

Stigma in the Post Crisis Age: external barriers to accessing HIV treatment, internalized
trauma, and strategies of support in Orlando, Florida

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Abstract

In 2017, The CDC (center for disease control and prevention) released a memo confirming popular medical opinion that an HIV positive person with an undetectable viral load was unable to transmit the HIV virus. While treatment and prevention options are advancing, this advancement may not translate directly into reduced stigma, which is produced and reproduced by external barriers to accessing healthcare, and internalized by HIV positive people as emotional trauma. This research explores the relationship between the availability of contemporary resources for the treatment and prevention of HIV/AIDS, and the environment of stigma experienced by positive gay and bisexual men in Orlando, Florida, a city among those leading the nation in new infections. The study found that structural barriers to access, such as a lack of public transit and the high price of medications, created an uneven distribution of available treatment and resources. It also found that both external experiences of stigma and exclusion, and social and cultural attitudes about queerness and HIV transmission, caused HIV positive gay and bisexual men to internalize trauma. Finally, the study revealed that HIV positive gay and bisexual men approached the management of stigma using various strategies, most commonly focusing on the formation of communities and safe spaces, which were largely determined by personal preference and life experience.

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Chapter 1 Introduction

“It is bad enough that people are dying of AIDS, but no one should die of ignorance.”

-Elizabeth Taylor

Known as one of the fiercest advocates for HIV/AIDS related issues during her lifetime, Mrs. Taylor’s words have not dulled in their relevance and importance over the decades since the early years of the AIDS epidemic. Though treatment options and available resources for the maintenance and prevention of HIV have developed to an unrecognizable level since the early 80’s, knowledge of the enormous impacts those changes have made on the physical quality of life and general risks of transmission for those living with HIV is still sorely lacking within the general population of HIV negative people. Stigma related to HIV continues to persist in spite of contemporary medical realities of treatment, contributing to social and structural barriers to accessing available resources and manifesting in the lived experiences of HIV positive people.

The experience of stigma as well as the kind of issues surrounding the availability of modern medical treatment for HIV, is largely dependent upon where those things are situated geographically; additionally, it is affected by the nuanced socio-political, economic and cultural contexts of the area. Ronny, a professional advocate and administrator of resources for the local HIV positive community in Orlando, Florida, offered some insight about this in an interview about the contemporary experience of living with HIV.

Well things have changed a great deal here. I think that this being the South, the influences surrounding HIV are different than they are in urban areas or major urban areas of the country. For a number of reasons. Financially, lack of mass transit, education, the lack of the Medicaid expansion down here prohibits a lot of people from entering service and maintaining services to fight HIV. So geographically each location is somewhat unique to the situation of HIV. (Ronny)

This research focuses on the relationship between contemporary medical realities of HIV treatment and prevention and individual experiences of stigma amongst gay and bisexual men in Orlando, Florida. Semi-structured interviews were used to explore how advancements in treatment affected and were affected by stigma, how stigma manifested in the lived experience of gay and bisexual men, and how that stigma and the experience of living with HIV was managed. The study found that stigma partially manifested in the form of structural and social barriers to accessing available resources, which were a large influence on how both groups and individuals were able to benefit from contemporary treatment and medications. It also found that stigma manifested within lived experience as both an internal fear of discrimination and as actual instances of exclusion. Finally, the study revealed various strategies used by HIV positive, gay and bisexual men to manage stigma and living with the virus. Among the most common strategies used were the use of education about HIV, treatment and prevention, and the maintenance of physical and emotional health through consistent access to health care and the creation of communities and emotional support systems.

This study approaches the topic of HIV and stigma from a biosocial and integrative framework which highlights the importance of both the context of treatment as well as personal experience within that context. This approach draws from the massive body of past research which has often relied on frameworks which focus purely on biomedical, interpretive, or political-economic theory. The study also seeks to subvert the “insider versus outsider” dynamic, which has been historically present within anthropological research, by featuring a principal investigator which identifies as apart of the subject community. In an age where many anthropologists have shifted their focus to “post crisis” HIV narratives in research, this study seeks to use critical medical anthropology and critically interpretive theory to integrate perceptions of HIV and the experiences of those living with it into a more nuanced whole.

Chapter 2 Background and Literature Review

Background

Something that became immediately clear during interviews and research about the contemporary environment of HIV treatment and prevention was that there was a substantial difference in the resources available in 2018, as compared to the earlier years of the AIDS crisis in the 1980's. Specifically in the area of available medications, there was a time when the only available drugs were highly toxic to the body and health care providers had little experience or knowledge of the correct dosages to administer them safely. Zidovudine, more popularly known as AZT, was the first antiretroviral medication to be FDA approved in 1987. Another medication would not become available until 1991, when Didanosine was approved (U.S. Food and Drug Administration 2018). These early medications had severe and often times fatal side effects, including intense diarrhea, vomiting, audio and visual hallucinations, loss of bone density, and organ failure. Side effects could be experienced within minutes of taking medications, which were often handfuls of pills that had to be taken every couple of hours. In the late 80s and early 90s, many medications were still in clinical trials, and many people did not have access to these drugs unless they were able to qualify for a research study. However, even qualifying for a study did not guarantee that you would be treated, as those early trials

used placebos as a part of their research design, leaving patients who were in those groups completely unaware that they were not on any medication.

Medications at those times focused on mono therapy, meaning that they only used one type of HIV medication instead of a combination like contemporary drugs. The use of combinations of three or more HIV medications, sometimes referred to as “cocktails” or HAART (highly active antiretroviral therapy) would not become the medical standard in HIV/AIDS related treatment until after 1996, when researchers presented the results of clinical studies using the treatment method at the eleventh International AIDS Conference in Vancouver. At this time, some of the first reports began to emerge of patients CD4 counts rising and stabilizing, allowing them to better fight off life threatening infections and ultimately increasing their life expectancy. Following the widespread adoption of HAART, morbidity rates related to HIV/AIDS began to steadily decline for the first time since the beginning of the epidemic (Hoesin 2016). However, these early “cocktails” had powerful side effects, much like the mono therapy medications that came before them, and general quality of life and life expectancy for those living with HIV was still low in comparison to contemporary circumstances.

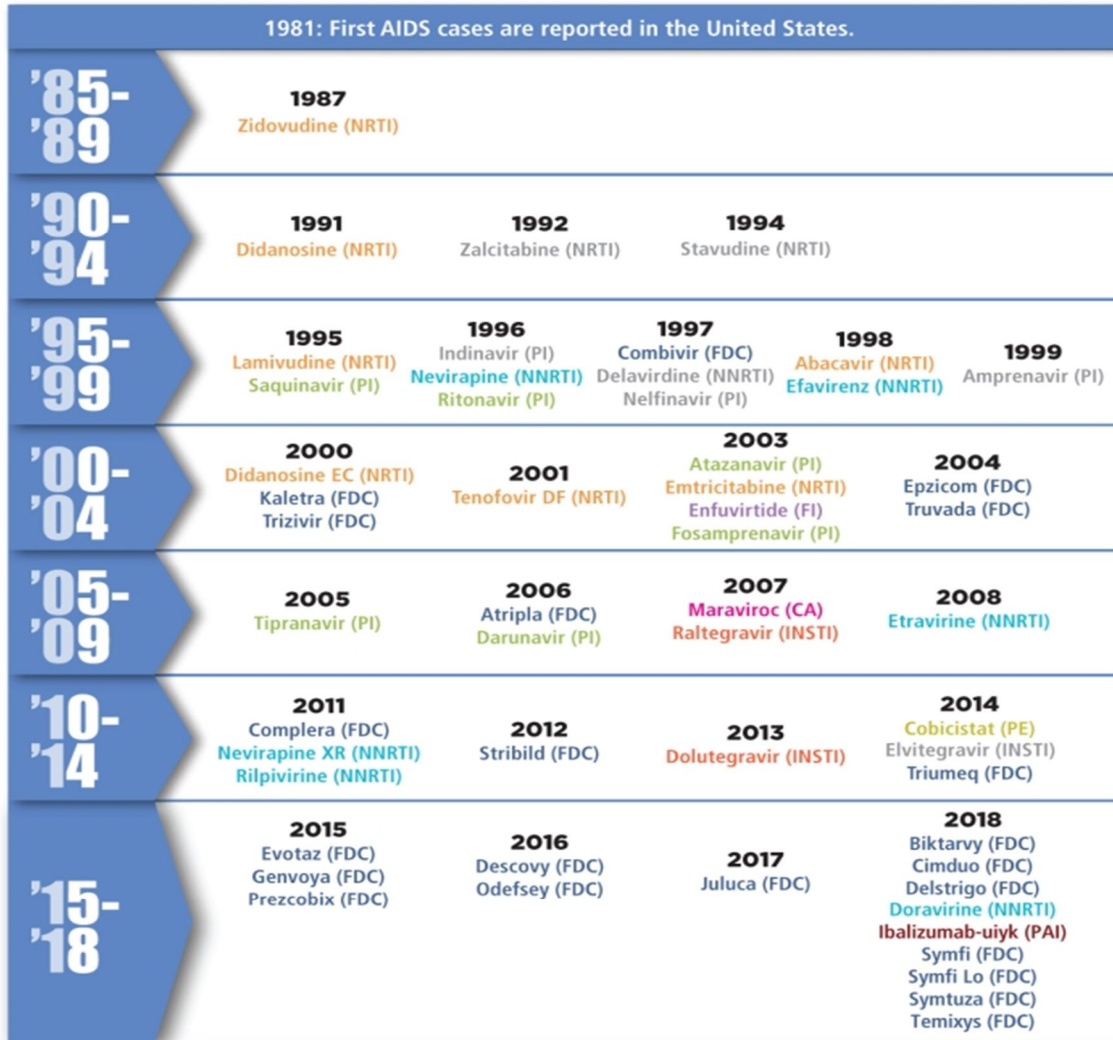
Today, there are around six main classes of HIV medications or antiretrovirals, which prevent the replication and spread of the HIV virus within the body at various stages of its life cycle. There are dozens of individual drugs which are categorized by class, and since the late 90’s, are taken in combinations in order to stabilize and ultimately suppress the virus in people who are HIV positive. Most modern regimens

combine two or more drug classes to target the virus in various ways, from how it attaches itself to cells, to blocking enzymes the virus uses to reproduce. This sometimes includes a pharmacokinetic enhancer to boost the effects of one or more of the drugs in a combination. Atripla, the first once daily, one pill Antiretroviral regimen was FDA approved in 2006 (U.S. Food and Drug Administration 2018), and since then, many other one pill regimens have become available and gained widespread use. However, even more modern, once a day regimens can still have significant side effects, sometimes severe enough to force a change in medication.

The recent wave of single pill, once a day regimens, such as Genvoya and Juluca, have aimed to lower severity of short- and long-term side effects, lower the chance of drug resistance and minimize pill burden to increase adherence. It is now common practice for health care providers to start patients with a positive HIV diagnosis on antiretroviral medication immediately, instead of waiting for their CD4 cell count to show a significant drop or develop other serious indicators of the onset of AIDS. With a much greater range of available medications which are safer for the body and more effective at stopping the virus, HIV positive people in the contemporary environment of HIV/AIDS treatment have a near normal life expectancy and a much higher quality of life than ever before. Figure 1.1 shows a timeline of the FDA's approval of HIV medications spanning from the mid-80s, to 2018 (U.S. Department of Health and Human Services 2019). The most recent drugs represent single pill regimens and combinations of drugs into a single pill which may be taken with another drug class. It should be noted that new

innovations in HIV medications are released every year, and new forms of treatment have been emerging such as long lasting, injectable antiretrovirals.

FDA Approval of HIV Medicines



Drug Class Abbreviations:

CA: CCR5 Antagonist; **FDC:** Fixed-Dose Combination; **FI:** Fusion Inhibitor; **INSTI:** Integrase Inhibitor; **NNRTI:** Non-Nucleoside Reverse Transcriptase Inhibitor; **NRTI:** Nucleoside Reverse Transcriptase Inhibitor; **PE:** Pharmacokinetic Enhancer; **PI:** Protease Inhibitor; **PAI:** Post-Attachment Inhibitor

Note: Drugs in gray are no longer available and/or are no longer recommended for use in the United States by the HHS HIV/AIDS medical practice guidelines. These drugs may still be used in fixed-dose combination formulations.

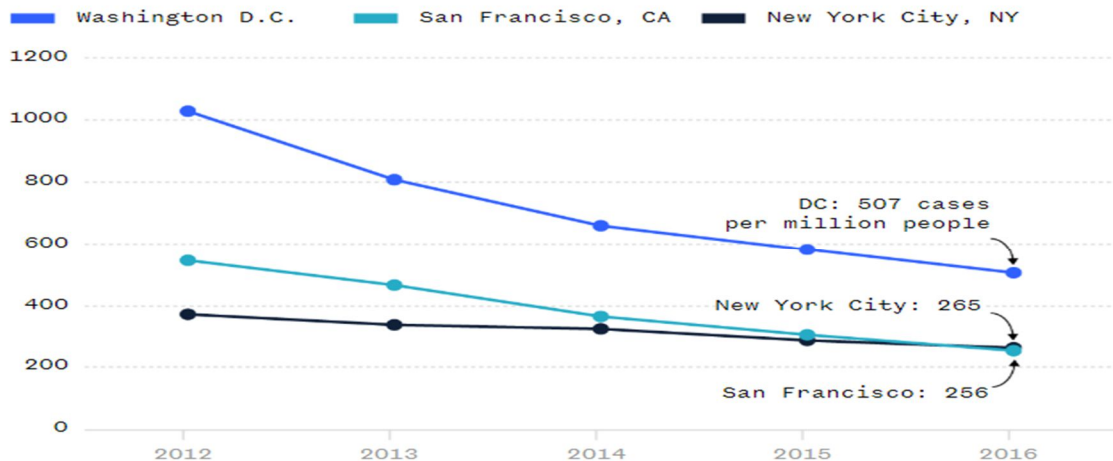


Figure 1.1 FDA Approved HIV Medicines Timeline

On July 16, 2012, the U.S. Food and Drug Administration approved Truvada (emtricitabine/tenofovir disoproxil fumarate) for pre-exposure prophylaxis (PrEP) in combination with safer sex practices to reduce the risk of sexually acquired HIV-infection in adults at high risk (U.S. Department of Health and Human Services 2012). This once a day pill regimen, if taken as prescribed by HIV negative individuals, has been proven by clinical studies to be over 90% effective at preventing the transmission of HIV. Information from District of Columbia Department of Health, New York City Department of Health and Mental Hygiene, and San Francisco Department of Public Health and Census Bureau have suggested that in cities where PrEP is easily accessible and prevention programs are well funded and developed, rates of new HIV transmissions have been in steady decline since 2012 (Fitzsimons 2018).

New HIV diagnoses since the introduction of PrEP (2012)

Number of cases per 1,000,000 people



Sources: District of Columbia Department of Health, New York City Department of Health and Mental Hygiene, San Francisco Department of Public Health and Census Bureau

Figure 1.2 Graph of HIV Diagnoses Since PrEP Introduction

Figure 1.2 shows a steady decline in new HIV diagnosis since PrEP's FDA approval for HIV prevention use in 2012, based on statistics gathered from the department of health in 3 major cities with wide distribution of the drug (Fitzsimons 2018).

On September 27th, 2017 in recognition of National Gay Men's HIV/AIDS Awareness Day, the CDC released an official memo which stated that an HIV positive individual who had successfully suppressed their viral load to "undetectable" levels through the use of ART (antiretroviral therapy) had effectively no risk of transmitting the HIV virus (McCray 2017). This means that through adherence to medication, HIV positive individuals are able to lower the number of viral particles in their bloodstream to such a small degree that the virus can only be detected by the most sensitive HIV tests, and that in this suppressed state the virus is untransmissible. This revolutionary statement has since been scientifically supported by a myriad of studies, namely the Partner 1 and Partner 2 studies conducted between 2010 and 2014, and 2014 and 2018 respectively, to apply to MSM (men who have sex with men). The most recent data, which showed zero cases of viral transmission from individuals with an undetectable viral load, suggests that the risk of HIV transmission in cases of successful viral suppression is scientifically equivalent to zero (Rodger, A et al 2018, 2016). The CDC recognized that according to the Morbidity and Mortality Weekly Report, through preventative efforts and treatment, the rates of new HIV infections among some gay and bisexual men, specifically White

men, had fallen by 2015. In the same year, only 61% of bisexual and gay men living with diagnosed HIV in the U.S. had achieved undetectable status, with African American and Latino men having the highest rates of new infections which were stable but not decreasing (Singh S. et al 2015).

The actions of the CDC also reflect a sort of paradigm shift in the way that researchers and medical professionals have traditionally approached HIV/AIDS. Eileen Moyer (2015) discusses in her article “The Anthropology of Life after AIDS” that within the past 30 years, the focus of research has shifted from “the age of AIDS” to “the age of treatment.” Essentially, in the late 80’s and 90’s, when much less was known about HIV/AIDS and treatment was still in its nascent stages, there was a global and general focus on prevention rather than maintenance. This was due to the heightened fear of transmission and accompanied stigma surrounding the disease, making even discussing it a subject of taboo politically, economically, and culturally. Across borders and socio-political climates, most researchers agreed that preventing the transmission of HIV was important and so funding was funneled towards research with a focus on prevention. Following the advent of more effective medication and treatment, i.e. PrEP and ART, individuals living with HIV are now living longer, healthier lives and so research has shifted its focus on to the experience of living with HIV, not as a death sentence but as a manageable chronic illness. However, access to the resources needed to manage it and prevent its further transmission are not equally available to all on a global scale or in the U.S, especially not for queer men of color.

In an article “Venezuela: violence, human rights, and health-care realities” Rafael Muci-Mendoza (2014), the president of the Venezuelan National Academy of Medicine, stated that “the constitutional right to have access to healthcare is a fantasy in our country today.” Referencing the humanitarian crisis in regards to health care and access to medication currently happening in several Latin American countries, the article advised that “Patients with HIV/AIDS or those with hematological disorders have been abandoned, as the blood banks are not receiving their funds from the government” (Muci-Mendoza 2014, 1968). This article reflects the unfortunate reality that the experience of living with HIV and access to health care are enmeshed in the cultural, political, and economic environments in which individuals are situated. In his book *Butch Queens up in Pumps: Gender, Performance, and Ballroom Culture in Detroit*, Marlon Bailey (2013) discuss how queer black men in Detroit's ballroom scene struggle to effectively approach the issues of access, education and prevention in their own communities. Bailey, having worked in a government funded outreach program targeting queer men of color, discusses at length how stigma is inherently built into the methodological framework of these programs and continues to alienate queer men of color and discourages them from seeking out treatment even when it is available to them.

In Monivette Cordeiro’s 2017 article “State of Denial,” she discusses how Florida stands out as one of the states with the highest rates of new infections, in spite of the general drop in new infections seen nationally. It states:

Although HIV rates have plummeted nationwide, in Florida the virus continues to ravage communities, with no significant decreases in new HIV infections since 2010 and more than 1,916 deaths in 2014. Among states, Florida had the second-highest rate of HIV diagnoses among adults and adolescents in 2015, with 27.9

new cases per 100,000 people, almost double the national rate, according to the Centers for Disease Control and Prevention. (Cordeiro 2017, 1)

Cordeiro essentially confirms that treatments such as ART and PrEP have radically changed the landscape of living with HIV in the U.S. but adds that more work is needed to be done to extend access to medical treatment to those in most need of it. In her 2019 article “Orlando Seeks to Eliminate New HIV Cases By 2030.” Danielle Prieur discusses The U.S. Department of Health and Human Services’ plan to eliminate 90% of new HIV cases by 2030 by utilizing a combination of prevention and treatment methods. These include connecting individuals who test HIV positive with service agencies and healthcare providers immediately, as well as generally increasing testing and offering preventative measures like PrEP. The Orange County, Florida government website provides a comprehensive list of different local service providers that offer HIV related services (Orange County Government Florida, n.d.). Though the Florida Department of Health advises in the article that there has already been a reduction in cases within high risk populations in the city, the Client Coordinator for Hope and Help, Abby Silverman, felt that the department’s plan was not addressing structural barriers to accessing HIV related services in Florida.

We don’t have comprehensive sex-ed in all of our schools here. We don’t have a clean needle exchange program in the state of Florida. So, we definitely need to start looking at some of the policy stuff that is prohibiting us from moving forward and tackling the problem. The other thing is we do need to use the tools that are available to us. We have PrEP now which is highly effective and readily available. We have treatment as prevention. (Prieur 2019)

It is clear that regardless of geological location or socio-political context, access to health care and treatment is a large determinant in the quality of life and general

experience of those living with HIV today. Specifically, in the context of gay and bisexual, HIV positive men in Orlando, Florida, structural and economic barriers in accessing available resources for the treatment and prevention of HIV influence how they are able to directly benefit from those resources and the ways that they experience and manage stigma.

Literature Review

Before explaining the study's findings, I would like to present a brief overview of past and current research which has explored the study of HIV and stigma. I intend to use a number of case studies, which vary in their direct relevance to positive gay and bisexual men, to ground my research within the work already produced by anthropologists in the field.

As stated previously, one such case study is Marlon Bailey's (2013) ethnography *Butch Queens up in Pumps: Gender, Performance, and Ballroom Culture in Detroit*. In his work, Bailey discusses how a community of queer, Black men and other gender fluid individuals use performance to create social spaces called "Houses" and "Balls" that offer safety, emotional support and sometimes physical refuge for the intersectional and marginalized queer Black community in Detroit. Acting as a participant observer and researcher, Bailey uses his first hand experiences within the Ballroom community to describe how its members use a unique system of gender, surrogate kinship structures, and ritual performance as strategies of survival within the unfriendly social and political climate of Detroit. He explores how the queer, Black community is stigmatized not only

by the greater heteronormative society, but also by White gay men and even the heterosexual Black community. Bailey also makes reference to his work in community-based HIV outreach and education programs geared towards queer Black men, explaining that the inherent racism, homophobia, and classism built into the administrative structures of these programs were to blame for their lack of effectiveness in reducing the rate of new HIV infections amongst queer men of color. He closes the ethnography by describing how HIV positive members of the Ballroom community have taken education and prevention into their own hands by creating “KiKi Balls” with a specific focus on HIV and sexual health. These Balls, which present information about HIV through a medium which is easily accessible and relatable to young queer Black men, seek to educate the community on its own terms and in the voice of its own members. This study relates to my own research questions in the way it exemplifies how a marginalized group of queer people experience disproportionate access to healthcare due to stigma that was present in the structure and application of HIV related services. It also described how community members responded to those disparities by reframing education and health care into medium that was more accessible to Black queer youth.

In a somewhat similar case study based in Swaziland Africa, Root et al (2017) discusses how community home based care (CHBC) for people living with HIV is largely made possible and effective through its Christian framed application. Using a phenomenological methodology, researchers conducted semi-structured interviews with 79 CHBC clients who were living with HIV in an attempt to “theorize phenomenological meanings of care, mortality, health, and sickness, and to interrogate authoritative

biomedically based rationalities that underwrite most HIV-related global health policy” (Root et al 2017, 231). In Swaziland, the population has one of the highest rates of HIV and TB infection in the world, and the government heavily relies on CHBC as a means of extending access to health care. Because the population is primarily of the Christian faith, health care systems enmeshed within a religious context help to create relationships of trust and willingness to seek out health care between people living with HIV and CHBC organizations. The study found that over half of the participants claimed that the services offered through these organizations were integral to their mental and emotional wellbeing, stating that they may have committed suicide without them. By normalizing HIV status through the eyes of the church, these organizations also helped to reduce stigma experienced by HIV positive people and helped improve their personal perceptions of their own health. This case study presents another example of how access to health care for the treatment of HIV and the effectiveness of that care are enmeshed in a greater cultural, social, and political context and that marginalized communities need health care administrators to reach out to them in a culturally relevant setting to be effective (Root et al 2017).

Jordan et al (2016) also produced an ethnographic case study, “Portuguese American Gay Men in Southeastern Massachusetts: Cultural Scripts and Risk for HIV” using phenomenological methodology, to get a better understanding of how gay Portuguese American men’s sexual behaviors were positioned within the greater social and cultural context of Southern Massachusetts. Using sexual script theory as a framework, the study explored the interplay of several sexual scripts, cultural,

interpersonal and intrapsychic, and how the negotiation between these scripts framed sexual practices in relation to risk and the prevention of HIV. The research design, which was structured around interviews with 8 Portuguese American gay men, focused on lived experience as a means for analyzing how these scripts manifested in sexual behavior. Like the other case studies, this study once again asserts that the effectiveness of education and prevention programs in relation to HIV is dependent on the cultural relevance and accessibility of their designs. It also champions the use of religious affiliated outreach programs and the integration of the family structure into treatment and prevention strategies.

In another study based in the San Francisco and Oakland California areas, Arnold et al (2014) focused on the relationship between stigma and the accessibility of HIV testing, adherence to medication for positive people, and perceived safety in disclosing HIV status among gay, Black men. The term “triple cursed” was coined by an interview respondent, referring to how gay Black, HIV positive men live at the intersection of multiple, marginalized identities that cause them to be rejected from multiple communities due to their race, sexuality and HIV status. The study used 31 semi structured interviews with “Black self-identified, gay, bisexual or ‘same-gender loving’ men aged 18 –30 years.” (Arnold et al 2014, 4) Interview data found that gay, Black men were often rejected from their families and the Black community at large due to their sexuality and HIV status. Many reported fears of violence from community members, but were unable to leave Black ghettos and Black communities because of structural issues including poverty and a lack of professional and educational opportunities. Many men

also felt that they were rejected from the gay community for being Black and for being HIV positive. Because of the stigma towards HIV, many Black men avoided getting HIV testing for fear that they would find they were positive and be rejected from their communities. Many who were positive found it difficult to adhere to treatment due to structural issues, and were afraid to disclose their status for fear of discrimination. The results of this study show that there was a kind of “silence” around the subject of HIV within the Black community which was already suffering stigma within the context of racism from greater society.

In a somewhat older article titled “Understanding and addressing AIDS-related stigma: from anthropological theory to clinical practice in Haiti.” Aruchu Castro and Paul Farmer (2005) discuss the connection between access to health care and AIDS related stigma within the context of clinical practice in Haiti. The article represents the beginnings of the theoretical foundation that this thesis research is based on, but also reveals many of the limitations of past frameworks that did not integrate analysis of the political, social, and economic context of treatment and stigma with individual, lived experience. The authors explore stigma in relation to structural violence in Haiti and draw attention to how previous research focused on individual characteristics that caused stigma rather than on relationships between social institutions and barriers to accessing health care. The short paper follows only one HIV positive subject who, through successful viral suppression, is able to overcome physical illness and be reintroduced into the workforce. It uses this experience to highlight how access to health care can transform AIDS into a manageable illness that is invisible to others. It does not, however,

go into depth about how stigma is internalized by people living with HIV, and how people who are in treatment can still experience the direct and indirect effects of stigma. Yet, it does champion future research taking a biosocial approach to understanding AIDS related stigma, which authors such as Singer (2014) developed further and whose work is discussed at length in later chapters.

Finally, Kgope P Moalusi (2018) discusses HIV stigma in the workplace in South Africa, in their paper titled “Employees’ experiences of the stigma of HIV in a retail organization: secrecy, privacy or trust?” According to the author, “South Africa has the largest HIV prevalence in the world, with 19% of the global number of people living with HIV” (Moalusi 2018, 2). The study used one on one, in-depth interviews, including 10 participants working for the same unnamed retailer in South Africa. The methodology focused on individual lived experience as a medium to explore the effectiveness of training programs designed to educate and spread awareness about HIV and stigma in professional settings. Additionally, it worked to define more clearly the reasoning behind HIV positive employees’ decision to disclose or not disclose their status in the workplace. The company that housed the study was known for having HIV training programs to reduce stigma, however, only two participants were open about their status with their managers. All respondents used non-disclosure with general coworkers as a means of mitigating stigma, out of fear of being discriminated against if their status became public. This study sheds light on one of the major themes of the thesis research findings, related to anxiety about HIV status disclosure in the workplace, and will also be explored in further detail in later chapters.

Chapter 3 Methodology

Thesis statement and Research Goals

This study found that gay and bisexual, HIV positive men experienced stigma at multiple levels of their social identities, and that the relationship between the environment of stigma and contemporary medical realities of HIV treatment in Orlando, Florida, was strongly influenced by structural and social barriers to accessing healthcare. The ways individuals approached the management of stigma and HIV varied greatly and were largely dependent on intersectional identity and personal life experience.

This study approaches the topic of stigma and HIV through an emic, humanist, and phenomenological lens which focuses on the visceral experiences and daily lives of positive gay and bisexual men, contextualized within the social, economic, and political circumstances of Orlando. It uses a phenomenological methodology to help ground the personal narratives of participants in sensory experiences which help make the partially metaphysical nature of the topic more tangible and relatable. It also uses critical medical anthropology to establish a context for structural, economic and social institutions which create barriers to accessing health care and create opportunities for the manifestation of stigma in the lived experiences of HIV positive men.

Methods

In terms of research design, the study focused on the use of ten semi-structured interviews with local HIV positive, gay and bisexual men, negative men, and healthcare providers. It was conducted at a local Orlando nonprofit organization called Hope and Help, which offers assistance and resources to individuals living with HIV. The resources the organization provides include, but is not limited to, assistance in accessing medical treatment as well as counseling, available health care providers on staff, access to a food pantry, and access to multiple support groups and HIV related community organizations. Hope and Help also hosts an open HIV support group for men called Re-Start, from which most interview respondents learned about the study and chose to participate. The study was conducted between June and August of 2018.

In the interest of protecting interview respondents and the integrity of the Re-Start support group, my direct participation in group meetings was limited to a few preliminary announcements about the study and its objectives before each meeting. However, I was able to meet and forge relationships with many group members throughout my time in Orlando and also attended several group activities outside of the support group meetings themselves. The structure of the Re-Start support group is unlike many others of its kind, and focuses most intently on education and the creation of a community of HIV positive men rather than on open sharing of personal experiences like an AA (alcoholics anonymous) or NA (narcotics anonymous) meeting. Each meeting is designed to have a speaker or activity which is most often centered on health issues, medications, or

pertinent concerns related to living with HIV, and are held bi-monthly. Other than the meetings themselves, the group meets outside of Re-Start for monthly potlucks, trips to local museums, and holiday themed parties. The group itself is open to all members, including all genders, sexual orientations, and people who are HIV negative but who seek to support positive loved ones and the HIV positive community more generally. Though there were certainly members which came to every meeting, many participants came and went as they pleased over the course of several months, with new members coming to meetings every other week.

Over the course of the study, interviews were conducted in a private office at the Stafford House, where Re-Start meetings are held, as well as at a private office on the Hope and Help main campus. Interviews were scheduled by appointment and participants were recruited through the use of flyers and announcements at Re-Start meetings. A total of six HIV positive gay and bisexual men, three HIV negative men and one nurse practitioner were interviewed over the course of the study.

Interviews designed for positive men focused on questions about their history with HIV, general experiences with stigma, how access to medication affected those experiences and how they managed stigma. Interviews designed for negative men focused on perceptions of HIV stigma, access to and the use of PrEP, and the willingness to engage in sexual, social, and romantic relationships with positive men. The health care provider interview focused primarily on the context of stigma and treatment, the management of stigma and the effectiveness of outreach, support and educational programs geared towards HIV.

Theoretical Influences/ Framework

Theoretically, this study draws heavily from critical medical anthropology (CMA) and critically-interpretive medical anthropology. It explores the interconnectedness of the social, economic, and structural context of health and the formation of social relationships, positioning personal, lived experience within that context. The study is informed by the work of CMA theorists such as, Merrill Singer (2014), Nancy Scheper-Hughes and Margaret Lock (2018) and sociologists such as Erving Goffman (1963). The study specifically makes use of Goffman's definition of stigma as "an attribute, behavior, or reputation which is socially discrediting in a particular way: it causes an individual to be mentally classified by others in an undesirable, rejected stereotype rather than in an accepted, normal one" (Goffman 1963). The use of personal narratives as well as working within a phenomenological methodology are supported by postmodernist theory. This research design is influenced by theorists such as James Clifford (1986), drawing from the concept of partial truths which is refracted through the prism of health and its relationship to stigma experienced by gay and bisexual, positive men. In this context, the lived experiences of individual gay and bisexual men and medical professionals act as pieces of a greater truth or story about the experience of living with HIV. The study, due to its methodology based in phenomenology, also draws from the work of theorists and philosophers such as Maurice Merleau-Ponty. In his 1996 book *Phenomenology of Perception* he states "Phenomenology is the study of essences; and according to it, all problems amount to finding definitions of essences..." (Merleau-Ponty 1996, 8) Other

researches, such as Sandra Thomas (2017), have advised that Merleau-Ponty's philosophies can be applied to medical research and methodology, specifically in reference to clinical psychology. Perhaps most relevant to this study, Thomas champions Merleau-Ponty's perceptions of Holism and Intentionality, stating that:

Our patients want to be known in their wholeness, an impossibility in most modern health care environments because Cartesian dualism has yet to be dispelled—even after more than 400 years. Within psychiatry and psychiatric-nursing, only recently has the inseparability of mind and body been recognized within the movement toward “integrated care.” (Thomas 2017, 4)

These theoretical foundations and their connection with the interpretation of research results will be explored in greater detail in a later chapter.

Stakeholders and Ethical Considerations

Privacy of information was and continues to be one of my greatest ethical concerns in conducting this research. Because of the nature of this topic, having someone's HIV status revealed publicly could make them vulnerable to the very stigma this research sought to study. However, the Re-Start support group and many of its members share a desire and mission to bring visibility to the HIV positive community and to dispel stereotypes and misinformation about the issues facing HIV positive people. In light of this, pseudonyms have been used to replace the names of interview respondents, but some identifiable information was used in the presentation of interview responses in relation to group membership. Verbal consent was utilized instead of consent forms so to leave no written record of respondent's identities or legal names.

In taking a phenomenological approach, participants were asked to recount traumatizing and deeply painful memories about their experiences living with HIV and stigma. Some respondents expressed a sense of therapeutic relief as well as empowerment by sharing their personal stories, one of the most effective ways of dispelling and dismantling stigma. As a safety measure, resources were provided on flyers and information sheets for counseling or the de-escalation of episodes of PTSD and other conditions that could be triggered by the interview questions. It was made clear on the research information sheet and flyers that participants could withdraw their responses and participation from the study at any time, even after they were interviewed.

Another consideration the study addressed was the fact that the population was skewed towards positive queer men who already had access to resources which could help them acquire health care. Flyers were advertised physically at the Re-Start site and digitally in a closed social media group on Facebook, meaning that most people who saw the flyers or heard about the study already had exposure to organizations which offered these services. It would be in poor ethical taste as a researcher who identifies with the subject population to purposefully seek out individuals who are known to have little to no access to health care and place them at a potential risk to be the target of additional stigma. As a result, the decision was made to base the study in the context of a HIV related non-profit and support group so that participants had access to resources which could better ensure their wellbeing while contributing to the project. Though all participants were in treatment at the time of the study, they still offered valuable insight on inconsistent access to health care.

Positionality

My position as a self-identified gay, black, HIV positive male from Orlando has had a significant effect on my level of access to the HIV positive community, as well as my personal understanding of stigma in relation to HIV. The research design, my questions, and methodology are informed by personal experience with stigma and living with HIV. This experience has allowed me to develop a rapport with the Hope and Help organization. It was through my personal experiences with HIV that I was able to contact the organizers of the Re-Start support group, who expressed a serious interest in facilitating the study in the summer of 2018. This written thesis will be made available to Hope and Help and the Re-Start support group.

Due to the nature of stigma, many HIV positive individuals tend to be secretive about their status as a strategy for avoiding discrimination. Throughout the interview process, I was explicit about my own HIV status with participants in the study in the hopes that shared experience would make respondents more comfortable in discussing personal stories which they may otherwise never talk about. I recognize the challenge that my status presents to the idea of objectivity in research, however I believe that the theoretical foundations of the study create space and need for authentic, subaltern voices both from the position of respondents as well as the researcher.

The dynamic of the outsider as researcher versus the insider as subject has historically created a large amount of tension within the field of anthropology. At times this relationship has resulted in research that is exploitive of subject communities and

shifts the benefit of research onto members of the academy. As a researcher who seeks to do applied work which benefits marginalized communities, I believe my position as a member of the queer HIV positive community is appropriate within the context of the study and within the field of applied anthropology. In the sense that it challenges the hierarchy of power which has formed between researcher and subject in past endeavors, if only by adding a more nuanced perspective of the experience of living with HIV, I believe that my personal experience with HIV helped create a space of trust and mutual understanding with respondents that deeply enriched the results of the study and the experiences of those involved.

Chapter 4 Findings

This study found that the relationship between stigma and the availability of contemporary treatment and medication for both the maintenance and prevention of HIV was strongly influenced by the accessibility of healthcare and organizations which offered HIV services and economic assistance programs. Structural barriers to access, such as the high price of HIV medications and health care, coupled with logistical barriers specific to Orlando like a lack of public transportation and an uneven distribution of HIV related service agencies, create populations of gay and bisexual men who have less access to treatment and education about HIV and are more likely to experience stigma. For some respondents, maintaining physical health through access to treatment and medication was an important factor in managing stigma in its relation to their self-image and social pressure to discuss or disclose their status. Stigma also created social barriers for respondents in accessing health care. Fear of discrimination if identified as positive by insurance agencies, employers, in housing, and other logistic imperatives could discourage HIV positive individuals from seeking out treatment or maintaining it. Many interview respondents were able to overcome barriers to access through assistance from the Hope and Help organization as well as other local HIV service agencies.

The study also found that HIV positive gay and bisexual men perceived and experienced stigma externally as instances of direct exclusion and discrimination. Stigma also manifested as an internalized fear of discrimination, and at times as a warped sense of self-worth which permeated respondent's professional, sexual and romantic, and social and familial relationships. In spite of a plethora of recent medical studies which have supported that HIV is untransmissible in cases of successful viral suppression, nearly all respondents perceived stigma related to HIV as continuing to be pervasive socially and culturally due to a lack of awareness of the contemporary medical realities of HIV. Stigma, in these contexts, was most often described by positive men as an internal shame or fear of discrimination which led individuals to have varying degrees of comfort with disclosing their status to others.

Finally, interviews also addressed the ways that HIV positive, gay and bisexual men managed stigma and living with HIV in their daily lives. Education for everyone, in relation to the contemporary reality of HIV treatment as well as available resources in relation to HIV, was among the most common strategies used to dismantle and manage stigma. Almost all strategies involved the formation of communities and safe spaces in various forms, including participation in support groups, faith-based communities, community outreach and advocacy work. Additionally, the maintenance of physical and emotional health, often times supported by participation in these communities, was of great importance.

The results of the study paint a portrait of the environment of HIV and stigma in Orlando as being one that is still in the midst of a major contextual change in relation to

healthcare options and HIV related resources. However, the availability of those healthcare options and resources does not translate directly into them being accessible by everyone, therefore their benefit and positive affect on diminishing stigma is dependent on being able to access them. Even respondents who had consistent access to health care and medication still reported experiencing stigma in their daily lives.

Structural and Social Barriers to Accessing Healthcare

Based on interview data, access to health care and insurance is one of the greatest struggles for HIV positive, gay and bisexual men in Orlando in maintaining consistent access to treatment. Though many respondents worked consistently from the time of their diagnosis through the present, the high price of medications and insurance were often times still unaffordable without the help of economic assistance programs which specialized in HIV/AIDS related services. One such program is the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act. This legislation, signed into law in 1990, identifies a set of services that can be offered to individuals living with HIV/AIDS and offers funding for those services. It is unique in that it is one of the few health care programs in the country that are disease specific (HRSA, n.d.).

Many respondents relayed stories about how they were able to get HIV medication through Ryan White, sometimes completely free of charge or copays, at times when they would have otherwise been unable to afford the cost of medication or insurance. A 2015 study showed that the Annual medical cost estimates for HIV-infected persons, adjusted for age, sex, race/ethnicity, and transmission risk group, ranged from

\$1,854–\$4,545 per month (Schackman et al 2015). Many of the more recent, single pill regimen medications such as Genvoya, have no FDA approved generic versions and can cost upwards of 3000\$ without insurance for a 30-day supply of pills (Nall et al 2019).

Rocky, a 28-year-old gay man from Atlanta, Georgia spoke at length about his anxiety over the high cost of medication without insurance, and how it initially kept him from getting tested, even though he suspected that he may be HIV positive. *“I probably knew something was up years ago, and just didn't do anything about it because I was so scared of the ramifications of not having insurance. This is the first time I've had insurance in a long time and for me, I kind of knew I probably...something was wrong with me, but it was like what am I going to do?”* (Rocky). He went on to explain how looking at the pharmacy receipt with his medication bottles each month reminded him just how much money his insurance saved him, over \$3000 a month, and how he felt lucky to have the assistance of a Gilead copay card and patient advocacy program that allowed him to pay nothing for his medication. His story is common amongst those living with HIV, who often times must face the frightening reality that their very lives depend on access to medications they couldn't even hope to afford without economic assistance, even while working full time jobs with insurance. This dependence also affects many HIV positive gay men's level of comfort with disclosing their status in professional environments, for fear of losing their only lifeline to life saving medications, a theme which will be explored in more detail in the pages to follow.

In spite of the availability of nonprofit, government funded, and privately-owned assistance programs which offer HIV related services in Orlando, these services have

only recently become more widely accessible there and the number of resources pales in comparison to larger cities such as New York, San Francisco and Los Angeles. Ronny, an animated Italian man in his 60s who also worked as a peer specialist for Hope and Help, spoke with me about moving to Orlando at a time when HIV related services were far less available. “...when I first came to Orlando, HIV services, treatment and support services were few and far in between and almost, as far as support services, almost nonexistent. So, having spent the last 3 decades in New York, San Fran, and LA, the 3 key cities that are considered to be ground zero cities for HIV, I learned a tremendous amount. Particularly in the value of community support groups” (Ronny). Even now, with more HIV related services and organizations in the Orlando metropolitan area than within the last decade, there continue to be barriers which can prevent positive, gay and bisexual men from entering into treatment or staying in treatment once they have begun. One such barrier is the cities lack of efficient public transit. The Lynx bus system is one of the only available modes of public transportation, which has a limited number of routes and stops within an expanding and spread out cityscape. Commutes from distant ends of the city can take hours, and bus schedules can oftentimes be unpredictable when it comes to timeliness. The Sun Rail, a commuter train which connects Volusia County and Osceola County through Downtown Orlando, has only been in operation since May 1st, 2014, and is extremely limited in accessibility with only 16 stops along a former CSX transportation line. This, combined with the fact that almost all HIV related service locations are based in the downtown or East Orlando areas leaves many gay and bisexual men, specifically those living in West Orlando, alienated from accessing important

resources if they are unable to afford their own vehicle or to solicit ground transportation through cab services, Uber or Lyft. This also happens to be where the large populations of African American residents reside, a group among those most at risk of new HIV infections. Randy, a nurse practitioner who worked with the Hope and Help Organization at the time of the study, spoke with me in detail about the environment of healthcare in relation to HIV in Orlando. When asked if an individual's racial identity or economic status had an effect on the availability of HIV related services, he had this response:

So, I wouldn't say availability. But access and availability are two different things. We know that one of the larger demographics are African Americans. Yet, on the westside of Orlando where that demographic is higher, there's not really a lot of agencies. So, it's one of those things that we are looking at, at Hope and Help, in a couple of ways. We're looking to do some kind of remote health... I don't think that availability would change based on demographics at all. But I think that the accessibility does change because, you know the Hispanic population is mostly eastside and the Kissimmee area, and the African American population is mostly the west side. These are all things that we know, it's just the way that it is. And if you think, coming from the westside to here, if you're using public transportation, some of my patients tell me it takes them 3 hours. I can't imagine. So, I think that definitely creates a barrier. (Randy)

Randy also spoke generally about the difficulty of providing health care for people living with HIV in Orlando due to a lack of resources, specifically those in relation to individual counseling and mental health. A part of this issue was also the fact that navigating the

health care system could be highly confusing for patients, and even for health care providers when it came to connecting multiple services together. *“I don’t think that we have quite ironed it out to the level that we need to. One of the unique things that, and I’m saying unique and again this is hard for me to even give it that quality, but what I know about Central Florida, is there’s lots of organizations that do similar work and they don’t always work together...And it’s very difficult to navigate health care. And I think that’s something that we don’t make easy for individuals”* (Randy).

Many respondents recounted stories of the difficulty in applying for aid programs, especially when transferring their insurance from other states. Many of these individuals expressed gratitude towards peer specialist such as Ronny and the efforts of organizations like Hope and Help, as well as Miracle of Love, in guiding them through the sometimes-byzantine processes of applying for and enrolling in aid programs.

The stigmatization of HIV also acts as a social barrier to accessing treatment, and maintaining it. Many respondents, especially those who had lived through the height of the HIV/AIDS pandemic, advised that association with HIV infection and disease could lead individuals to be the target of discrimination when seeking various kinds of insurance, housing, and even jobs. Jack, an older man and member of Re-Start who moved to Florida from Ohio years prior to our interview, recalled some chilling memories about the fears surrounding stigma and HIV in the 80s. When asked to tell the story about his initial diagnosis, Jack had this to say about the fear associated with any connection with HIV. *“But all the professionals, all the gay professionals were saying don’t get tested. Because once you were diagnosed with HIV, HIV positive, you will be a*

target and you won't be able to get any type of insurance, life insurance, health insurance, you won't be able to get jobs. So that scared a lot of people, were talking 1988, 86, 87. And I believed that, so I didn't get tested for two years” (Jack). Fear about possible discrimination in regards to logistic imperatives like being insured or finding work, combined with the fear of social exclusion, intersect to create situations where seeking out treatment, and maintaining it could be interpreted by individuals as a greater immediate threat than the physical symptoms of HIV infection itself. Stigma of this kind is also reproduced and enforced by social and cultural responses to HIV as sickness and disease.

Manifestations of Stigma in Lived Experience

Interview data showed that in spite of the proliferation of safer, more effective medications as well as the CDC’s 2017 endorsement of the concept “Undetectable = Untransmissible”, meaning that those with a successfully suppressed viral load through medication could not transmit the HIV virus to another individual, nearly all respondents reported stigma as still being pervasive culturally and socially. This stigma manifested both externally, as instances of direct discrimination and through barriers to health care access, and internally in the form of a fear of being discriminated against based on HIV status. These circumstances had a cascading effect on multiple aspects of people’s lives, including their professional careers, romantic and sexual lives, and social and familial relationships. Individuals had varying levels of comfort with the level of risk they perceived was involved with disclosing their status in specific social interactions and

settings. One area which many respondents expressed the greatest level of discomfort and perceived risk associated with disclosing their status was at their jobs and in general professional settings.

Stigma in the Workplace

Rocky worked in nearby Winter Park, and often spent leisure time in the downtown Orlando area. He spoke at length about his anxieties with discussing his HIV status in professional settings. Having just moved to Orlando from Atlanta, he advised that part of his reasoning for this was the conservative political environment of the South, one he perceived to be less friendly towards people living with HIV. He told me the story of how he had recently been seeking out a tattoo artist, but that he wanted to make sure they were comfortable with his HIV status before soliciting their services. After being denied services by the shop he had been working with once he disclosed his status, he explained his feeling of shock at the areas of his day to day life that had been affected by HIV.

I think I really just accepted the fact that it would happen when I was...in my early 20s. Just thought it always was going to be this inevitable thing, you know? And so, then when it was like presented to me, I think I had done enough mental preparation where it was like... 'ok this is a problem and now you're just going to like fix it.' I didn't really worry about like, other ramifications of it. I guess at the time and like now slowly but surely, I'm like getting them, like that woman recently denied me for a tattoo which was like, you know, technically illegal but

it's like, what am I going to do? Sue this chick because she's scared? Like...you know, I feel for her. Part of me is of course like 'ignorant bitch' but the other part of me is like 'of course' it's a scary situation for anybody, you know? There're times at work where like I will nick myself and I just get like really scared, you know, like thinking either somebody's going to be ignorant or lalala. So that kind of stuff, those situations, never really...um, presented themselves when I was thinking about how I would process and how I would handle the situation.

(Rocky)

Rocky also talked about working in a local restaurant in Orlando and how the thought of discussing his HIV status at work made him uncomfortable, especially due to the context of food service and fears about transmission.

So that gets me scared you know? Because if I like bleed at work or anything like that, I don't need anybody...you know? It's like a White affluent Trump neighborhood. I don't need anybody thinking like who is this gay boy with HIV serving my children. Like 'he had a band aid on the other day.' And I think that's like, it's so interesting because I think, you know, you are, I think all of the modern information, unless you seek it out, is like you're sick. Or that it's like so contagious, like super contagious. (Rocky)

In reality, the HIV virus is not able to survive outside of the body for long periods of time, and is killed by substances such as alcohol, hot water, soap and bleach. Even in the event that HIV infected blood were to come into contact with food and then be ingested by a restaurant patron, contact with the air and digestive fluids would kill the virus before

it could be transmitted. However, the lack of widespread, detailed knowledge of the risk of transmission makes the likelihood that a customer at a restaurant could react negatively or severely towards an HIV positive employee, especially out of fear, all the more real.

When asked how likely they were to hire someone who they knew to be HIV positive, two HIV negative respondents expressed similar unease about the prospect of a negative situation arising around fear of transmission in a restaurant setting. Hector, a younger gay man who worked as a cook in a popular downtown restaurant, decried the ethical problem with denying someone employment due to their HIV status, but could not help but express fear about the possible risk of transmission. The 23-year-old admitted to having little knowledge about HIV in general, or the risks of transmission before our interview. What little information he knew generally about STI's he had gathered from his own experience contracting Gonorrhea several years prior, as well as a budding relationship with a man who he understood to be HIV positive. *“No, it shouldn't be a problem. No, that would not be a problem and that's just morally, it wouldn't be ok to stop someone from getting a job because of that. But me working in a kitchen for so long, I know how often people hurt themselves. I hurt myself all the time, I bleed all the time. Obviously not on people's food or anything but you never know how shit could go down and you never know if it could accidentally just by contact”* (Hector). Hector retracted his response when I explained the unlikelihood of HIV being transmitted through contact with food. However, he admitted that the fear of transmission would always remain in the back of his mind if he worked with someone, he knew to be HIV positive.

Gregory, 24, had a slightly different perspective on the situation which centered around the same concerns. A Florida native from Miami, Gregory worked in a butcher shop in Winter Park, a historic suburban city apart of the greater Orlando Metropolitan area. Having been raised by his mother, a nurse who had lived through the AIDS crisis in Miami, he had a substantial amount of previous knowledge about HIV and the risks of transmission. However, his concerns about an HIV positive employee in the butcher shop were focused more on how customers might perceive the possible risk of transmission while handling their food.

...not because I have an issue with it. The people I work with, all, I know them fairly well. As far as on a professional level, they are all on top of their shit. It would be, honestly, out of fear of like somehow a fucking customer finds out that one of our people is HIV positive, that would be a fucking nightmare. Just because it's a butcher shop, we're playing with knives all day. I've, in the month that I've worked there, I've cut myself once and even then, it was a minor nick. But that happens. A piece of chicken slips, whoops that's my finger, you know what I mean? (Gregory)

Gregory went on to explain that even though the area where the shop was located was considered to be an affluent neighborhood, the general political tone was more conservative among patrons, and that he feared customers might react negatively towards an employee they knew to be HIV positive, out of fear and lack of knowledge about the risks of transmission.

These perspectives seemed to echo Rocky's internal fear of the possible consequences of being open about his HIV status at his restaurant job. Though he advised that he had disclosed to a few coworkers who he also considered close friends, he also feared that knowledge of his status had already begun to spread as rumor within the restaurant. His main concerns focused on how possible discrimination might affect his access to healthcare and medication. *"But, yea the only place that I'm really kind of mum about it is with coworkers. I just don't, that's like the kind of thing where I think in my work environment, I just.... it's scary. Because that's a cascade of issues, you know, losing my job, losing my insurance"* (Rocky). Florida is considered an "at will" state in which an employer or employee may terminate their employment at any time and for any reason, so long as that reason is not illegal. Under the expanded protections for people living with HIV, under the Americans with Disabilities Act, firing an employee because of their actual or perceived HIV status is illegal. However, an employer could simply find another, legal excuse to fire an HIV positive employee and could not be held legally accountable without proof that action was taken explicitly because of HIV status. This places positive, gay and bisexual men in Orlando in a precarious legal gray area, where protections for them exist but are easily side stepped through legal loopholes.

Other respondents recounted experiences of direct discrimination in the workplace. Ronny, who had previously worked as an entertainer and actor in Las Angeles, told me the story of how he found out he was HIV positive through a mandatory health check when auditioning for a movie role. Having experienced the deaths of many of his close friends from AIDS and related complications, he had avoided being tested for

years out of fear that he too had contracted the virus during his more promiscuous behavior as a young man in the 80s. Officially diagnosed in 2002, Ronny was a rare example of case where the HIV virus laid dormant in his body for almost a decade before it started to deteriorate his immune system.

So, I have, in over a decade, had one infectious disease after another invade my body. Infections, infections, infections and then infections. Because my immune system was so weak. And I was up for a movie role in Hollywood and even though this was against the law, one of the criteria from the backers, from the producers, was that everyone that was to be cast in the film had to get a health check and HIV had to be one of those health checks. But again, this is Hollywood, and there's big money involved in that. Even though it was against the law, and if you wanted to work, and that's what you wanted to do in Hollywood, then you bow down to the rules and you say 'ok, yes.' So, I had lost a lot of weight and I was tired all the time, and as I said earlier, I had one infectious disease after another invade my body. And I went to have the test, because I was cast in the part in the film. And I went to have the test. And at that time in California, you were allowed to find out your diagnosis over the telephone. Can you believe that? Over the telephone. So, I went to the doctor, and the doctor wasn't sure. He said there's something going on but I'm not sure that you're HIV positive. So, you know, another week went by. And then he finally called, and he told me over the phone 'yes, you are HIV positive' I was very weak at that point, tired, and it was a relief to know that. (Ronny)

Ronny advised that after the producers found out about his HIV status, he lost his part in the movie after already being cast. However, he was so physically weak at the time, having been given an AIDS diagnosis immediately, that he claimed that he was relieved by the situation, knowing he was not well enough to participate in the production anyway. Ronny made sure to emphasize that he was healthy and undetectable at the time of our interview, having come from “heaven’s gate” to being a mentor and resource for HIV positive people in Orlando through his position at Hope and Help and Re-Start. Unfortunately, the circumstances of stories like his were common among respondents.

John, a 57-year-old negative gay man from New Jersey, told a story about some friends of his who had faced similar discrimination in the workplace.

In New York there was a friend who had HIV and he also started to develop the lesions. And he tried to cover it with makeup but the makeup was not doing its job. And he would be at work, and they would think that he was sick.... well two of my best friends got fired because they knew what they had on their body....

They ended up suing, and it must have been the lawyer they had, not good. So, it was sad. And then they ended up dying, the both of them, and no family, just friends. And I remember all the friends coming together to pay for it and having a memorial service after. (John)

John, who had worked in the funeral business and volunteered for the famous Gay Men's Health Crisis in New York city during the height of the AIDS crisis, advised that such occurrences were common place among his friends and acquaintances during those times. Several other respondents, who did not necessarily relay experiences of direct stigma or

discrimination in the workplace, did express fear or discomfort with the prospect of coworkers gossiping about their status within the work place which could lead to their reputation or credibility as a professional being challenged.

Edward, who worked as an entertainer and dancer and regularly attended Re-Start meetings, advised that he avoided the topic of HIV while on company property because he feared that gossip about his status would make the workplace environment uncomfortable for him. Jack, a former professional biologist, expressed a similar sentiment as the reasoning behind his extreme caution and tendency to be more private in regards to discussing HIV generally with friends, family, or coworkers.

Yet, there were instances where respondents reported feeling safe disclosing their status in the workplace, even if it was only at a specific job. Daniel was a gay man who worked alongside Ronny as peer specialist for Hope and Help. Before working in a field that focused on HIV related services and education, he worked as a bartender and dancer in a gay bar when he was initially diagnosed in the early 90s. Being employed in an establishment that was owned by a gay man and frequented by gay clientele, he explained that he made the conscious decision to be very explicit and open about his HIV status in the workplace, partly because he wanted to present an image of a person living with HIV who was not sickly or emaciated like the common stereotypes of that time.

I told...I was working at the gay bar and at the time, I can't remember if it was the day I found out. Within the first week of finding out I was telling the other bartenders and the people that I worked with. And the management staff and the owners of the bar, they knew pretty quickly. And like I said, I was at the height of

my beauty and I pretty much wanted to be the poster child of HIV. So, I was telling people, I was showing people you know, you don't have to be sickly, you don't have to dying to have HIV. (Daniel)

Daniel went on to explain that after that initial job at the gay bar, he was never open about his status at work again until he began working with Hope and Help.

Archie, another Re-Start regular, spent more than 30 years working for an advertising company in New York City. He explained that he was open about his status in the workplace for a similar reason, wanting to spread awareness about the virus and also confident in the legal protections safe guarding his position in relation to his status. What this suggests is that context and environment can have a considerable effect on the amount of risk HIV positive people perceive in being open about their status in a professional setting, and that environments where employers, coworkers, or customers are less educated about HIV and transmission, or are not exposed to HIV related issues, may in fact pose a greater risk of negative consequences for HIV positive individuals who do chose to disclose their status in the workplace.

Effects of PrEP and Stigma in Romantic and Sexual Relationships

Another area where HIV positive respondents reported experiencing stigma in the form of internalized fear of rejection or discrimination, and sometimes in the form of direct exclusion, was within the context of romantic and sexual relationships. However, this was an area where the availability of contemporary medication for the treatment and prevention of HIV seemed to be having a positive effect on lessening or dismantling

stigma among HIV negative people, specifically within the LGBT+ community. Factors contributing to this included the knowledge that HIV positive individuals with an undetectable viral load had effectively no risk of transmitting the virus to another person, a concept that was made more widely acceptable by the backing of the CDC in 2017. The availability and use of PrEP by HIV negative gay and bisexual men was another major contributor to what some respondents viewed as a lessening of stigma caused by contemporary medical realities of HIV treatment and prevention in Orlando, specifically in regards to romantic and sexual relationships. PrEP specifically has been shown by a multitude of studies to be associated with lowering rates of new HIV transmissions since its release in 2012 (Fitzsimons 2018).

All three HIV negative respondents reported that they felt comfortable having a sexual or romantic relationship with someone who identified themselves as HIV positive and undetectable. Unsurprisingly, all three respondents also advised that they would be more wary of having those interactions with someone who was positive and not undetectable, but that it would not necessarily be a point of non-negotiation. Of the three HIV negative men interviewed during the study, only one was actively taking PrEP. John, who at the time of the study was in a serodiscordant relationship with an HIV positive man, advised that he had gotten access to PrEP through a clinical study. Participation was free and even paid at some locations. John expressed his personal feelings about PrEP and the peace of mind it provided for him. *“I just feel like it has...it keeps you more protected and much safer than it did before. Then anything out there, other than thinking about a condom. You know condoms can break of course. But a lot of people now, like if*

they are on PrEP, they are like 'ok, fine.' Of course, you still want to be cautious, nothing is 100%. But I, since I've been on PrEP, I'm very happy" (John). When asked if he believed that the use of PrEP was helping to lessen or dismantle stigma about HIV, John was uncertain but optimistic that people would feel safer and more willing to have sexual and romantic relationships with HIV positive people if they knew they had the extra protection. Studies have supported that PrEP can lower the risk of HIV transmission when taken as a daily regimen by HIV negative individuals with up to 90% effectiveness (Centers for Disease control and Prevention 2019).

Hector, who had never taken PrEP before and who had limited information about its use, also expressed an optimistic hope for the future of HIV. Having only learned about it recently from a romantic interest who worked in HIV related services, Hector advised that hearing about the potential effects wide distribution of the drug could have on HIV prevention sold him on its importance. *"...honestly when he first said it, everyone should be on PrEP, me in my gay mind was like 'why?' being ignorant that I was. And him going through that and saying that to me, I was like 'you know what, that's a movement. That's a movement I could very much get behind.' If like everyone just got on PrEP, like everyone, we would literally in me being born to me dying, in that span of time, in one person's lifespan it would be gone"* (Hector). If only it were as simple as handing PrEP out to every HIV negative person, free of charge. Yet like HIV medication generally, the cost of Truvada (One of two drugs approved by the FDA for use as PrEP) can be highly expensive without insurance coverage, leaving many people without access to it without the help of clinical trials, specific insurance or assistance programs. Hector

advised that he had simply never pursued getting on PrEP previously, and that he had health insurance coverage through his mother who would very likely be supportive of him seeking extra protection against HIV transmission.

Gregory, who had more general knowledge about HIV, was still unaware that PrEP could be taken as a daily regimen to help prevent transmission of the virus. When asked why he had never pursued getting access to it, he responded that he was uncomfortable taking too many different medications at once because of his body's sensitivity to different drugs. Economic hardship or lack of insurance coverage was not among the reasons he reported having reservations about taking PrEP.

HIV positive respondents had a more ambivalent reaction to the effect PrEP might be having on stigma. When asked if he thought the use of PrEP was lessening stigma in relation to people living with HIV, Archie had this to say: *“I think that it just hasn't had a full effect yet. Because a lot of people still don't really know. I didn't know myself. I kept hearing PrEP, what is that? And then I finally saw what it was and everything. But I'm sure it's had a lot of an effect on self-image. You don't feel like a pariah anymore. I always had to be careful if I bled somewhere or something and all kinds of things. At least you can't, at least I can't transmit it anymore”* (Archie). The idea that a lack of knowledge about available resources for the treatment and prevention of HIV dampened the positive effects of those same resources was a common theme among respondents.

Daniel, who was also in a serodiscordant relationship with an HIV negative man taking PrEP, expressed disbelief that he was living in a time where he no longer needed to fear transmitting HIV to his partner. However, he too expressed a similar sentiment

that it was too early to say that stigma had been impacted in a meaningful way by the use of PrEP, especially outside of the gay community.

It's too soon to tell because unfortunately the gay community knows about it. Were still getting the word out to the Black community, to the Hispanic community, to the heterosexual community. So, it's a slow process. I think for sure, were chipping away at stigma. But unfortunately, there's just still a lot of ignorance. There is still a lot of people who want to think bad. In the gay community yes, but outside of that I'm not sure if it has helped yet. But I do believe it's going to help. (Daniel)

Some respondents expressed concern over the idea that because negative, gay and bisexual men were starting to use PrEP, they were taking more sexual risks and possibly contributing to an increase in STI's such as gonorrhea and syphilis. This idea has been coupled with recent statistics that show a steady increase in reported cases of STI's among men who have sex with men since the early 2000s. While there is not enough evidence to draw a direct correlation with PrEP use, some studies have shown that in clinical trials where placebos were used and unblinded, participants reported using condoms less once they confirmed they were actually taking the medication. Randy, who weighed in on the topic from a healthcare provider's perspective, offered some insight to ease people anxieties of the possible drawbacks of PrEP use.

A lot of naysayers with PrEP say exactly those lines, that you just said, about there being this mixed message about don't use protection. Or look at this, we have all this rampant amount of gonorrhea or whatever. So, a couple of things.

First of all, I don't know any prescribers that give the message, take PrEP and don't use condoms. That's not at all what it is. It's very clear, even on marketing material that comes from the manufacturer, it says this is meant to be used in addition to existing safe practices. So, it's not to replace condoms by any means. As for the higher results, it is true. Now we have more results. But do you know what else we have? More testing. So, a patient who is on PrEP is coming into the office every 3 months. And we do a quick assessment with the individuals to determine whether or not they should have additional STI screening based on a questionnaire. So, we ask how many new sexual partners they've had. How many times they did not use protection? And then based on that, we give them a risk rating and we then would either suggest or encourage it. We offer to everybody. Anyone can come in and do full STI screening. But based on that score we may suggest or encourage it. And then there's also a tipping point where will say, "if you're going to remain on PrEP and you're still going to have these practices, were going to need to do full STI screening every time." So, I try to put it in a framework where someone doesn't feel judgement. We are a sex positive office; I want my patients to have sex. I just want them to do it healthy. So, yea, the naysayers, will go head to head with them anytime. This is, it's not oh my gosh we have more STI's because of PrEP. No, we are catching more. So, if you look at it from an epidemiology standpoint, we are actually probably decreasing it.

(Randy)

In spite of the revolutionary potential of prevention strategies like PrEP, and the comfort in knowing U=U, respondents still reported experiencing discrimination in the dating pool in relation to HIV. Many HIV positive respondents advised that fear of rejection or discrimination caused them to avoid seeking out romantic or sexual partners all together.

Edward explained in his interview that when he was first diagnosed, he was living with a man who he had been dating at the time. After noticing that Edward was taking medication frequently, he questioned him about the reason until he revealed that he was HIV positive. Unfortunately, his partners reaction was negative, and the couple separated immediately. Edward explained that the emotional stress of facing similar rejection had turned him away from seeking out physical intimacy with others in general.

As bad as it sounds, I am avoiding it right now. I'd rather be friends. I put this barrier around myself, I don't let someone get too close to me. I think it goes back to that trust issue. I don't want to hurt that individual. Nor do I trust this individual not to hurt me. So, like I said, I think I'm slightly walled off right now but if I wanted, I could have a relationship. Maybe someone might break that barrier, or I might break that barrier. But as of right now, today, I have a barrier around myself to prevent being hurt. (Edward)

Other respondents relayed similar tales of misconceptions, resulting in a withdrawal from dating.

Jack spoke with me about a man he had been dating online soon after his initial diagnosis, who let him down easy after he revealed his status to him. Even though the

man was kind about the rejection, Jack advised that it had grown difficult for him to “go past the point of no return” in romantic or sexual situations. What he referred to as an irrational fear prevented him from being more up front about his status in the beginning of a potentially intimate interaction. He pointed out that he had seen other positive men list their HIV status in their online profiles on mobile dating applications, but that he did not feel comfortable doing so himself. The concept of being open about HIV status on dating apps was something that came up in several interviews. The use of mobile applications and social media while seeking out casual sex or romantic liaisons is something that has gained more and more popularity amongst gay men since the early 2000s (Wu, S., & Ward 2018).

Rocky, who had only been diagnosed about a year before our interview, came of age during a time when online dating and the use of mobile apps such as Grindr was becoming the social norm among gay men. Fortunately, he had not yet experienced any kind of direct stigma or rejection in relation to his status while dating or seeking out sex partners. He counted himself very fortunate that he had not yet had a negative experience, but felt that it would certainly happen to him eventually. Still, he also expressed discomfort with disclosing his status publicly online. *“I’m on Grindr and stuff like that but it doesn’t say that I’m positive and I don’t know if I... I don’t think I would be comfortable. I know I wouldn’t be comfortable displaying it. You know, I would probably do that like admission by omission thing where it’s like you don’t say you’re negative. So, people could infer and I would never lie about it, but I would never advertise myself, I think, relating to that community”* (Rocky). He went on to explain that his fear stemmed

from the possibility of his status becoming public knowledge within his work place, risking his employment and ultimately access to health insurance. However, some respondents had a more optimistic perspective on the internet's effect on stigma and the way HIV positive people were able to approach dating.

Daniel, who had been in a monogamous relationship for some time, explained that he assumed technology would lessen the anxiety of disclosing one's status because it could be done through text rather than face to face, thus making the possibility of rejection less intimidating. *“It’s strange, in today's day and age, I think it would be different. Because I’ve never been on a dating site or Grindr or anything like that, but I feel like if I was sexually active and let’s say looking for a partner, I’m able to put that out there without verbally saying it.... So, if your discriminated against or rejected, it can be over text and not right to your face. Like I don't want to see you again because you're HIV positive. So, I would think that it would be easier through technology”* (Daniel).

Many dating applications geared towards gay men, including Grindr, now have options where users can identify their HIV status on their profile, allowing for the specification of being listed as undetectable. These options have been a more recent development in the midst of advertising campaigns which focus on education about HIV and prevention, and also inclusivity within the LGBT+ community. These campaigns and the inclusion of options for undetectable status listings have helped to raise awareness about HIV generally, and also to normalize HIV to the point where many positive men feel comfortable being explicit about their status online.

When asked if being HIV positive had affected the process through which he sought out romantic or sexual relationships, Ronny, who was one of the few respondents who expressed a general approach of being very explicit and forthright about his status, explained that he found disclosing early the most comfortable way to approach things.

There are several factors that go into that. First of all, at this point, I'm so comfortable living with HIV, I'm such an educator, such an advocate, that being an advocate is who I am. It's how I identify myself. I'm an advocate in the fight against HIV. I'm a peaceful, I chose to be a peaceful advocate. There are times though that one tends to get angry. But by in large I am a very peaceful educator, because that's what I do. That's what peer specialists do. I have to be a kind of symbol or an example for so many people. And so, I try not to let them all down, anybody down. So as far as romantic interludes, no. The best way for me, and again this is for me, might not be the best way for someone else. But I identify the situation immediately. Because I am very comfortable with it at this stage of the game. (Ronny)

In spite of the extreme differences in terms of the risk of transmission between the early years of the AIDS crisis and the present, interview data showed that stigma was still a major issue facing HIV positive gay and bisexual men in the context of romance and sexuality. Attitudes about the effects of resources such as PrEP were ambivalent, however there was a sense of hope expressed by respondents that they would show a stronger impact in the future.

Stigma in Familial Relationships and General Social Interactions

When it came to perceived stigma in relation to family members, nearly all HIV positive respondents reported that they had the support of their immediate families. Many turned to family members immediately after being diagnosed, seeking emotional and financial support. The concept of having a strong support system to help manage the many dimensions of physical and emotional stressors associated with living with HIV was a theme that surfaced in almost every interview. Daniel told a touching story about his relationship with his older brother, who knew about his HIV status through information passed on by his parents, but who Daniel had never actually spoken personally with about his diagnosis until recently. Daniel would visit his brother and his family in Cape Code for summers in his early 20s, right around the time he was diagnosed with AIDS. At that time, the early 90s, little was known about HIV and its transmission, and there was still a great amount of fear surrounding the virus. However, Daniel advised that his brother never made him feel like a pariah, never showing fear of being physically close with him or sharing eating utensils, things that would have generally caused many people to give pause when interacting with someone with an AIDS diagnosis in those days.

Similarly, Edward explained in his interview that after being hospitalized and given his diagnosis, he moved from Florida back to New Jersey to stay with his family while recovering. He cited that time as being a period where he reconnected with his spirituality, family, and friends which ultimately lead him to regaining his health before

eventually moving back to Orlando. Unfortunately, not everyone is lucky enough to have a supportive family.

Archie, who's own family was aware of his diagnosis and supportive, told a chilling story from the early days of the AIDS crisis about a close friend, Ed, who had been abandoned by his family on his deathbed.

Back when It first started back in the 80s, I had a best friend and he didn't tell anybody at all, except me, and that made me feel like it was up to me to save him. I tried but obviously I couldn't. So finally, when he went into the hospital, the last few days, they told his friends and everything and his friends started coming by, and his family came by. And, they hated me because they mistakenly thought that we were lovers and that I'd given it to him, but that wasn't true and even though the doctors were telling them he's gonna go in the next few days, his parents just left. (Archie)

Archie and Ed had met while working as singing waiters in New Hampshire. His death and unfortunate story are just one of many like it from the early 80s, when the LGBTQ+ community was being ravished by the epidemic.

John, who was working as a funeral director in New York city in the 80s, told me that it was common in those times for families to refuse to claim the bodies of gay men who had died from AIDs related illnesses. *"I had a friend when I was, I want to say 21, 22, who was really sick. And he was only like 2 years older than me. And he suffered, he died like 2 months later. So, his family disowned him, and it was really bad. They didn't want to bury him or do anything; they disowned the body or whatever. And I felt so bad, I*

said ok I need to do something and that's when I decided to step up and say I'm going to take action. And I did. And to me, it was the best thing in the world" (John). Fortunately, deaths associated with AIDS related complications have been on a steady decline since the advent of antiretroviral therapy in the late 90s. Based on interview responses within this small sample of gay and bisexual men in Orlando, stigma directed from family members did not appear to be a major issue facing positive, gay and bisexual men. Only one respondent, Jack, advised that he had not disclosed his HIV status at all to his family. However, in his case specifically, his decision was also linked to his decision not to disclose his identity as a gay man to his family, from fear of their reaction and the weight of the many years he had kept it hidden.

When it came to friends, social acquaintances, and every day social interactions, individual approaches and experiences of stigma varied greatly among HIV positive respondents. Some respondents felt more comfortable being very open about their HIV status with friends and social acquaintances, and were less afraid of rejection or negative reactions to knowledge about their status in more casual social settings. Daniel and Ronny, both peer specialist who worked with Hope and Help to connect HIV positive people from all backgrounds, genders, and orientations with services and resources, were among those who were the most open in general interactions about their own HIV status. This was a level of comfort that came from years of experience living with HIV and working in the positive community. Ronny had this response when asked if he disclosed his status to anyone other than his partner at the time of his diagnosis 2002.

No, because again there was that shame. There was that personal shame that some people have, that most people have. No, but I was a very high-profile figure and the idea of you know, letting people know that you have the virus was.... It's something it takes time to adapt to, at least for me. And in a short period of time I was able to deal with it. Because when I first went for treatment at the gay and lesbian center in Hollywood, you walk in there and there's several people in the waiting room that you know. So, it's like, why are you here? I think it's obvious. So once that happened, you had that exposure, that helped me become more comfortable. And over time I became very comfortable because HIV is not who I am, not who I am at all. It's a very small part. I live with HIV but I live in harmony with HIV. (Ronny)

However, years of experience living with HIV was not necessarily a determinant factor in how open someone felt about disclosing their status in social interactions and with acquaintances.

Rocky for example, who had only been diagnosed about a year before being interviewed, felt a similar comfort in being explicit about HIV with friends and even strangers. He cited the importance of visibility in dismantling stigma and that he relished the opportunity to show friends and acquaintances that people living with HIV can live normal, healthy lives and are not necessarily visibly sickly or different from anyone else. When asked if his HIV status had affected the way he sought out new friendships or social acquaintances, he made reference to a humorous quote he liked on twitter.

It would have an effect in the fact of like, I can definitely gauge people's reactions to it. What did...I just liked some tweet on twitter and it was something like.....'Growing the fuck up means not having to fuck with everyone, but also not having to beef with the people you don't fuck with' and that's how I feel about telling people, where it's like, oh, if you have the kind of reaction to it where it's like I know I kind of don't have to fuck with you. I'm at the age level where I feel able to handle things sufficiently. (Rocky)

However, not everyone had such capricious feelings towards the possibility of being discriminated against in social interactions due to their HIV status.

Jack, who was generally more reserved about his HIV status in almost every aspect of his social life, advised that he was really only open about his status in a select group of close friends, many of which were positive themselves or identified as gay men. Within groups of friends who did not identify with the LGBTQ+ community, Jack explained that he was not open about his queer identity and especially not open about his HIV status, preferring to take an approach of caution to avoid discrimination. Edward had similar feelings in that he felt it was unnecessary to disclose his HIV status with social acquaintances and friends, especially because his friend group primarily consisted of coworkers, who he was extremely weary of discussing HIV with.

A theme that echoed throughout these varied responses to HIV and social interactions was the concept of intersectionality. Specifically, the intersection of one's queer identity and their HIV status seemed to have a substantial effect on the way HIV positive respondents perceived the risk of stigma and discrimination when interacting

with others. At times, racial identity also came into play within this arena. It's notable that two of the respondents who were the most comfortable being open with their HIV status came from supportive families who were aware of their queer identities, and who also worked in professional settings that catered to the LGBTQ+ community and the HIV positive community. Often times, respondents also had a difficult time distinguishing between stigma that they perceived as a result of discomfort with people who identified as queer, or their HIV status. Many felt reluctant to draw a direct correlation with the experience of being a gay or bisexual man with HIV, because of the negative connotations that relationship has had in the past and how gay men have historically been stereotyped for contracting the virus. However, it is indisputable that HIV/AIDS has had a deeply traumatic effect on the LGBTQ+ community on a cultural level in the United States, as painful stories of loss and suffering permeated throughout the entire study. This coupled with the statistical reality that men who have sex with men are a high-risk demographic for new HIV infections in the United States, makes it clear that the intersection of these identities holds meaning. It is also important to note that while rates of PrEP use have been on the rise since 2012, and rates of new infections have begun to decline since then, rates of new infections among Black and Latino men who have sex with men have remained steady. This is due to the fact that White gay men over the age of 25 are the most likely to take PrEP, meaning that again, the accessibility of important resources for the prevention of HIV is still not reaching the communities most in need of them.

Strategies for the Management of Stigma and HIV

Finally, but none the lesser in its importance, the study sought to explore the ways that HIV positive gay and bisexual men in Orlando manage stigma in light of the cultural and structural circumstances of treatment and prevention. Interview data suggests that these strategies are informed by personal, intersectional experiences of identity. Perhaps the most obvious and universal way of mediating HIV stigma is by choosing if, when, and where to disclose one's HIV status. Several respondents reported being highly cautious about disclosing their status, either choosing to avoid the subject entirely when possible, or only discussing it with trusted friends, family, or other member of the HIV positive and LGBTQ+ communities. Still, some respondents were very open about their status with friends and strangers alike, some going even as far as being completely transparent about their status professionally, romantically, and socially.

Unsurprisingly, many respondents advised that maintaining their physical and emotional health was an important part of managing living with HIV generally, as well as a response to both external and internalized stigma. Maintaining physical health was especially important for men who were older, and who had been living with the virus for long periods of time. For some respondents, this was an imperative due to the fact that they had been diagnosed in the earlier years of the epidemic and thus had significant damage from the virus to their immune systems, making them more vulnerable to opportunistic infections. In some cases, where respondents were not entirely open about their HIV status with friends and family, being physically healthy made people feel less

pressure to discuss HIV. When discussing some recent health issues he had been facing, Jack had this to say about how his physical health had an effect on his mental and emotional state: *“I had some heart issues that had been under control, but my heart went into atrial fibrillation. So, never having been in the hospital before, but they took me by squad that day to the hospital. I was in intensive care for 5 days. So, my family came down and I felt the pressure of, you know, is it related to HIV? Is it related to my immune system? Probably, but I wasn’t going to tell them that... And that’s always been in the back of my mind until February which made that more prominent”* (Jack). Jack went on to explain that he had always kept a close eye on his physical health by regularly having routine checkups with his health care providers, and that he even worked in his leisure time as a fitness instructor at a local gym. The sudden upset to his otherwise stable health temporarily prevented him from working out, which jostled his confidence and sense of control over the virus and his life. Though he also advised that he was recovering well from these complications, which may or may not have been HIV related, the experience revealed additional ways that a personal sense of wellness affected the way someone managed HIV generally.

Something that many respondents reported as being a priority in maintaining one’s physical health while living with HIV was having a close and trusting relationship with health care providers. Many individuals living with the virus saw an infectious disease specialist at least every 3 months to have routine labs and health checks performed. This is a way that health care providers can closely monitor an individual's viral load, CD4 count, and other areas of the body which could be affected by

medications or the virus itself. It is also how providers can detect if resistances to medications develop, and allow them to quickly change a regimen if needed. In light of the cultural and social stigma already attached to HIV, being able to speak frankly and honestly with health care providers about it is essential for those who are living with the virus. Unfortunately, stories about negative experiences with health care providers were common amongst respondents, and often precluded their eventual change to providers they felt more comfortable with. Many of these negative experiences also occurred when individuals were initially diagnosed, or soon before or after their diagnosis. Archie had this response when asked about how he initially found out he was HIV positive:

I had a bad doctor is basically what happened. Um, when I first heard about It...I figured I could have it, back in the 80s, so I got tested over and over and over again, and it was always negative. For so long, that I started going in maybe every two years. Then I guess there was a period of about three years probably, when I didn't get tested, and I started getting sick. You know one thing after another, and I got all of the symptoms, and uh, I was pretty sure I had it. So, I called and tried to get an appointment and I couldn't. That office was just so terrible, they wouldn't give you an appointment for like three weeks. And eventually, my best friend went with me and we just sat in his office until he would take me in, and finally he said, I'm sorry to tell you have HIV. And I said I know that, just tell me how bad it is. (Archie)

Archie advised that he immediately switched to a new health provider after his initial diagnosis, and that he had a much better relationship and care from his providers then

after. Even still, he reported at least one other instance when a health care provider acted unprofessionally and caused him to change offices due to discomfort in their relationship.

Daniel also recounted a negative experience when he was initially diagnosed with the virus in the 90s, at a point when treatment options were still limited, and life expectancy was low. He told the story of how after waiting 30 days for the results of an HIV test, his test results were given to him without allowing for him to prepare to have his support system present for what he described as a life changing experience.

Back then it was a death sentence, it wasn't like today. We weren't told you're going to live a full life until the 2000s; They started telling people that. So, in my day and age, you weren't told you were going to live a full life. So, I wanted someone with me, and so I was upset the way I was told. You know when you're told that you're HIV positive, it's a life changing event. And I think most people will remember the day they were told they were HIV positive. (Daniel)

Like Archie, Daniel advised that he soon after found a supportive and empathetic provider who started him on antiretroviral medication immediately after his diagnosis, a practice that would not become commonplace until the late 90s.

In consideration of how nuanced and sensitive the relationship between a provider and HIV positive person can be, many respondents were very conscious of the type of individuals they sought out for treatment. Having a strong sense of empathy, and also being perceived as caring and even loving, were some of the criteria respondents reported as being characteristics they looked for in a healthcare provider. In relation to the intersection of respondent's queer identity and their experience of living with HIV,

interview questions also sought to explore the importance of having a provider who identified themselves as LGBTQ+ or advertised as being friendly to LGBTQ +issues. For many, this was an important part of having a relationship built on comfort and trust. Rocky, who had recently been diagnosed at the time of his interview, explained his view on this.

I mean, it's super important to me. It's like, you know, they're certain risks and I think there's...I mean it's just like a different world. I mean I think it could be its own specialty, you know there's so many different factors and things...it's very important to me. And there's not that many resources with it, you know? So, you kind of just have to like, you know, poke and prod and stuff like that. And I remember my doctor at OIC, she told me like I asked for her sheet of referrals and she was like circled three people's names and she was like 'they get it' you know wink. And that means the world, you know? (Rocky)

A part of Rocky's and several other respondents concerns about having an LGBTQ+ identified or adjacent specialist came from a desire to feel comfortable talking about sexual health, practices, and also intersectional stigma related to both being a queer person and living with HIV. Not feeling comfortable talking about queer sexual experiences, especially if that was due to fear of stigma about one's queer identity, made talking about sexual health as a queer individual difficult and strained. Still, feeling comfortable with a healthcare provider was not dependent on them identifying as a queer person for all respondents. Some individuals were able to have a close and effective

relationship with their provider because they perceived them as genuinely caring about their wellbeing and being empathetic to their situation.

Ronny, who also identified as a fierce advocate and educator of HIV related issues, had this to say about what a positive individual should expect of a healthcare provider and the importance of being identified as a part of the LGBTQ+ community:

I don't think that it's vital. I think it's important to have a doctor you're extremely comfortable with. Both in San Francisco and West Hollywood, the doctor who resuscitated me twice when I was first diagnosed, was a beautiful woman. And I loved her, I fell in love with her. Everything about her, physically she was beautiful, she was smart, she was a doctor, she had two beautiful twins. But her warmth and how she dealt with me, I knew she loved me and she was going to make sure that I made it. If you don't have that feeling that you know your doctor is there, you know that they're gonna help you make it, change. (Ronny)

Like many elements of the experience of living with HIV, this is one where personal experience and identity had a substantial effect on what respondents valued as necessary or helpful. However, there was a universal agreement amongst respondents that feeling comfortable with one's provider was important to maintaining one's physical and emotional health.

Emotional health was also perceived as highly important to living well with HIV, and maintaining emotional health was approached in a variety of different ways among respondents. Some individuals had more clinical approaches to dealing with trauma and stigma related to HIV, seeking out therapy as a means of managing those experiences.

Archie, who lived through the worst of the AIDS epidemic in the early 80s and who had experienced significant loss in relation to that, advised that he used cognitive behavioral therapy as a way of mediating negative habits and feeling triggered by certain ways that HIV/AIDS was depicted in popular media. Randy, as a local health care provider, also weighed in on the importance of mental health within the HIV positive community, and the lack of resources available to address it.

I think as far as mental health services, it's not as great. If I get somebody enrolled in our program and I need to get them mental health services, I'm looking at best, three to 6 weeks before I can get them in to see somebody. And for individuals where that's a new diagnosis, that's not appropriate...But I really like that individual counseling and I feel like the resources are just not very great. But that's a health care dilemma on a whole, and it's really exacerbated in Florida. (Randy)

The majority of respondents relied more heavily on the presence of a strong support system in their lives to manage stigma and the general challenges of living with the virus. That support system could manifest in various forms, family members being one of the most common among respondents. When telling the story of how he was initially diagnosed, Daniel advised that his parents were the first people he told about his status almost immediately after finding out. They offered him both emotional and financial support at a time when he was struggling with addiction as well as the new knowledge that he was HIV positive, even going so far as to prepare a burial plot and arrangements for him in the case of his death, which at that time was likely to occur

within 5 years after being diagnosed. He went on to describe that from an early age, he felt supported by his parents and siblings as a queer man, and was later deeply touched by the empathy acceptance that his brother and his family showed to him when he was living with them shortly after being diagnosed. In a time when fear about transmission was at a high, Daniel describe his family as a major source of support and unconditional love that helped him survive against all odds.

Edward told a similar story about his initial diagnosis and his reliance on family as a means to heal both physically and emotionally from the trauma of becoming severely ill soon after being diagnosed.

I took a break from Florida, I went to Jersey to be around my parents and my reason was, if I'm going to die, I'd rather die back in New Jersey around my parents and stuff, not around here. But when I went back home, I caught up on a lot of the stuff that I had missed over the years, while living down here. I saw my nieces and nephews for the first time. I was finally home for Christmas and Thanksgiving, something I really missed for a long time... So, when I went back to Jersey, I went back to church a little more often, and through that, my spirituality started growing again, so that spiritual fulfilment.... And I just relaxed and I just took care of myself, and my parents watched over me. And I just started...healing. Physically, emotionally, spiritually, mentally. (Edward)

Edward's mention of a need for spiritual fulfillment as a part of his healing process was something that multiple respondents brought up during interviews. In Edward's case, his connection with church came from his religious upbringing and

schooling. Participating in a religious community helped him connect with his family and the values which had been instilled in him from his childhood. However, for other respondents, participation in faith-based communities was based more so on a sense of belonging to a community of peers who offered spiritual and emotional support.

Jack spoke at length about his participation in what he called “Healing Weekends” in Ohio. These were seminars funded by the Methodist church that included workshops, support groups, and programs that helped people living with HIV bond and find a sense of community. The focus of these gatherings, though being funded by and held in the context of a church, were not necessarily focused on religious practices in their structure. Jack described them, rather, as bringing together diverse groups of people living with the virus from all walks of life. He advised that he was so touched by the experience, that he eventually became involved with the management of the events for years before relocating to Florida. Some respondents had an even more abstract relationship with the concept of spirituality and its connection to dealing with mental and emotional health.

Archie explained that due to his staunchly catholic upbringing, and the tension that caused him as a young queer man, he felt estranged from religion and that part of his early identity. However, he still felt a connection with the concept of spirituality from a philosophical perspective. *“It has helped me with questions that are a part of the big picture, you know, why I’m here and all that kind of stuff. And there is no particular spirit that I’m faithful to so, a long time ago I was into crystals. I’ll do, you know whatever happens to strike my mood at the moment, as long as it’s positive and, uh, helpful.”*

Everybody has to get better in their own way I guess” (Archie). Though individual approaches and interactions with religion and spiritual communities varied greatly among respondents, there was a general sense that connecting with those ideas and participating in those communities centered around them was a common way people living with HIV used to mediate and manage their emotional health and stigma.

Easily the most commonly mentioned strategy for managing as well as dismantling HIV stigma was education about the virus. This included learning about how the virus affects the body, the actual risks of transmission, and the logistics of prevention as well as the maintenance of HIV related treatment. Many HIV positive respondents reported seeking out education about the virus early into their diagnosis for the purpose of empowering themselves to take charge of their personal health. Ronny, who was diagnosed in his late 40s, often spoke at length about the importance of being an advocate for one's own health when living with the virus, especially as one aged and their body became less efficient at fighting infections and comorbid health conditions. Many Re-Start meetings were centered around presentations about the early detection of health conditions such as anal and prostate cancer, diabetes, and other health concerns that men living with HIV were more susceptible too, especially as they grew older.

Jack, who had spent much of his career working as a professional biologist, explained that he was adamant about speaking in depth about any test results with his health care providers so to keep a close eye on any changes which could show signs of health complications, a trait he attributed to his educational background. *“Well I majored in biology in college and taught high school science for 2 years. But then I went right into*

the laboratory, so I was a technologist. Then over the years you just move up the ladder, and then I got into management, and that's where I retired. But then I've always had an interest in the science part of HIV too...Some of my doctors get irritated with me because I know that any little symptom can mean something” (Jack). This sentiment of personal empowerment through education was echoed by most respondents, and in Jack’s case it also led him to an interest in volunteering and advocacy work. For several years, along with attending “healing weekends” and working as a fitness instructor, Jack also traveled around the state of Ohio doing public speaking about HIV related issues such as prevention and treatment. He described these experiences as both therapeutic and fulfilling, and even felt comfortable speaking candidly about his status in those spaces even though he was very cautious about discussing it in most other contexts. Both Daniel and Ronny, who worked as peer specialists and made their living as educators and resources for information about HIV, directly applied their knowledge to support local members of the positive community and administrative support systems for its members like Re-Start. Even John, an HIV negative member of Re-Start and a PrEP user, had worked for over 20 years as a volunteer and educator for the Gay Men's Health Crisis organization in New York city, an experience he also described as deeply fulfilling and meaningful on a personal level.

The concept of both educating and helping others was not only perceived by respondents as personally gratifying, but as a logistic imperative to improve visibility for the community and dispel common stereotypes and misconceptions about the contemporary environment of treatment, medications and prevention options. This was

seen by some as a needed rebuttal to media representations of HIV and those living with it that often-centered narratives during the epidemic in the 80s and early 90s, when deaths were at their highest and medication options were few and far between. These kinds of representations were perceived as being the only exposure many HIV negative people had about the experience of living with HIV. Especially outside of the LGBT community, celebrities such as Magic Johnson and Charlie Sheen were the only examples many people knew of or related to outside stories created by Hollywood and popular media which often focused on death and tragedy, or reduced HIV positive characters to their diagnosis. *“Even when you look at major literature or major art, like Angels in America or like fucking Philadelphia or anything like that. The only touchstone for showing America is like death, when relating to gay men”* (Rocky).

Again, the concept of intersectional identity and its effect on how stigma manifests in lived experience became more apparent when discussing the ways that HIV was represented in popular media. Gregory, who was both negative and fairly educated about HIV generally, expressed his concerns about how existing stigma about LGBT representation in media and an overall lack LGBT characters also contributed to the lack of well developed, three-dimensional HIV positive characters. When asked about how he wanted to see HIV positive people represented in media, this was his response.

Yea, just like this person loves the color mauve. They like to go pick strawberries, they are HIV positive, their partner is not. They happen to have an interest in vintage cars. You know, just like stupid shit. Have it be a trait you know, that’s just, it’s there but it’s not a fucking thing. But I don’t even see it represented at all

for the most part. And I feel that might tie in to the fact that there is this idea that it's a gay virus and there's already so few LGBTQ+ characters in media as it is.

(Gregory).

Some respondents made note of the fact that over the past decade, positive representation of HIV positive people in popular media has become more common and sensitive to the way media has dehumanized people living with the virus. Shows like FX's *Pose*, though still taking place in the 80's, approach the topic of HIV from a more emic perspective that contextualizes positive characters as complex individuals who are not defined by their experience of the virus. Other popular television series like Netflix's *Elite* and Showtime's *Looking* have included HIV positive characters in primary and supporting roles which do not focus their narratives on experiences of tragedy centered around their status. These examples, though few in number, represent a sense of optimism for the future of the representation of HIV in popular media which will help to shift the cultural narrative of the virus from epidemic to present and future.

Educators and advocates are also working to disrupt stereotypes and crisis narratives on the ground. Ronny, who advised that the best way to dismantle stigma was sharing one's personal story, passionately described Re-Start's participation in the Orlando Pride Parade and the importance of communities of support and their ability to inspire both negative and positive people to take action in empowering themselves and others.

It's very easy to feel alone. And that's again, the importance of support groups like Re-Start. You walk into a room, and now they're 20 sum individuals, and

most of them are men. And I see new comers, the first time they walk through the doors their heads are down and they're inward and quiet. Because you don't know what to expect. Am I going to see someone I know? And over...when they keep coming back, then you know you've influenced them as a group. Because that's the best way to learn about services, that's the best way to learn about finding new pharmers. This happened to me, so I'm going to share my story. Sharing stories, the best way. And then all of a sudden, a lot of these young people who come through the door, there is a fierce advocate inside of them waiting to be brought out. And over time, over nurturing these people, they get more and more involved. Until last year, Re-Start was the first organized group of HIV positive individuals that ever marched in the pride parade in Orlando. And we had our Re-Start t-shirts, so we were one. We had signs that said U=U, PrEP, love positive, my partners on PrEP. And you should have seen the crowd. The crowd here was like, they looked at us, there we all are with our uniforms and our shirts and our signs. "Is that what I think it is?" You could see the expression on their faces. And then you could see the look that changed, and then you heard the cheers and the roars and the applause. It was exhilarating. (Ronny)

As a whole, the interviews revealed that the connection between experiences of stigma by HIV positive gay and bisexual men and contemporary medical realities of HIV treatment in Orlando was strongly influenced by structural and social barriers to accessing available resources and health care services. These barriers included the high price of medication and treatment which caused widespread reliance on economic

assistance programs. They also included a lack of public transit options and the uneven distribution of agencies offering HIV related services across the Orlando city scape, as well as a general lack of knowledge in the most vulnerable communities about available resource. This was also coupled with difficulties navigating the healthcare system.

In relation to the ways that stigma was perceived and manifested in the lives of HIV positive gay and bisexual men, an internalized fear of discrimination was the form most commonly reported by respondents. This fear lead individuals to have varying degrees of comfort disclosing their status across professional, sexual-romantic and social contexts, sometimes manifesting as actual experiences of direct exclusion or discrimination in these areas both in the early years of the epidemic and in the present.

Finally, interview data showed that the most common themes among strategies for the management of stigma and the experience of living with HIV included choosing if and when to disclose one's status to others in various social settings. Specific attention to the maintenance of physical health through adherence to medication and regular doctors' visits was also reported as particularly important among respondents, which was achieved by having an open and close relationship with one's health care provider. Of equal importance was the maintenance of one's mental and emotional health through strong support systems of various forms ranging from family members to support groups like Re-Start. The strategy commonly reported as the most effective tool for the management and dismantling of stigma was education about the contemporary medical realities of HIV treatment and prevention. This included education about how the virus affects the body as a form of self-empowerment by HIV positive individuals. It also included

education for negative peoples through volunteer, outreach and advocacy work, and the sharing on people's personal stories and experiences as a means to transmit both knowledge and create connection between people and communities.

Chapter 5 Discussion and Conclusions

Analysis and discussion

Critical medical anthropology offers an appropriate theoretical framing and entry point into the analysis of the biosocial and biocultural connection between contemporary medical realities of HIV and stigma. In his book, *The Anthropology of Infectious Disease*, Merrill Singer refers to CMA as a framework which:

...views health as an expression of social relations within society, especially the ways that social inequality structures health disparities and vulnerability, patterns morbidity and mortality, and contributes to the social distribution of disease-related social suffering but also to health-related resilience, agency, and social action. (Singer 2015: 18)

This is especially relevant when considering the many structural and social barriers to accessing HIV related health care and services within the context of Orlando, Florida. These barriers limit the level of benefit individuals reap from advancements in medical technology and reproduce stigma and inequalities in lived experience. The biosocial and biocultural approach in anthropology recognizes that biological life does not exist in a vacuum and apart from social and cultural life. As stated previously, this study seeks to take a more integrative and emic approach to HIV related research as a foil to the biomedical focus of past endeavors.

Crucial to an understanding of how social, cultural, and biological life are intermarried within the context of stigma and HIV is the concept of embodied personhood (Turner 1986). Using a critical-interpretive approach within medical anthropology, it is essential to consider how the individual is situated within the context of economic, political, and cultural realities. This focus on the relationship between culture and practice, and their connection with the human body as well as manifestations of health and illness, privileges the body as the arena where these seemingly external forces coalesce into lived experience as a dynamic whole. Viewing the body and the individual as inherently a part of the greater network of social and cultural relationships directly challenges the historical, epistemological position of biomedical science rooted in cartesian dualism (Lock and Scheper-Hughes 1996). In this way, personal lived experience is both a direct manifestation of cultural, political, and economic circumstances, but also an avenue to communicate agency and resistance in those circumstances through practice. Using the frameworks of critical and interpretive medical anthropology, I will discuss how stigma contributes to the production of structural, syndemic relationships that create vulnerable populations of people living with HIV in Orlando. I will also discuss how personal experience acts as a manifestation of those syndemic relationships, as well as a means to interpret individual agency and resistance to social and cultural circumstances through body praxis (Lock and Scheper Hughes 1996).

The concept of disease syndemics is especially relevant to an analysis of the uneven distribution of health care access and new HIV infections in Orlando. Syndemics

refers to the damaging interaction of co-present diseases which is made possible by adverse social, cultural, and environmental contexts (Singer 2015), however It also describes the interaction of disease with these contexts in a more general sense. Structural issues like the high price of health care and medication, coupled with environmental concerns like an uneven distribution of HIV related service agencies across the Orlando city scape, creates a sort of syndemic relationship between instances of poverty and location. Without the financial means to afford insurance and thus treatment, as well as a reliable and affordable means of transportation to and from health care providers, individuals who find themselves living on the westside of the city are more likely to experience disparities in consistent access to treatment. The westside of the city also happens to be an area with a high population of African Americans, who already experience structural violence at the intersection of race as well as social conceptions of disease and sickness. Considering these interactions, it is no wonder that rates of new HIV transmission among Black and Hispanic men who have sex with men are amongst the highest of any other demographic.

Another syndemic relationship which was more evident in my daily interactions with Re-Start members than within interview data was the high instance of histories of substance abuse among group members. Intravenous drug use and the sharing of syringes has been proven to increase the risk of HIV transmission for obvious reasons, however the relationships between cultural stigma directed towards gay and bisexual men, internalized homophobia, depression and increases in “high risk behavior” are not as apparent. Research has shown that gay and bisexual men who experience self-

condemnation and internalized homophobia are more likely to engage in risky behaviors such as drug use, unprotected sex, etc. and to be HIV positive (Stokes and Peterson 1998). This association represents yet another way that cultural mores interact with biology to create vulnerable populations of people in reference to the spread of infectious disease.

Of great importance and relevance to this is what Paul Farmer (2004) refers to as Pathologies of Power, or the ways that poor and marginalized people are framed as being the cause of their own health disparities. The focus by biomedicine, advocacy programs, and educational initiatives on curtailing what is interpreted as “high risk behavior” instead of mobilizing action to address structural violence, inherently frames people living with HIV as being responsible for their own illness in the eyes of society. This generates stigma both within the healthcare system and in everyday social interactions by deflecting responsibility for HIV onto individuals, rather than the circumstances which make them vulnerable to being infected or the barriers which prevent them from receiving treatment. This kind of framing, coupled with media narratives that represent HIV as a fatal, untreatable disease suffered by gay men, causes gay and bisexual men living with the virus to internalize stigma in the way that they view and value themselves. This was especially evident in interview responses in relation to how stigma manifested in lived experience, the most common form appearing as an internalized fear of discrimination and sense otherness. This internalized stigma has the effect of distorting an HIV positive individuals body image, which psychiatrists have linked to conceptions of the individual self (Schilder 1970: Horowitz 1966). In conversations with interview

respondents, body image was oftentimes a strong influence on how individuals approached physically and emotionally managing HIV and related stigma in their everyday lives. When respondents talked about periods of time that they felt physically unhealthy or that their bodies were a source of danger for themselves or others, specifically related to the risk of transmitting the virus, they tended to report being more likely to isolate themselves physically and socially, and to be generally less happy in their emotional states of mind.

Lock and Scheper-Hughes's (1996) reference to the concept of the "three bodies" is helpful in understanding how structural, syndemic circumstances manifest in personal experience. The individual body, which encompasses the phenomenological experience of everyday life, also represents a sense of embodied self which is separate from other bodies (Mauss 1985). In regards to stigma, the individual body acts like a field where socio-political, economic and cultural circumstances interact to create experience. This is where the social body, encompassing the symbolic way that health and sickness are conceptualized in relation to cultural values (Douglas 1970), interacts with the political body, the way power relations outline how the body or individuals are controlled. In the US, being "healthy" is symbolically understood as a kind of status that is achieved by avoiding inappropriate behaviors, and having regular access to health care. In the context of HIV and stigma, the social body represents the way people living with HIV are seen as being responsible for their own illness for engaging in practices which are deemed inappropriate by the dominant culture. For gay and bisexual men, homosexual sex, promiscuity, and or not having the financial means to afford health care are considered as

inappropriate behaviors that embody a lower status, and thus legitimize being “unhealthy.” This symbolism and reasoning are inherently political as well, representing the political body in how the stigmatization of certain identities, and practices that are seen as related to those identities, are a kind of social control exerted by dominant culture. By othering those who deviate from the cultural norm, and ascribing responsibility onto them for their own health disparities, the dominant culture is able to justify the exclusion and marginalization of people living with HIV as a way of protecting itself from a perceived threat of sickness and lower status.

This dilemma is also illustrated by discussions of the micropolitics and macropolitics of disease. Micropolitics refers to the ways that suffers of serious illness must engage in a political and narrative process of explaining and legitimizing the circumstances of how they became ill. Involved in this process are interactions with healthcare providers and treatment by others (Gay Becker 1999). Macropolitics, conversely, relates to dominant ideas about the source of disease as well as how those who are infected are portrayed socially and the way that affects their access to health care. These concepts manifested in the lived experiences of interview respondents in the way that they described being initially diagnosed with HIV, entering into treatment and fielding the various ways that their diagnosis affected a variety of social relationships. Many respondents described a sense of disbelief after their initial diagnosis, especially in cases where the respondent did not interpret their sexual history or behavior as fitting the social narrative of “who was supposed to contract HIV”. These individuals often passed through periods of denial, often times avoiding getting tested in spite of signs that they

could be infected, because they could not rationalize it based on their preconceived notions of what it meant to HIV positive. Followed by this period, many respondents switched their focus to regaining a sense of control over their own bodies by staying physically healthy through adherence to treatment and regular monitoring by healthcare providers. However, when it came to discussing their status with others, many interpreted the risk of possible discrimination and exclusion due to their status high enough that they chose not to disclose it all, or were very selective about how, when and with whom it was disclosed. This sense of risk and fear was described as originating from the way the general public understood the experience of living with HIV. This understanding was tempered by a lack of knowledge about successful viral suppression and prevention options such as PrEP, as well as a sense that the environment of treatment was still as it was in the 80's. This misinformed and pervasive perspective was also seen as being reified by popular media and a lack of media that represented HIV people in their wholeness or as normalized.

All HIV positive interview respondents were in treatment at the time of the study and had consistent access to healthcare in spite of structural barriers to treatment. This was due in no small part to their affiliation with the Hope and Help organization and other local agencies which offered HIV related services and economic assistance. However, all respondents still reported stigma as being pervasive socially and culturally as they experienced it as individuals. The way that individuals approached the management of that stigma varied greatly from person to person. This is an area where postmodern theory lends a hand in supporting the phenomenological framework of using

lived experience as a medium to explore the relationship between contemporary medical realities, stigma, and the way gay and bisexual men approach living with HIV. Specifically, James Clifford's (1986) concept of partial truths is useful in legitimizing how different sets of life experiences ultimately shape the narratives people create about the experience of living with HIV and how they chose to exercise their own agency in that experience. Though Clifford's writing focused specifically on texts and how ethnographers create "true fictions" by refracting their own knowledge through a cultural lens and literary devices, that concept can be extrapolated to relate to the way individuals tell stories that relate their personal experiences with the experiences of others. In this way, each interview provided a piece of a greater truth about what it meant to live with HIV and how someone could best approach the struggles that entailed.

In relation to phenomenology and Merleau-Ponty's concepts of Holism and integrated care, as discussed by Thomas (2017), strictly biomedical approaches and methods fall short of being able to frame the experiences of positive gay and bisexual men in a way that highlights personal choice and experience as a part of maintaining emotional and spiritual health. For some respondents, such as Ronny and Daniel, who worked in the context of HIV services and helped offer access to those resources as a part of their professional lives, advocacy and education were major sources of emotional fulfillment. In both of their interviews, they spoke at length about the importance of education in dismantling stigma and sharing one's personal story as an invitation to making connections with positive and negative people around the subject of HIV. Unsurprisingly, both were very open about their HIV status in all aspects of their social

lives and relationships, and enjoyed strong support systems from family members and friends throughout their lives. Both were highly confident in their sense of self, Ronny even describing himself as living in harmony with HIV. Other respondents, like Edward, found comfort in being a part of a spiritual community and regularly attending church services as well as participating in Re-Start. Edward's desire for spiritual fulfillment came from his African American culture and family history within the church, where he was able to practice his love for dance and performance and later integrate them in his career. However, past trauma and experiences also led Edward to be more reserved about disclosing and discussing his HIV status, and even in seeking out romantic and sexual relationships. Some respondents, like Jack, described using a combination of participation in spiritual communities, volunteering, and working as an educator and public speaker. For him, these were areas that he felt a sort of relief and freedom to discuss his experiences with HIV where he would otherwise never discuss it outside of specific social circles.

The way these men approached the management of stigma in relation to HIV represents the importance of body praxis (Lock and Scheper-Hughes 1996) in understanding how people living with HIV communicate agency and resistance to the political control over their bodies. In continuing to pursue physical and emotional health, and creating communities around the characteristic of being HIV positive that were supportive and privileging of their status rather than demeaning, these men effectively inverted the framework which legitimized them being othered and excluded by the dominant culture. Through actively educating the general public about contemporary

medical realities, and advocating for the fair treatment of those living with the virus, these men expressed a kind of resistance to the syndemic and symbolic systems which ultimately created their vulnerabilities to infection and barriers to treatment. In this way, the very act of sharing one's personal story and lived experiences of HIV and stigma is an act of free will in the face of the greater political, cultural and economic circumstances that are beyond the individual's control.

Conclusions

In relation to the research questions which guided this study, the relationship between contemporary medical realities of HIV treatment and the environment of stigma experienced by gay and bisexual, positive men in Orlando is inseparable from the context of structural violence which creates barriers and uneven distribution of access to health care within the city. This is manifested in the high price of medications and treatment, coupled with issues of location and the distribution of agencies which offer HIV related services. A lack of access to needed resources, combined with less exposure to and knowledge of the kind of resources available, effectively creates communities with greater vulnerability to the spread of infection and access to treatment.

All interview respondents had consistent access to treatment at the time of the study, and all respondents reported stigma as still being pervasive socially and culturally. There was not a consensus on whether or not contemporary medical treatment and prevention options had a substantial effect on lessening the amount of stigma experienced by respondents, many claiming that they were optimistic that changes would be more

apparent in the near future, but that it was too soon to see them presently. This stigma manifested in the form of an internalized fear of discrimination and exclusion, externally in the form of structural barriers to accessing health care, as well direct instances of discrimination and exclusion across a variety of social contexts. This stigma was interpreted as being fueled by a lack of knowledge about contemporary medical realities of HIV treatment and prevention among the general public, and reified by symbolic violence through media representations which centered the social narrative of HIV during the epidemic, or not representing people living with HIV at all.

The ways that people managed HIV stigma were dictated by personal life experience and preference. Among these strategies were patterns of choosing if or when to disclose one's status, reliance on strong support systems, and the creation of social communities through participation in spirituality, advocacy and educational work.

As stated previously, anthropologists have begun to shift their focus in HIV/related research to "post crisis" narratives that are attempting to address the same questions explored in this research. It is highly important that researchers continue to add to this discussion by offering nuanced perspectives that are grounded in the specific context of different communities of HIV positive people. It is equally important that research does not fail to integrate the experiences of the individual with those contexts, and present the subject of HIV stigma as a complex assemblage of phenomenological experience and social, structural circumstances beyond individual control. Researches need to help mobilize action against structural barriers to accessing health care, and in doing so, help to dismantle stigma which is built into the fabric of our culture world

views. Researchers need to empower HIV positive people by providing platforms for them to share their experiences, while also using their expertise to contextualize those experiences within the back drop of social and cultural networks. Part of this should include creating space for HIV positive researchers to take the helm of research projects and write about contemporary issues and experiences of HIV positive peoples which are informed by an insider's perspective. Having HIV positive scholars produce more knowledge about HIV related issues will help to humanize those living with the virus and present them to the public as capable and productive members of society and the academy. It will also help to legitimize the personal stories and experiences of positive people, and allow for those stories to be shared with wider audiences and in turn help to dismantle stigma on a larger scale.

More research needs to be done on communities of HIV positive people living in countries, such as Canada, which utilize universal health care and effectively solve many of the structural issues created by the health care system in the United States. These communities likely face different kinds of barriers to access, and are influenced by different histories with HIV that may cause stigma to manifest in substantially different areas and forms. Though the breadth of HIV/AIDS related research is vast on the global scale, there is more research to be done about the contemporary social environment of HIV as well as the environment of treatment in various political and economic settings.

Most importantly, HIV related research must continue to present those living with the virus in their wholeness and as agents which do have control over their own representation in academia and media, and over their own lives and bodies. Too often,

research and media reduce positive people to their status, to memories of tragedy and loss, and to stereotypes about transmission and what it means to live with chronic illness. Research needs to further develop the connection between individual experiences of stigma and the greater context of health care, while illuminating the many ways that available resources and quality of life has changed since the early years of the epidemic. Though available resources for the treatment and prevention of HIV are more effective than ever before, we all must continue to discuss the many ways that stigma persists culturally, structurally, and socially for positive peoples and empower them to share their stories and experiences to educate the general public and dismantle stigma by transforming fear with knowledge and empathy.

Personal experience, contextualized by the interaction of the three bodies, challenges biomedicine's homogenous conceptualization of what it means to physically and symbolically live with HIV. That homogeneous conceptualization, inherently influenced by cartesian dualism which separates the body, mind and self from cultural and social life, both produces stigma on the structural level and reproduces stigma as it is internalized within the individual body. That is why it is important to analyze the relationships between contemporary medical realities of HIV, the environment of stigma experienced by positive, gay and bisexual men in Orlando, as well as the ways stigma manifests and is managed in individual experience, as parts of an integrative whole that that is situated within the body's physical, symbolic, and political forms. By combining critical medical anthropology and critical interpretive approaches, this complex whole of biological, socio-political, economic, and cultural relationships can be better understood

through the context of structural, syndemic relationships of inequality in health care, and the manifestations of those inequalities in the form of internalized stigma and acts of resistance and agency in individual experience.

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