have employer-sponsored health insurance, but they have access to an infrastructure which provides them with social service agencies which helps them to navigate the process of getting established in treatment. The network of agencies and governmental programs provide a safety net which helps HIV-positive people get healthy and stay healthy even in the event of a job loss, an out-of-state move, or even a vacation out of

the country. The CCC provides pharmacy services to patients. After having some issues with a local pharmacy in Clarksville Kevin started getting his HIV medication prescriptions filled at the in-house pharmacy. He told me about a time when he was concerned that he would run out of pills while he was out of town:

I went to Germany in March for two weeks, and I noticed that I was counting them out one day, and I was like 'I'm going to run out while I'm there.' And they, I called ahead and was like I need my pills before, but my insurance doesn't actually roll over until right before I leave and I can't wait until the day of my flight. And they said, 'well, we will mail it to you and just bill your insurance right then'. They were awesome.

There are shockingly high rates of diagnosed individuals who do not maintain care and viral suppression (CDC 2010). In the "Chronic Disease" era (Chu and Selwyn 2011) getting diagnosed is just the first step in a lifelong process of managing disease and illness effects. HIV is highly manageable as long as it is treated properly along every step of the continuum of care (Kim et al. 2014), and addressing this continuum of care involves focusing on the intersectional factors which contribute to inabilities to access and maintain treatment (Watkin-Hayes 2014). The allocation of care resources disproportionality impacts some communities over others, and *geography*, as much as race and class, has been shown to be an indicator of wellness outcomes (Martin, Strach, and Schackman 2013; Nunn et al. 2014). Sean and Kevin have had issues with lapsed insurance or unfilled prescriptions and Jeremy and Justin face long commutes to visit a specialized HIV clinic for treatment. These barriers to care can be extremely prohibitive for many HIV-positive people,

but when people are able to readily utilize these services, as the men I worked with have been, the expectations should be high. Justin and Jeremy both describe having very high expectations of care from other providers considering the exceptional care they have received thus far. This is a hopeful sentiment, and goes to show that when social services and healthcare providers coordinate efficiently the outcomes can be extremely efficacious.

SOCIAL NETWORKS

“I’m not really concerned with whether other people know or not, I mean, I’m not going to hide it, I’m not going to lie about it.”

- Jeremy, HIV-positive since 2014

Justin dropped out of high school during his senior year on account of persistent bullying from the “good ole’ boys” in his middle Tennessee high school. He went on to earn a general education diploma and decided to enroll at the local university to pursue a career in nursing. Justin was raised by a single mother from a working class background so when he decided to go to college he chose a field of study which would provide him with occupational and economic stability. He lived in a house off campus with two close friends during the last two years of pursuing his undergraduate degree. His living situation afforded him the ability to focus primarily on his education while working part time as a server.

After graduation he and his friends relocated to Nashville from Clarksville, where he was born and raised. He secured a well-paying nursing job and chose to live on his own, but purposely chose an apartment not too far off from where his two former roommates bought a house. Shortly after making the move two of his friends were diagnosed with HIV. When he got his diagnosis a year later it was to little fanfare: “In my close group of friends I already had two people that found out that they were HIV-positive. And, so, it was kind of old news.” Being the

third person in the close group of friends to test positive presented Justin with a unique situation which made him initially hesitant to confide in the group: “I have a group of friends who are very comfortable with the idea of HIV-positive individuals, however, they’re also a bit insensitive, and I wasn’t in a, I wasn’t in a joking mood, about it, so I kept it to myself.” Justin’s group of friends had always been a pillar of support in his life, and although he describes the initial experience of telling them that he was HIV positive as “awkward” the group continues to be very close.

Sean relied heavily on support from his friendship network in the early months after his diagnosis. “I had a really good group of friends, some positive and others not. They would go with me to all my appointments and things like that, and they were also there for me when I needed a shoulder.” Sean told me about a night he went out to a dance club with friends and met a guy he was interested in seeing again.

At the time it was really important for me to tell people right away, you know? Like, I’d rather have you know on day one than have to tell you after I already like you. I started talking to someone at the club and we hung out for a while and he asked for my phone number. I was really, really excited, but I knew I wanted to tell him right away. I did, and, he just said, ‘I didn’t know.’ He kinda just wandered off and I didn’t see him again that night.

When he got home, Sean crawled into his sleeping roommate’s bed and curled up next to him. He cried in his friend’s arms that night until he fell asleep. Sean describes the experience leading to a persistent fear or rejection and this leaving him feeling isolated from potential romantic partners in the gay

community. He eventually took to a strategy of *serosorting* (a sexual partner selection process which involves filtering out HIV-negative people) potential sexual partners to alleviate the potential for rejection based on HIV status alone. He did eventually find a negative partner who was comfortable with his status and they are still together today.

For Sean, Justin, Kevin, Charles, and Xander having close friends to support them, especially during the traumatic time after receiving a life-altering diagnosis, was important to their adjustment in the period after their initial diagnosis. These networks of close friends provide the men with emotional and instrumental support. Their close friends provided them with a shoulder to cry on as well as a partner to go along with them to doctor appointments and visits with social service agencies. With the exception of Jeremy and Xander the men have little contact with their biological families so they turn to their friends to fill gaps in the family role left by their biological kin. These gaps primarily stem from enacted stigma from their family rooted in fears of homosexuality, immorality, sexual deviance, and disease. In the absence of parents and other immediate family, friends become primary support for many gay, positive men.

Social Roles & Friends as Family

When considering the role of social networks in the lives of the men there is a striking difference between their relationships with their friends versus the relationships they have with their biological families. While they may have some

contact with their biological kin their primary support network is made up of friends and associates. These typically fall into two categories: the friends they have known for many years and view as family, or *fictive kin* (Muraci 2006; Stack 1974), and the *wise* (Goffman 1963:28) associates they view as sympathetic or as targets of their advocacy. These two groups provide differing types of resources to the men which help them cope with their illness. Disclosure to close friends tend to primarily be related to need for emotional or instrumental support. Disclosure to more casual friends and associates tend to be characterized as either reinforcing self-empowerment or as an opportunity to act as an advocate and educator for HIV/AIDS related causes. Disclosure to casual friends and associates will be addressed in the discussion of overall well-being, because I find that it plays a different role than disclosure to close friends.

While disclosure may lead to increased social support (Emlet 2006), self-efficacy and empowerment (Berg and Ross 2013), reduced drug abuse and depressive symptoms (Benotsch et al. 2011) the paradox is that disclosure also brings risks of social rejection and isolation (Bird and Voisin 2013; Moore and Amey 2008), rejection by potential sexual partners (Gillard and Roark 2013), and even potential criminal prosecution (Tenn Code 68). Often times not knowing one's status is an affirmative defense against criminal conviction, so this leads some to avoid testing altogether in order to maintain plausible deniability. The strain caused by these opposing forces and the decisions on whether or not to disclose all become part of the HIV-positive person's *moral career* (Goffman

1963:32). Disclosing one's HIV status can be a deeply traumatic act (Emlet 2006; Moore, Kalanzi, and Amey 2006) so there are careful calculations made when considering to whom and how one will disclose their HIV status. The potential availability of increased social support for concerns specifically related to HIV is contingent on the positive person being willing to disclose their status.

American cultural norms dictate that the primary providers of social support are immediate family (Gittins 1985; Lewin 1993; Muraco 2006). The nuclear family, constructed through marriage, reproduction, and/or adoption, is held to such an exalted status that it affords members within the group legal rights and privileges to each other which are denied to members outside of the nuclear unit (Oswald 2002). The sanctity of the marriage as the linchpin of the American family, and presumably American society, is so pervasive that the decision over who has access to this fundamental institution had to be decided by the Supreme Court (*Obergefell v. Hodges* 2015). The privilege afforded to family is ostensibly predicated on its ability to provide instrumental and emotional support to the members within the family unit. The assumption that families serve a foundational role in the individual's life comes from the expectation that familial bonds are durable whereas friendship bonds are assumed to be more flexible (Muraco 2006; Oswald 2002).

This narrow view of the family becomes problematic when members of the family abdicate their social responsibility. Lewin (1993: 974) argues against the expectation, "that deep and enduring commitments are only to be found in the

domain of kinship based on blood and marriage and that, by implication, ties between gay men or between lesbians are more likely to be ephemeral or artificial." Fictive kinship is not unique to members of the LGBT community, but rather are characteristically found among marginalized groups (Stack 1974). These intimate social networks function as a survival tool by those who do not receive emotional support, financial assistance, and/or care and are alienated from family (read biological) support networks (Muraco 2006).

Xander is working on overcoming a fear of needles which left him untreated for several months after his initial diagnosis, because a panic attack drove him from his first doctor visit.

I actually had to leave and come back to get my labs done. I got everything done but my initial labs. It was, I had what you call a panic attack. Or an anxiety attack. I was breathing really heavy. I started crying because they were getting ready to get me with this needle. And I just really ... I had to leave, because I was making other people uncomfortable.

Compared to the other men Xander has a relatively close relationship with his immediate family, although he is unique in that he just recently came out as gay to his parents and siblings. Despite the close relationship with his biological family, Xander first confided in his network of friends after his diagnosis. During the interview I asked for clarification in response to a disclosure story if he was referring to romantic partners and he responded, "Nah, Friends. Family. Borderline family, friends." Xander describes his close friends as "family" and they do fulfill the social role expected to be filled by bio-kin. He co-habits with his

best friend of over a decade (instrumental support) and he turned to his friends for encouragement and care after being diagnosed (emotional support). Justin and Sean also describe having had similar domestic situations. These fictive kinships ultimately were instrumental to Xander's health after he was chastised by friends for not going back to the doctor after leaving his initial visit on account of his fear of needles.

And I was telling them about it, and they were like 'so have you gone to the doctor yet?' I was like, 'I did but this is what happened.' So I pretty much told my friends that this is what happened when I went and they tried to get my blood from me. They were like, 'Xander, are you serious?!' I was wacked upside the head. 'Get your life together!' So it was with those same friends that I went back to the doctor with. Pretty much in January I had my arm out and I was breathing heavy and things, it was January 2014, and they was pretty much like, 'Xander, sit there. You've got to get this done now.' And my friend Gerald pretty much told the nurse to sneak attack me.

Gay men in this country have a shared *moral career* which involves stigmatization based on sexuality and assumption of infection – regardless of actual HIV status. This shared socialization provides a frame in which HIV disclosure to gay friends is done in the context in which there is a societal expectation that both parties involved in the disclosure may become infected with HIV. Additionally the intimate relationship existing between fictive kin affords the person on the other end of the disclosure a personal context in which to frame HIV which is not available to other gay men in the community who may not know the individual on a personal basis. "It is also plain that being able to identify an individual personally gives us a memory device for organizing and consolidating

information regarding his social identity - a process which may subtly alter the meaning of the social characteristic we impute to him” (Goffman 1963: 65). This shared moral career may provide a level of empathy regarding HIV which nongay family members do not have access to.

Parents and Other Family

Disclosure of one’s HIV status can be particularly problematic when that disclosure is made to one’s bio-kin (Bird and Voisin 2013; Harris 2010; Winstead et al. 2002). Telling close friends provides a social support network with peers who often share similar moral careers which primes them to be more accepting. Most of the men I spoke with are alienated from their biological families, so these fictive kin function in that role. Although the common perception is that biokinships are durable than friendships (Muraco 2006), it is estimated that 40% of homeless youth are LGBT and of those 68% cite family rejection as the cause of their homelessness (Durso and Gates 2012). Existing familial strain related to one’s sexuality can be further exacerbated by the admission of one’s HIV status. Charles shared his experience with this, “I called [my brother], and I was like, ‘hey, this is going on, you gotta’ talk to mom.’ And ever since that night he won’t talk to me. He won’t even take my phone call. And, he told me that she, it was another reason for her to write me off.”

Disclosure to close friends seems to be motivated by an intrinsic need for support. This need puts the confessor front and center in their disclosure and their admissions are with little concern for how it would impact their friend. Xander describes telling his friends as being “liberating.” The same need for support from family members was not needed, and disclosing to them was cited as a source of additional stress. A common reason for not disclosing to family members is the need to avoid worrying them (Moore et al. 2006; Winstead et al. 2002). Justin explains why he decided to not tell his family: “They don’t know, because it’d just be something that they would worry about, and it wouldn’t affect, it wouldn’t make me feel any better for them to know, and they wouldn’t feel any better knowing, so I just keep it to myself.” Jeremy shares a similar sentiment:

I don’t want them to fear for me, and I don’t want them to have to stress about it. I don’t think that they need to. I’ve already determined that I’m not telling my grandparents under any circumstances. They are 89 years old and they will not understand it. It will confuse them and scare them. And I don’t need them to live their last years thinking about that when I’m healthy and as long as I’m healthy it doesn’t need to be a big deal.

Despite having strained relationships they express concern over worrying their parents needlessly. Jeremy and Xander employ a technique of *impression management* (Goffman 1959) in which they predicate parental disclosure on wellness. Jeremy laments not having a closer relationship with his mother and thinks that telling her will help strengthen their relationship. He expressed to me that it is becoming increasingly more difficult to converse casually with her without mentioning HIV in some way. The day of our meeting Jeremy had just

received the news that his viral load was suppressed to undetectable levels. For him, a promise of health will help his mother adjust to the news:

Today has given me the means to do it, so I can soften the blow and say look I'm already undetectable and perfectly healthy. We've already managed this, we got this nipped in the bud with two months of meds. So that will help facilitate that conversation. That was a big relief for me.

Xander, the only one of the men who disclosed his HIV status to most of his family, waited until he was on treatment and his viral load had dipped to undetectable levels. He first told his mother, and although he feared telling his father he had motivation to tell him while he is healthy.

My mom prompted me to tell my dad. I was a little afraid to tell him. Just a hair, because the way his mother passed. His mother didn't tell anybody that she had cancer. And when she told him it was, she died like a week later. So when it comes to stuff like that, my dad doesn't really do well with finding out about that stuff. So I wanted to make sure that I told him long before anything ever happened to me. And I can say that there's not really a lot of copies of it in my blood. So you don't really have anything, you know, to worry about. I take my medicine. I'm here.

The conception of what HIV/AIDS was at the height of its visibility, for many people, is still emblazoned on their minds. As I discussed earlier, the unique socialization of gay men in America primes them to have an awareness of the ever-evolving HIV/AIDS epidemic. Some in the research and advocacy field discuss the stages of the epidemic going from being focused on the *disease* of HIV/AIDS to the *illness* of HIV/AIDS (Vaswani and Vaswani 2014). The shift of focus on illness puts the focus more on the social role of HIV/AIDS as well as chronic disease management which incorporates dealing with co-morbidities and

aging (Chu and Selwyn 2011). The shift in focus in the HAART era is in sharp contrast from the period of crisis management and treatment of acute symptomology.

Despite the hopeful prognosis that the men in this sample have, thanks to their access to quality healthcare, the rest of the world has not been forced to catch up with what it means to have HIV three decades since the horrifying images of the sick and dying were the hallmarks of HIV. While there is legitimate concern from parents and family about the health of their loved ones, some of the men worry that already contentious relationships with their family members will become volatile if they found out about their HIV status. Kevin describes why he has not told his family:

Well, I, still to this day I have not told anyone in my family. And I'm not really close with them anyways over the gay thing, but I had, for one I hadn't told them because I knew my father's first words would be 'I told you so.' And then, to me, I won't let any negativity surrounding it come into my life. And it's not, all they would see out of it is the horror from the eighties. And that's all they would receive about it, they would receive like how it is today. You know, nearly 30 years later.

Kevin's hypothetical fears of being doubly rejected by his family for being both gay and HIV positive turned out to be a very real experience for Charles. Charles was tested for HIV during a routine physical while he was in the Air Force in 2011. After getting confirmation from bloodwork after his initial mouth swab he was called to his admiral's office and was honorably discharged, because of his medical condition. Air Force policy does require mandatory HIV screening. While the official policy of the Air Force states that active duty

members cannot be discharged based on HIV infection alone, there are caveats built in the policy which allow discharge if the active duty member is deemed unfit for duty (AF 2010). Charles tried to maintain contact with his family, but most of his family including his mother and brother had “shunned” him upon him coming out as gay.

After his discharge from the Air Force Charles spent some time living with his aunt. He initially hid his HIV status from her, but when she discovered his prescription bottles and confronted him Charles decided to tell her. After an incident at his aunt’s pool with friends and family members, she asked him to leave her home. Charles’ aunt expressed anger over the fact that he chose to hide his HIV status and cited it as one of the reasons why she asked him to leave. “She’s like, I don’t care that you have it, you know, I didn’t care that you were gay, I already knew that you were gay ... and she said, and then, you know, you weren’t open about that. I think what got her the most is the fact that I didn’t tell her.”

Charles’ social identity was so “contaminated” that his family members were able to rationalize removing him from their lives. Goffman (1963) describes stigma as so deeply discrediting that it becomes reductive to the personhood of the stigmatized individual. Stigmatized persons face multiple barriers to negotiating their stigmatized role, especially for those stigmas which are seen as a blemish of an individual’s character, like homosexuality. HIV’s conflation with gayness situates the illness in a stigmatized context which links one’s infection to

moral failing. The stigmatized person then who is *discovered* concealing their status is viewed as practicing the immoral behavior patterns they were trying to avoid being labelled with, “hence justification of the way we treat him” (Goffman 1963: 6). For Charles his dishonesty caused him to be rejected by his only sympathetic family member. His dishonesty was seen as proof of his poor moral character.

The role and composition of the family for gay men often times do not fit within normalized social constructs. The need for support drives many into networks of fictive kin (Muraco 2006; Weston 1991). These networks become particularly salient for HIV-positive gay men, because gay peers can provide insight and understanding that is lacking from those not in the community (Gould 2009; Ueno and Adams 2001). Other research (Hays et al. 1990) suggests that some gay men turn towards family as their health worsens. Considering the life expectancy of HIV-positive men now, relative to when that research was done, this may no longer be a legitimate finding. Either way, this does not appear to be the case for the men within the first five years of diagnosis. For now friendship networks are the primary providers of social support.

WELL-BEING

“I have a lot of positivity around me. Uhm, my faith reassures me of a lot of things. And, you know, good doctors of course always helps.”

– Xander, HIV-positive since 2013

I met with Xander on a Thursday afternoon in the food court of a local mall where he works. He is heavily involved in his church, starting his own ministry as well as singing in the choir. Between all the commitments in his busy life I was thrilled that he was able to carve out a window of time to speak with me after work. Xander describes having very little knowledge about HIV prior to receiving his diagnosis. He credits Nashville CARES for educating him and providing him with resources and information at the time he was diagnosed. He told me that one of the first things he was told by social service workers and medical providers is that HIV does not have to be a death sentence. Despite this reassurance, Xander still feared for his ability to have a future.

I was afraid of dying. I just had really bad crying spells. Like, I was working at a salon and a couple would walk past and they had a baby in their front cart and I would break out crying, because I knew that would never be me. I would never be able to have a kid. Uhm, I just knew. I just felt like my life was over ... I knew people were really dying from this. And, I just knew that I just did not want that to happen to me.

Despite his initial anxieties Xander has been able to get to a place where he is optimistic about his future health and wellness. When transcribing his

interview I was struck by the difficulty Xander had in answering my questions about the major negative impacts of HIV in his life. He stammered and *uhmed* for many seconds, before finally answering, “other than my ability to reproduce and that’s about it, but now there’s even ways around that.” In a way that I had not consciously realized at the time when we were speaking, he labored to answer this question, and even found a way to negate the potential negative impact, because of his awareness of his situation. Xander also spent a lot of time stressing the importance of the role of the church in his life. For him, his faith provides him with reassurance, but the *community* he shares around his faith provides him with an opportunity to express agency over his situation.

For Xander, Charles, Jeremy, and Kevin they came to a point in their *moral career* where they not only accept their diagnosis and *illness*, but they began to see it as a platform in their lives to help others. Goffman describes this point of acceptance as being the final phase in which the stigmatized person becomes mature, well-adjusted, and accepts and respects himself to the point where “he feels no need to conceal his failing” (1963:101). Xander’s respect and acceptance is illustrated in his disclosure to the congregation at his ministry.

Me and my roommate Gerald have a, had a ministry that we were founders of. At the, at one of the services that we held I pretty much got up and told everyone, because no one really talks about this stuff at church. And, I wanted to do that, to bring awareness to people for a lot of different reasons. Uhm, I pretty much got up and said it, and I was like you know, it’s more of a situation, it gets real when you, when it’s somebody that you know. It gets very real to people. I don’t think people are as aware as they should be to it. I don’t really think that they are and it’s not until, ‘wow, he’s been leading worship all this time, he’s been singing all this time with so much conviction, he’s been walking around dealing with this at 25, 24 years

old. Man, that makes me want to go get checked.' Because a lot of people believe that when you, when you have cancer, all those things that you know, things like that, they feel like God is punishing them, and I have to reassure them that this is not a punishment, God is not going to get you for making mistakes. You are not the mistakes that you made.

He went on to tell me that the reason he feels the need to be an out advocate is that he does not want anyone going through what he went through when he was diagnosed. For Xander, Jeremy, Kevin, and Charles the gains from being open about their status offsets potential consequences and contributes to them framing a positive self-image because of their ability to view themselves as being part of a larger social justice cause.

Attitude, Advocacy, and Knowledge

Well-Being is an amorphous concept with no universal definition (Igreja et al. 2000; Jia et al. 2007; Ramierz-Valles et al. 2005). While addressing issues of access to care and social support was straightforward, my conceptualization of the well-being dimension was fairly vague until I scoured the data for emergent themes. Having quality medical care and a network of supportive kin are contributors to overall well-being, but these two dimensions are distinct and clearly defined. What emerged in the time I spent with the data was a theme of self-efficacy and self-empowerment which was a distinct coping mechanism from treatment and support. The utilization of adaptive coping techniques has been found to buffer some of the harmful physical and mental health impacts of HIV

(Earnshaw et al. 2014). Affective and empowered well-being manifested in three ways: Attitude, Advocacy, and Knowledge. Xander's experiences summarily describe how these three measures of well-being provide him the ability to redefine his stigmatizing label.

A risk of accepting a stigmatized identity is the internalization of stigmatizing beliefs held by others (Bird and Voisin 2013; Emlet 2006) as well as the beliefs of the stigmatized person themselves (Goffman 1963). Because none of the men in this study were born with HIV, and they all contracted the virus at a point in life when they had already formed attitudes towards and about HIV, they embarked on a process in their moral careers where they had to reconcile their existing beliefs about HIV with their new reality. We are all products of our socialization through our interactions with social objects (Blumer 1969). Those interactions do not happen in a vacuum, so we typically will adopt the attitudes and beliefs of those around us, which in our formative years are those from parents and older relatives (Mead 1934). So when we have negative attitudes towards a particular social *status symbol*, beliefs often held by those around us, and then find ourselves threatened with having to receive that stigmatized status symbol there is a process of incorporation. Goffman (1963: 32) describes this process:

One phase of this socialization process is that through which the stigmatized person learns and incorporates the standpoint of the normal, acquiring thereby the identity beliefs of the wider society and a general idea of what it would be like to possess a particular stigma. Another phase is that through which he learns that he possess a particular stigma and, this time in detail, the consequences of possessing it.

So how then do the men deal with internalizing a stigmatized identity? For Kevin, Justin, and Jeremy the process happened without excessive trauma, because they had already framed HIV in their minds not only as a possibility, but also *not* as a life-ending diagnosis. After an acute grieving process they adopted an attitude which gave them agency over their lives and their health. The process of *adaptive coping* provides an avenue for discriminated individuals to take on an active role in maintaining their well-being (Earnshaw et al. 2014; Ramirez-Valles et al. 2005). Kevin describes the moment he decided that he would take control over his situation:

I think I was just in shock the first few days. I had to go to work that day ... I was just like, I thought probably I should call out of work and not go there. But I was like, you know this is how it starts. This is how, if I let it affect me now I will give it the power to continue to affect me. So, I'm, not that first day, but maybe that second or third day, I remember screaming in the mirror at myself saying I'm not going to let this affect me. I'm gonna take action now.

Jeremy also adopted a self-deterministic attitude after his diagnosis: "I can't allow myself to fall too far into regret. That would be toxic. Uhm, I can't do that. I've got responsibilities now. I've got my kids to think about. I got a business to start. And dwelling on the fact that I have HIV is not going to help me or anybody else." The privilege of being able to choose a non-fatalistic attitude seems to also be related to the awareness that HIV is highly treatable and that with ideal circumstances life expectancy for HIV-positive people is congruent with the general population. In the *chronic disease era* (Chu and Selwyn 2011) the

expectation of survivability affords the men the privilege to compartmentalize HIV in their lives as a series of treatments and pill schedules which has little impact on their daily functioning. Justin drew analogies between other chronic health issues and HIV: "It's one more piece of luggage that I carry around with me ... other things that I deal with are depression, or uhm, laziness, and those are things that I can overcome or cope with. It's manageable, until it's not. So, I don't know. I don't have too many long, deep thoughts about it." Kevin shared a similar sentiment: "This may be a virus that may kill me, but I'm going to treat it like something to empower me."

These men benefit from having varying degrees of interaction with HIV and HIV-positive persons prior to their infection. Jeremy and Kevin both had relationships with HIV-positive men. Justin and Sean have close friends who are HIV-positive. Extant interactions with illness divorced from social and cultural depictions of HIV/AIDS is shown to ease one's own diagnosis (Jackson 2009) and this was particularly true for these men. Charles not only had little knowledge about HIV/AIDS, but he also adopted highly stigmatizing views towards HIVpositive people. "So, I thought by me and you sitting down and having a conversation like this, I'd have to go home take like a shower and wash myself and have to go get tested, just because all we're doing is sitting here talking." He went on to tell me about how he had acquaintances who he learned were HIVpositive and upon learning this information he began actively distancing himself from them: "I did distance myself from them, because I didn't know ... like

... I wasn't, I wasn't educated about it. I didn't know how they got it. I was scared to ask questions about it, and I'd much rather leave it alone."

Charles' initial fatalistic reaction seems to be as equally predicated on fear for his health as well as a fear that he would be treated poorly by others. Charles saw his diagnosis as a cosmic comeuppance for past cruelty, "That's what I use a lot. It's a lot of this stuff is karma, because I was bad to people." Goffman (1963) describes this reconciliation process as happening early in one's moral career. We are aware of how others may view us and our moral failings, and because we may share those same attitudes we may begin to agree about our moral failings. Not all of Charles' apprehension was unwarranted. In addition to his bio-kin turning away from him he had friends who did the same:

Like, some of my friends, as soon as I would tell them, they weren't my friends anymore. I could call them all day and leave them a message, Call them, and give them a text message, whatever, nothing ... And they're like, you're just going to be another one that's going to die before we reach the age of 30 ... 'cuz I didn't take care of myself. It kinda hurt.

Charles tells me that he internalized this blame and described his diagnosis as being his "fault." The negative reactions he received came to be a humbling experience for Charles. He expresses remorse and laments his treatment of others, and he chooses to credit his post-diagnosis experiences with making him a better person:

Being positive has made me come out of my shell more than I probably would have had it not. I woulda still been an asshole, I woulda still been a dick, I would still been the guy that I was then, and at that time I didn't care. I was freely who I was,

but I was a different person at that time, I was, to me, I was an asshole to everybody it seemed like. Like, if you weren't in my inner circle, don't talk to me.

Kevin, Xander, and Sean adopted a similar attitude towards their HIV status. They came to it at different times and in their own ways, but the common thread was that they chose to frame HIV as somehow contributing to, and not taking away from, their lives. The ability to choose a positive attitude is helped by having knowledge on what it means to have HIV. Charles and Xander experienced great difficulty with their initial diagnosis, because they did not know anything about HIV. They both attribute part of their ability to adopt an optimistic attitude to being educated on the *actual* prognosis for HIV as opposed to what they thought it would be.

The suggestion that a high level of knowledge regarding one's illness contributes to better overall well-being and self-efficacy is supported in data (Chu and Selwyn 2011; Kalichman et al. 2006; Kim et al. 2014; Shahani et al. 2012). The argument is twofold. On the one hand, actively engaging with the latest medical information can be utilized as an adaptive coping mechanism which provides a sense of self-empowerment, as well as hope. "I like to visit different websites every so often and see what the latest word is on, uh, on treatment and things like that. I like to see that progress is being made, you know? I also can sometimes bring questions about things I read and talk about them with my doctor when I see him," Sean told me. Engagement with one's own care also provides physical benefits as well. As part of the continuum of care for chronic

illness it is recommended that patients be aware of their infection and be actively engaged in HIV care (Kim et al. 2014). High levels of education are also attributed to people's ability to understand and interpret health information as well as promoting wellness and health care seeking behavior (Shahani et al. 2012). In addition to the personal benefits of maintaining a knowledge base of information about HIV pathology and outcomes, this information is also often utilized as a point from which the men engage in active HIV/AIDS advocacy within their communities.

Engagement in advocacy has been shown to provide myriad benefits towards mitigating mental and physical health issues as well as overall well-being (Kobasa 1991; Ramirez-Valles et al. 2005). Some of the participants engage formally with HIV/AIDS outreach services as volunteers while others use disclosure as a means of educating and advocating to peers and colleagues. Durkheim (1897[1951]:167) documents the role that social integration plays in providing a protective force against alienation. He attributes the accountability held toward the group as superseding the individuals "private interests" or *egoism*. This was demonstrated in the earlier discussion of Xander facing his fear of needles only after disclosing his status to his friends. In that particular discussion of social support I omitted disclosure to casual friends and acquaintances in order to preserve the discussion for here. The reasoning for this is that the men disclosed to close friends and fictive kin to *receive* support. The trend I observed in disclosure patterns outside of primary social networks tended

towards a desire to give back or support others. At this point the progression of the *moral career* reaches what Goffman (1963:102) sees as the final stage where disclosure of one's stigmatizing symbol is rooted in self-respect and acceptance.

Jeremy, Kevin, Charles, and Xander expressed a sense of duty to use their public disclosures as a tool for activism. The utilization of self-disclosure frames the discussion of issues surrounding HIV/AIDS in such a way that people are compelled to acknowledge the *humanness* of the illness and potentially reframe their thinking (Goffman 1963). This approach is particularly true for Xander. Like Charles, at the time of his diagnosis he knew very little about HIV and had deeply internalized stigmatizing ideology: "I felt unclean, almost. Uhm, I felt like people would judge me based on how I got it. And so I really didn't tell anybody, because I didn't want that type of judgement to fall down on me or any of my friends." Xander describes drawing on his own prejudices as reason for being a visible advocate, because he does not want other people to go through the same fear or shame he experienced when he received his diagnosis.

Jeremy's own experience of being rejected for a life insurance policy on account of his HIV status reignited a lifelong passion for social justice which he says he "never really ended up doing." During a discussion with his neighbor the topic turned toward the urgency of getting life insurance. He used this opportunity to describe his own experience with applying and being rejected for life insurance. Jeremy is highly educated and feels that he has a lot to offer to advocacy, so much so that he is using his own experience as a starting point

from which to create a non-profit called 'HIV for Life Insurance' which advocates for qualifying HIV for life insurance. Jeremy's goals are right in line with the new era of HIV in which outmoded policies are being questioned and confronted. Just recently in 2014 the CDC lifted the ban on gay men giving blood, a policy rooted in the acute-AIDS era fervor over transmission fears (Tavernise 2014). As an aside, gay men are still held to a highly restrictive standard of sexual abstinence which effectively disqualifies a large portion of the gay population from donating blood.

As discussed earlier, the common refrain from healthcare providers is that HIV is more manageable than diabetes. Although, as Jeremy notes, the standards and practices of the insurance industry are not cognizant of the latest medical view: "Because you know, diabetes, you can get life insurance with diabetes, because it's considered a manageable disease. HIV is still not cleared for life insurance, because it's still considered a terminal illness by the life insurance industry even though it's become a manageable disease." (While some life insurance options, like specialized *high risk* policies, have become available to HIV-positive people in the past few years they are typically highly cost prohibitive (IIA 2015).)

At the root of Jeremy's initiative and Xander's public disclosures is the goal of changing antiquated perceptions of HIV. The goal is laudable and timely considering that more than a third of young people express stigmatizing attitudes towards HIV (Kelton 2014). In addition to this grass roots educational activism

many of the men are involved with organized volunteer opportunities. Kevin participates in a meal delivery program for infirmed clients at Nashville CARES. That organization sponsors an annual 5K walk and run to raise money and he is running in that as well. Charles also participates in fundraising for the AIDS 5K and sees it as an opportunity to give back.

I raise money for the AIDS walk and stuff like that since I found out, 'cuz it goes for research and for some people who, unlike me, my insurance pays for my medication. I went to CCC to get it and stuff like that, and I still have to pay for it out of pocket, some of it, but some people can't afford it. Period. They can't afford, even to pay 20 or 30 bucks for it, you know.

Participation in these formal community engagements also helps to provide a sense of social support for Charles. He had a particularly difficult time with his early diagnosis and experienced rejection from friends as well as family, and he found some solace in the community of people he met in his philanthropic engagements. Involvement with community organizations has been shown to be a "resilience resource" in confronting anticipated and enacted stigma (Earnshaw et al. 2014; Kobasa 1991).

The data suggests that the men are overall experiencing high quality of well-being. In regards to their access to quality healthcare and social support networks they are a homogenous group. They are also consistent in the engagement of adaptive coping in which they choose to frame their illness not as an impediment, but as a source of purpose and meaning in their lives. They also utilize disclosure as a tool to engage in activities which promote

selfempowerment, a technique which has been documented by other researchers (Berg et al. 2013). At the close of our interview Kevin shared a final optimistic declaration: “I turned a mistake into a learning opportunity ... this is not the 80’s anymore, testing and early treatment are so important. This may not be curable, but I’m not going to let this beat me up.” I would argue that the type of resilience expressed by the men I worked with is attributable to their maintenance of their well-being by engaging in education, advocacy, and having a purposefully defiant attitude. The data I collected seem to suggest that these components help these men ascend from a point of simply surviving HIV, but thriving with HIV.

LIMITATIONS AND FUTURE RESEARCH

The intent of this research is not to offer a generalizable paradigm by which we can attempt to understand the experiences of HIV-positive people. My sampling method precludes any generalizability. Justin and Sean were recruited from my personal social network. I was diagnosed with HIV prior to Justin and Sean and they saw me through my diagnosis. They may have benefited from my experience and knowledge with local service agencies and healthcare providers. There is a trend toward activism and community involvement with Kevin, Charles, and Xander. This *activism bias* most likely influenced the type of people who were willing to speak with me. HIV-positive men who were already actively involved in community engagement were likely more willing to participate in this work as part of their greater activism agenda. Acknowledging this fact, I would add the caveat that the men who are engaged in activism all admitted that their community involvement (of any kind) was predicated on their HIV-diagnosis. So, while not all HIV-positive men will engage in this type of work, for these participants activism manifested as a type of coping mechanism.

Future research utilizing a similar episodic qualifier should focus on different demographic cohorts. The participants in this study all benefited from having employment, transportation, insurance, access to care, and social support. Their experiences indicate that for those who can have support needs met the first years post diagnosis can be navigated without extensive trauma.

Future research should investigate how women, heterosexual men, trans-people, members of various ethnic minorities, or other cohorts cope with early HIVinfection. There is existing research which suggests that gay men may be uniquely able to cope with issues surrounding stigma versus heterosexual men, because they hone these coping tools over their lifetime (Missildine, Parsons, and Knight 2006). Researchers may investigate if this existing stigma association is present in other stigmatized cohorts.

FINAL ANALYSIS

In the time I spent with the men in this study I have learned that they all have some traits in common which can be viewed as contributing to their success so soon after their HIV diagnosis. Some of these factors are external and rely on an effective treatment infrastructure and access to this infrastructure. For example, a couple of the participants take long commutes from where they live to visit their HIV specialist. Although the care received at this specialized clinic is lauded across the board, accessing care at this clinic can be extremely cost-prohibitive for some people. It is estimated that the availability of these clinics will dwindle in the coming years so primary care physicians are called forward to engage in “shared care” initiatives and utilization of remote technology as tools to widen the breadth of quality HIV care beyond the specialized clinic.

Although having employment, insurance, and transportation is important to helping the men overcome these difficulties, material factors are not always the most salient inhibitors to accessing care (Tobias et al. 2010). The men in this research also benefit from having access to supportive social networks. Even though sexuality has caused strain in relationships with biological family for several of them, the men have built networks of fictive kinship on which they rely for material and social support. Access to care and social support may make it easier for the men to adopt the attitudes which contribute to their overall wellbeing. Several of the men told me about very specific instances where they made deliberate decision to not be taken over by their illness. They maintain their

agency by engaging in activism and advocacy and being available to others who may need to draw from their knowledge and experience.

Implications

These findings illustrate that in the presence of an effective healthcare infrastructure HIV can be a highly manageable illness. Regarding public health policy, increasing access to HIV-care specialists and drugs in rural areas would help to assist underserved communities. There are already calls within the healthcare community to increase cooperation between HIV-care specialists and primary care physicians (Chu and Selwyn 2011; Kim et al. 2014). An aspect of effective healthcare engagement for the men I worked with is a level of comfort with care providers. Stigma from non-specialized care providers may prevent some HIV-positive individuals from initiating and continuing care. Educational outreach from HIV/AIDS-centered social service agents to rural care providers may help alleviate enacted stigma from these care providers.

Support from close friends was the primary means of social support for the men I worked with. These kinship networks provided them with emotional security against perceived and enacted stigma. The implication here is that HIV/AIDS education efforts need to reach beyond just those considered at high risk for infection. Support from peers is instrumental to the well-being of those infected with HIV, so creating a public consciousness about HIV will increase infected persons' access to sympathetic allies in the general community. This

level of educational awareness is particularly salient in light of research showing that young people are poorly informed and hold stigmatizing attitudes towards HIV and HIV-infected persons (Kelton 2014). The relative invisibility of HIV in the modern era is a testament to medical advances, but visibility is needed to keep the population engaged and to reduce misunderstanding of the illness.

Conclusion

The stories of these men are not meant to be representative of any larger cohort. Because of the sampling techniques there is a high chance for bias. It may be easier for someone who is living well with their diagnosis to speak about their experiences. During my recruitment efforts I was politely rejected by several men, so their stories are not known. However, what can be taken from these narratives are ideas and suggestions. We are currently in a time in this country where we have the medical technology, resources, and infrastructure to make living with HIV seem so manageable that some doctors say they would rather have HIV than diabetes. This type of rhetoric would be unheard of just a decade ago. This rhetoric is hopeful. But despite it, there are still many people who fear for their lives in the presence of HIV. The men in this study, as well as their families, feared that their lives would be over. There is still the fear that they would succumb to the wastes and ravages of AIDS like the images of men they had seen on screen and in print many years ago. These depictions are not common in the media any longer, but their impact is lasting. The irony of the era

in which HIV is considered chronic and manageable is that for those whom it does not impact there is very little exposure to what it means to live with HIV. Because of this, the old tropes of HIV/AIDS persist.

The stories of the men I worked with are hopeful. They are early in their lives as HIV-positive people. But with continued success they can all expect to lead healthy lives. These men are all caught at the perfect intersection of support, employment, and geography. Other studies have shown how quickly health can diminish when even one of those pillars are removed. As these men continue on in their lives they may face unforeseen difficulties. Fictive kinships can be susceptible to fracturing just like biological ties. Jeremy, Sean, Kevin, and Justin have already faced difficulties with maintaining care. These difficulties may manifest again as the men may deal with job loss or other disruptions in their lives. For now they have the tools and resources to face those challenges. At a time when HIV infection meant certain death this kind of research could not have been completed. We now view the past three decades of HIV in America as progressing from acute infection to chronic management. This progression also means that we must begin to understand and investigate the unique difficulties which HIV-positive people face during different temporal periods in their lives. The next five years may look different than the first and the five after. The era we live in allows researchers to investigate these segments of lives in a way which was not possible before. This thought should be hopeful to other HIV-positive people as well as prospective researchers.

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APPENDICES

APPENDIX A
IRB APPROVAL



4/22/2015

Investigator(s): Marcus Brooks and Foster Amey

Department: Sociology

Investigator(s) Email: mb6c@mtmail.mtsu.edu; Foster.Amey@mtsu.edu

Protocol Title: "The first five: Narratives on coping and living with HIV "

Protocol Number: 15-275

Dear Investigator(s),

The MTSU Institutional Review Board, or a representative of the IRB, has reviewed the research proposal identified above. The MTSU IRB or its representative has determined that the study poses minimal risk to participants and qualifies for an expedited review under 45 CFR 46.110 and 21 CFR 56.110, and you have satisfactorily addressed all of the points brought up during the review.

Approval is granted for one (1) year from the date of this letter for **15 (FIFTEEN)** participants.

Please note that any unanticipated harms to participants or adverse events must be reported to the Office of Compliance at (615) 494-8918. Any change to the protocol must be submitted to the IRB before implementing this change.

You will need to submit an end-of-project form to the Office of Compliance upon completion of your research located on the IRB website. Complete research means that you have finished collecting and analyzing data. **Should you not**

finish your research within the one (1) year period, you must submit a Progress Report and request a continuation prior to the expiration date. Please allow time for review and requested revisions. Failure to submit a Progress Report and request for continuation will automatically result in cancellation of your research study. Therefore, you will not be able to use any data and/or collect any data. Your study expires **4/25/2016**.

According to MTSU Policy, a researcher is defined as anyone who works with data or has contact with participants. Anyone meeting this definition needs to be listed on the protocol and needs to complete the required training. **If you add researchers to an approved project, please forward an updated list of researchers to the Office of Compliance before they begin to work on the project.**

All research materials must be retained by the PI or faculty advisor (if the PI is a student) for at least three (3) years after study completion and then destroyed in a manner that maintains confidentiality and anonymity.

Sincerely,

Institutional Review Board

Middle Tennessee State University

APPENDIX B

INTERVIEW PROTOCOL

Demographic Information:

Age?

Level of Education? Occupation?

Sexual Orientation?

Initial Diagnosis:

When did you receive your diagnosis?

Why did you get an HIV test?

- Routine testing or post-possible exposure?
- Were you alone? If not, who was with you?

What was your initial reaction upon receiving your test results?

- If someone was with you, what was their attitude?

Did you receive educational materials at the testing facility?

- Were you provided contact information for medical providers or community outreach organizations?

How were you treated by the test administrator?

- Before and after testing?

What was your response to diagnosis in the following days?

- Did you experience Shock? Depression? Anxiety? Isolation?
- What did you do to cope with your diagnosis in those first days?

How much did you know about HIV before your diagnosis?

- Do you have any positive friends/family/associates?
- Did you do any research after getting your test results? ○ If so, did what you learn change how you felt?

What were your major concerns after receiving your diagnosis?

Disclosure:

Tell me about the first person you told about your HIV status.

- How long after diagnosis?
- Who did you disclose to?
- Why did you choose this person?
- Did you have any hesitation to disclose to this person?
 - Concerns about rejection or privacy?
- How did this person respond?

In what circumstances do you feel the need to disclose HIV status?

Who have you disclosed your HIV status to since?

- Friends? Family? Co-Workers? Intimate Partners?

Why did you feel the need to disclose to various people in your life?

- Friends? Family? Co-Workers? Intimate Partners? Who have you not told about your HIV status?

- Why not?

Is there anyone you regret disclosing to?

- Why?

Access to Care:

Do you get regular treatment with a medical provider?

- If not, why?
 - o What barriers do you have in getting treatment?
 - Insurance? Appointments? Transportation? Other?
 - o Have you sought aid from social service providers?
 - If so, what was your experience like?
- If so, what was the process of finding healthcare provider like?
 - o Did you have hesitation to visit healthcare provider? Why?
 - o HIV/AIDS specialist or general practice?
 - o Are you satisfied with the level of care that you get?
 - o Do you feel like your healthcare provider treats you badly, because of your HIV status?
 - o Do you ever have problems affording medications or appointments?

Do you have other healthcare providers (like a dentist) that you have disclosed to?

- o Why or why not?
 - If you have, was there any reaction?
 - Do you feel like you are treated differently?

Do you ever avoid seeking medical care, because you fear how you will be treated?

Well-Being:

How often do you think about HIV in your day-to-day life?

- When you do, why?

Do you worry about being discriminated against, because of your HIV status? - Why or why not?

Have you been hurt by someone's reaction to your HIV status?

- Do you ever think people are afraid to be around you?

Do you feel that people blame you for having HIV?

- Do you blame yourself?

Do you avoid making new friends, because you have HIV?

Does your HIV status impact your relationship status?

- Do you seek out positive partners?

In what ways do you think HIV has negatively impacted your life?

- Financially? Emotionally? Access to support networks? If what ways has HIV positively impacted your life?

- Have you gained friends?

- Are you involved with any volunteer or service organizations?

- Have you gained access to community?

- o If so, have you been able to incorporate your old friends with your new?

Are you optimistic about your life?

- Why or why not?

Do you think HIV will be a larger part of your life as time goes on? -

- Why or why not?

Any other comments or information you want to share?