

Aiding the Epidemic:

The effects of PrEP, PEP, and TasP on the Historical Stigmatization  
of HIV and AIDS

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*“Inclusion happens because of intention, not by magic.”*

*--Laurel Sprague, national coordinator of the People Living with HIV Stigma Index*

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## **Introduction**

We live in a world where medicine provides a security blanket. In 1928, the discovery of penicillin provided mankind the first antibiotic to fend off microbial species that cause infections. Soon after, in 1944, the discovery of streptomycin helped lower tuberculosis infection rates and aid those who were suffering. Since then, tuberculosis has developed resistance and our arsenal of antibiotics has diminished with each new drug-resistant bacterial strain. Faith is placed in the medical community for definite answers and quick solutions, yet when there are no immediate solutions, society anxiously questions the capacity and capability of medicine as that is challenged by the nature of an unknown disease. The combination of these two was key for the panic around the human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS) epidemic.

Since their formal recognition in the 1980's, both HIV and AIDS have had a global impact on many aspects of life. The unknown nature of HIV led to a social and cultural marginalization of individuals with either condition that was built upon fear and anxiety. Biologically, two fronts were presented: first, both challenged our confidence and reliance on antibiotics as HIV and AIDS, cannot be currently cured with them, creating a technological race to be able to eliminate both; the other front is the opposite, both set a standard in comparing other diseases or infections to the grand scale of the HIV and AIDS epidemic. Fortunately, now in 2017, medical advancements have been made in treating and prolonging the lives of people living with either HIV or AIDS and people who may be potentially exposed to HIV. New antiretroviral medications have been developed to help prevent exposure and may even eliminate the virus after exposure to HIV. While the HIV and AIDS epidemic may not be as biologically lethal as it once was, its social ramifications remain in society, and now the question that remains

is will new antiretroviral medication help change and replace society's past and present stigmatization of affected individuals with one of empathy and understanding?

Through a historical analysis of social and cultural stigma around HIV and AIDS within the LGBT community, this thesis will observe whether there has been a shift in how stigma is perceived with the introduction of new antiretroviral medications, such as pre-exposure prophylaxis (PrEP), post-exposure prophylaxis (PEP), and Treatment as Prevention (TasP). While it will acknowledge both homosexual and heterosexual means of transmission, this thesis will specifically focus on how stigma has affected the LGBT community. The foundation of this thesis will focus on literature and media, within the United States of America, during the 1980's, which is the time that HIV and AIDS came to be recognized and feared. To trace this timeline, modern representations from the 2000's and 2010's will be used to present a shift in the understanding of the nature of both HIV and AIDS. The modern forms of representation will include media, personal interviews and films.

Through this thesis, by no means, shape or form, is it a critique on individuals living with HIV or AIDS. This thesis does also not attempt to present a definite answer as to how to end the stigma towards individuals living with either HIV or AIDS, but it aims to allow the reader to know how society and culture gave influenced one's opinion. This is key as it highlights how not much is done for the resilience towards stigma, even though medicine attempts to highlight achievements primarily through a biological perspective. I chose to undergo this because I believe that there has been a primary focus on the biological effect of both HIV and AIDS, which is by no means a negative factor; however, I wish to bring awareness that I believe have changed from when HIV and AIDS first appeared. I have also chosen to focus on this topic, as I believe, it is still a taboo subject even with the advancements that have been made. In bringing awareness

to this topic, it is my goal that any reader may learn to recognize the impact that HIV and AIDS have had on interpreting how medicine is perceived and how people may be reduced to a body that is simply characterized by its biological attributes. In reminding others about the history of HIV and AIDS and tracing how each have been perceived, which is by no means an easy task, and I do hope this work is built upon in future generations, each respective, yet intertwined history emphasizes how medicine and society are interdisciplinary factors that can help change the biomedical model.

### **Methods of Research**

The groundwork for this thesis is literature from and around the time HIV and AIDS were discovered. Some sources for this literature came from Professor Roebuck's "Anthropology of HIV & AIDS" course alongside texts from the AIDS library, located in Philadelphia. For statistics, the Centers for Disease Control and Prevention (CDC), and the World Health Organization (WHO) will provide accurate information on HIV and AIDS prevalence. Websites like the People Living with HIV Sigma Index will provide fieldwork data in which stigma is measured and quantified while other websites like the ACT UP Oral History Project will provide testimonies from around the time HIV and AIDS were occurring. These interviews will be compared and analyzed with interviews that I have conducted.

The interviews that I conducted were done so in line with the IRB committee here at Haverford College within the time frame of mid-December 2016 to mid-March 2017. I chose this timeframe as I would be able to conduct interviews during winter break back home in California and then conduct additional fieldwork in Pennsylvania. The reasoning behind this was to compare how each coast view the national and global presence of HIV and AIDS. I advertised my thesis by placing flyers within health centers and local gay bars, cafes, and restaurants.



Five to six adults were sought out to participate with the majority being adults that identify as members of the LGBT community and one or two adults that do not identify as such members. Six interviews were conducted in total, however, only two interviews could be used: one from Ontario, California and the other from Ardmore, Pennsylvania<sup>1</sup>. Participants were encouraged to select a location in which they were comfortable speaking about a sensitive topic and were compensated with reasonably priced food for their time. They were not asked to disclose their health status, but rather their knowledge about HIV and AIDS was inquired alongside their general feelings towards both. Through this information, a contemporary perspective will be represented as the participants were alive around the time that the HIV and AIDS epidemics were happening, and can help emphasize a shift in stigmatization.

### **An Abbreviated History of the Stigmatization of HIV & AIDS in the 1980's**

Between October 1980 to May 1981, the *Morbidity and Mortality Weekly Report* reported the first cases in Los Angeles, California, where five homosexual males were diagnosed with biopsy-confirmed *Pneumocystis carinii* pneumonia, a pneumonia exclusively limited to severely immunosuppressed patients (Centers for Disease Control [CDC] 1981:250-251). While medical officials were unable to definitively diagnose the patients, they concluded that the “observations suggest the possibility of a cellular-immune dysfunction related to a common exposure that predisposes individuals to opportunity infections such as pneumocystis and candidiasis (CDC 1981:251). Although there was no clear biological agent that lead to the symptoms, notes were made correlating biology with sexuality as “the fact that [the] patients were all homosexuals suggests an association between some aspect of a homosexual lifestyle or

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<sup>1</sup> Four participants opted out of this study after the current President was elected. The participants were reassured that their information would be confidential, yet their fear of being exposed led to their opting out.

disease acquitted through sexual contact and *Pneumocystis pneumonia*” (CDC 1981:251). This medical report was the first of its kind, and from this point, it marked the “beginning of the AIDS crisis” (Roebuck 2016:12).

Soon after this discovery, newspaper publications began to arise describing an “outbreak occur[ing] among men in New York and California” in which 41 cases of a “rare and often rapidly fatal form of cancer” began to arise “in... *homosexuals*” (Altman 1981: A20; emphasis added). After identifying the mysterious cancer as Kaposi’s Sarcoma, Altman describes how medical officials were baffled as they were taught that Kaposi’s Sarcoma begins on the legs after ten years, but the emerging cases seemed to defy this (1981: A20). He visualizes the cancer as “spots [that] generally do not itch or cause other symptoms, often can be mistaken for bruises, sometimes appear[ing] as lumps and can turn brown after a period of time” while also causing lymph glands to swell up and then kills the patient (Altman 1981: A20). The medical community continued to be perplexed as the CDC predicted, at the time, that Kaposi’s Sarcoma occurred in “less than six-one-hundredths of a case per 100,000 people, annually, or about two cases in every three million people,” and was strongly associated with equatorial Africa, primarily in children and young adults (Altman 1981: A20). Within the United States, it primarily affected men that were older than 50 years, yet the emerging cases described how doctors, in both New York and California, diagnosed men ranging from 26 to 51 (Altman 1981: A20). The strong association of Kaposi’s Sarcoma with homosexual men became reinforced as Altman refers to Dr. Curran, who claims “there was no apparent danger to nonhomosexuals from contagion [as] ‘the best evidence against contagion...is that no cases... have been reported to date outside the homosexual community or in women (1981: A20). This negative connotation of illness towards the homosexual community intensified as Dr. Friedman-Kien claimed most cases described

“homosexual men who have had multiple and frequent sexual encounters with different partners, as many as 10 sexual encounters each night up to four times a week” (Altman 1981: A20). This statement reinforced a negative stigma towards affected homosexual men, one that generalized that they were unsanitary through their deviant promiscuous actions resulting in illness.

Per the Oxford English Dictionary, stigma is defined as a “sign of severe censure or *condemnation*, regarded as impressed on a person or thing; a ‘brand’” (Stigma, N. n.d.; emphasis added). Emphasizing Allan Brandt’s “AIDS: Social History to Social Policy,” I will highlight how society is challenged and transformed when presented with ambiguities and obstacles from diseases. Brandt describes how “the way a society responds to problems of disease reveals its deepest cultural, social and moral values... [which are] patterns of judgement about what is good or bad- shape and guide human perception and action” (1988:147). Regarding HIV and AIDS, they were “shaped not only by powerful biological forces, but by behavioral, social and cultural factors as well” (Brandt 1988:147). The unknown nature of HIV lead to the immediate condemning of the most affected group at the time, which were homosexual males. This condemnation is elaborated upon in David Black’s *The Plague Years: A Chronicle of AIDS the Epidemic of Our Times* as:

“an attempt to come to grip with gay and lesbian issues, particularly AIDS, the disease that for the few years... had been doubling its victims every six months, mostly in the gay community- an increase that, if it continued at that rate and if it spread into the *general population without check*, would in a decade kill everyone in the United States and in another decade kill everyone in the world ten times over.” (1986:16; emphasis added).

This quote presents an interesting perspective as the beginning of the quote begins to divide society in a subtle manner by presenting HIV and AIDS as not only a struggle, but more of a struggle between gay and lesbian *against* the heterosexual community. By describing the heterosexual community as the “general population,” it implies that any sexuality apart from heterosexuality is a minority in comparison. Following this, the idea of regulation through “checking” creates the idea that monitoring another party is necessary and required to be able to control and isolate the threat against the normative community. With pamphlets and newsletters being created on how to “deal with death, denial, and grief; [and] telling people where to get help, both medical and psychological; and giving descriptions of the early symptoms of AIDS...people [were driven] into the bathrooms where in the stalls they nervously checked themselves...”, which questioned the capacity of medicine itself as an individual had to not only self-check, but presumably misdiagnose themselves as well from their paranoia (Black 1986:17). Environments become affected as workshops were held on “*compulsive* sexuality” and additional locations and actions like “...bathhouses and bars that offered backrooms for anonymous sexual encounters, organizing AIDS projects in small towns, the communicability of AIDS, safe sex, AIDS and substance abuse, opportunistic infections, and homophobia among doctors and nurses” are present (Black 1986:17; emphasis added). By associating irresistibility with a certain sexuality not only implies that there is a lack of control, but that there must be a need to control the body and maintain order for both sexuality and health.

In “Sexual Inversions”, Judith Butler addresses sexuality and order by referring to Michel Foucault, who argued that during the eighteenth century in Europe, “famines and epidemics start[ed] to disappear and that power, which had previously been governed by the need to ward off death, now becomes occupied with the *production, maintenance, and regulation* of life”

(1996:60; emphases added). The italicized words become reinforced through the “regulatory cultivation of life,” which becomes naturalized through heterosexuality as “it is designed to regulate and secure the *reproduction* of life” (Butler 1996:60; emphasis added). Butler continues to refer to Foucault by describing how “sex, whether male or female, operates as a principle of identity that imposes a fiction of coherence and unity on an otherwise random or unrelated set of biological functions, sensations, [and] pleasures” (1996: 67). Through this principle of identity, it encourages that for one “to qualify as legitimately human, one must be coherently sexed. The incoherence of sex is what marks off the abject and the dehumanized form from the *recognizably* human” (Butler 1996: 67; emphasis added). Through these quotes, heterosexuality continues to be reinforced as the sexuality that orders the functions and sensations of life while also unifying the body and resulting in it being recognized, as sex is “always positioned within a field of two mutually exclusive and fully exhaustive identities; one is either male or female, never both at once, and never neither one of them” (Butler 1996:66). Recognition itself becomes tricky as a body may be recognized, but not completely as a human.

In associating humanity with heterosexuality, it can negate recognition of other bodies, and so, it is critical to engage marginalized communities. Butler introduces the inversion of heterosexuality: homosexuality, in which the “male homosexual is figured time and again as one whose desire is structured by death, either as the desire to die or as one whose desire is inherently punishable by death” (1996:61). In relation to the power that can help produce, maintain and regulate life, this same power produces the “homosexual subject as a *bearer* of death” because of the discourse created by the AIDS epidemic (Butler 1996:61; emphasis added). Butler acknowledges how Foucault could not have predicted the AIDS epidemic, however, draws upon an interesting point by stating that “if homosexuality is pathological from

the start, then any disease that homosexuals may sometimes contract will be uneasily conflated with the disease that they already are” (1996:70). This quote introduces a powerful point as it questions where exactly one is recognized as a person, and not solely based on a condition that they may have. Foucault warned us that “we must not think that by saying yes to sex, one says no to power; on the contrary, one tracks along course laid out by the general deployment of sexuality. It is the agency of sex that we must break away from” (Butler 1996:72). This is not to say that we must ignore heterosexuality, but rather that in constructing heterosexuality as the sole identity that constitutes a recognized human, there should be no requirement of a human to establish *the* identity. Even then with removing the establishment of an identity, it becomes more complicated as:

“political decisions that administer the scientific, technological, and social resources to respond to the epidemic of AIDS, the parameters of that crisis are insidiously circumscribed; the lives to be saved are insidiously demarcated from those who will be left to die; ‘innocent’ victims are separated from those who ‘deserve it’” (Butler 1996:73; emphases added).

While technological advancements may be made, it questions how life becomes recognized and by what means of justification should they continue to live. This quote highlights how recognition and judgement is still to organize and value some lives and prefer others over them in comparison.

In *Illness as Metaphor and AIDS and Its Metaphors*, Susan Sontag how bodies are essentially the same, yet through characterizations, humans become unequal. Sontag refers to Rudolf Virchow, who claims that all organisms, simple or complex, are “simply ‘multicellular’-multicitized as it were; the body is a ‘republic’ or ‘unified commonwealth’” (1977:95). This

recognizes the body as not only a biological manifestation, but as a symbolic social factor that must appear as a unified front. Within this construction:

“everyone who is born holds dual citizenship, in the kingdom of the *well* and in the kingdom of the *sick*. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place” (Sontag 1977:3; emphases added).

The binary between being healthy and sick becomes reinforced through as our bodies efforts against disease are described as a constant “fight, a struggle, a war” (Sontag 1977:99). About AIDS, it allows for a “spectrum of illnesses: that allows AIDS to have ‘a dual metaphoric genealogy. As a micro-process, it is described as cancer is: an *invasion*. When the focus is transmission of the disease, an older metaphor, reminiscent of syphilis, is invoked: *pollution*” (Sontag 1977: 104-105; emphasis added). Focusing on the concept of invasion, it is interesting to see how the HIV virus, which is “about one sixteen-thousandth the size of the head of a pin, [can overwhelm the immune system’s helper T cells while changing] the body’s own cells [into additional HIV copies]” (Sontag 1977:105-106). It is astounding to see how such a small being can not only cause the body harm, but through this harm, it creates “*stereotypes* of... character”, and in doing so, manifests concepts, like pollution, to comprehend the nature of the virus itself.

By interpreting living with HIV or AIDS as polluting factors towards the human body, it disrupts intimate actions like sexual intercourse, and associates it with “the blood or sexual fluids of *infected* people” or acts of helping like “contaminated blood products” (Sontag 1977:105-106; emphasis added). In describing people living with HIV as “infected people”, it removes personhood from the affected individual and focuses primarily on language that promotes “managing, avoiding or eradicating disease, rather than enhancing health” (Dilmitis 2012). Apart

from the social implications set out by language, the biological effects become prominent as HIV replicates and weakens the immune system until AIDS achieved; as a result, members of a certain risk group are flushed out as “the illness... [reveals] an identity that might have remained hidden from neighbors, job mates, family and friends” (Sontag 1977:113). This identity is:

“confirmed, and... in the United States [this confirmation] has been a creator of community as well as an experience that isolates the ill and exposes them to harassment and persecution [leading unaffected people to believe that] the unsafe behavior that produces AIDS is judged to be more than just weakness. It is indulgence, delinquency-addictions to chemicals that are illegal and to sex regarded as deviant” (Sontag 1977:113).

By describing the physical act of sex as deviant not only reinforces heterosexuality, but continues to expand the stigmatization of individuals living with HIV and AIDS. It produces a new environment in which individuals can thrive, yet it is through marginalization that creates the difference amongst individuals. Nevertheless, it is through these differences incorrect perceptions of bodies and intentions are created.

The coining of both acronyms was a difficult process as stereotypes limited the biomedical perspective to only focus on the homosexual community instead of expanding their horizons to other potential carriers of each condition. In New York, hospitals began to informally refer to the cause of death of many homosexual males as WOGS: the Wrath of God Syndrome; it later was informally called GRID: Gay-Related Immunodeficiency (Triechler 1999:27). As Triechler presents, “the nature of the relation between language and reality is highly problematic...” to which WOGS and GRID alongside the medical practice respectively fulfill



(Triechler 1999:11). Triechler refers to James Curran, who states that “scientists avoid issues that relate to sex, and there is not much understanding of homosexuality” (1999:15). This, however, was an understatement as scientists claimed that they did not know how HIV could be transmitted, but Joseph Sonnabend argues that it was an ignorance towards gay male sexual practices that was “‘unnatural’ to the straight (in both senses) scientist: ‘the rectum is a sexual organ, and it deserves the respect that a penis gets and a vagina gets. Anal intercourse is a central sexuality activity, and it should be supported, it should be celebrated’” (Triechler 1999:25).

Unfortunately, it is through the recognition of anal intercourse that creates fear as the heterosexual community believed that “killer sperm” existed and only a vagina could fend off such a force as people suggested that “‘God’s plan for man was for Adam and Eve and not Adam and Steve.’ Women, the ‘natural’ receptacles for male sperm, have evolved over the millennia so that their bodies can deal with these foreign invaders; men, not thus blessed by nature, become vulnerable to the ‘killer sperm’ of other men” (Triechler 1999:21). Even with the correction of GRID to AIDS in 1982, and the affected community expanding from homosexual males to hemophiliacs, intravenous drug users and blood transfusion recipients, the stigma still did not change. If anything, such an expansion created more dichotomies such as “‘homosexual and the ‘general population’ ... guilty and innocent...safe sex and bad[/good] sex...” (Triechler 1999:35). Again, AIDS is constructed and reinforced “through language... and through the discourses of medicine and science... [it results in the] construction [of] ‘true’ or ‘real’... in certain specific ways” (Triechler 1999:11). Triechler elaborates upon this by declaring that “the name *AIDS* in part *constructs* the disease and helps make it intelligible. We cannot... look ‘through’ language to determine what AIDS “really” is. Rather, we must explore the site where

such determinations *really* occur and intervene at the point where meaning is created: in language” (Triechler 1999:11).

Referring to the incorrect term of GRID, it is interesting to see how the media itself, like *The New York Times*, can publish articles titled ““New Homosexual Disorder”” and reinforce what has been mentioned before: it isolated a specific community followed by describing it as a disorder, implying that it was disrupting the ordinary (Black 1986:27). Black recounts on how he joked with his friend about the article and how they “spent the next few minutes joking about what... was a very unfunny subject- which was typical of the reaction of the straight males [that Black] knew (1986:27). He broadens the responses from his personal circle to society as people make so-called “jokes” about HIV such as “What disease do gay crocodiles get? Gator-aids.”, “What’s the medical definition of AIDS? A disease that turns fruits into vegetables.”, and the one I found difficult to understand and process, “What does *gay* stand for? Got AIDS yet?” (Black 1986:28).

If these statements were not difficult enough to process, Black quotes a woman who claims that “[AIDS] affects homosexual men, drug users, Haitians, and hemophiliacs... thank goodness it hasn’t spread to *human* beings yet” (1986:29; emphasis added). This quote presents many accurate, yet judgmental statements; it is true that the individuals that were described are amongst the most likely to be affected, yet by disregarding them as “non human” is troubling as it clearly identifies homosexual males, but also generalizes communities to include both homosexual and heterosexual communities. In including the heterosexual community, it is also interesting to recognize how that community, which is seen as the norm, uses physical characteristics to break apart those that are affected by either HIV and AIDS. This idea becomes further complicated as religion is introduced by another woman, who states that “Good Christian

people have nothing to fear... as long as we stay a million miles away from the slimy creatures who may have it” (Black 1986:29). This quote presents how one can use their religious beliefs to classify and condemn others while contrasting notions of purity to contamination. Also, in describing another person as a creature connotes a sense of savagery and obscurity. Language like this comes from “moral judgments attached to disease... [around what is] beautiful and the ugly, the clean and the unclean, the familiar and the alien or uncanny” and contrasts “decomposition” with ‘something organic” (Sontag 1977:129).

Previously, HIV and AIDS were constructed by the medical establishment and society as a “gay plague”, while currently, they have been normalized as chronic diseases that can be “managed medically over the long term” (Fee and Krieger 1993:1477). Within its origins, AIDS suddenly emerged as a deadly disease as it was not known how it was transmitted and how it originated. Fee and Krieger claim that “it seemed to resurrect the true meaning of *epidemic*: a disease that spreads like wildfire, consumes lives, and then burns out, leaving devastation in its wake” (1993:1478). Nevertheless, such a devastation was challenged by gay and lesbian communities as they rejected traits that would label them as the culprits due to the unknown nature of both the virus and the syndrome. Black describes how in the “late 1979 and early 1980, Dr. Joel Weisman, a former New Yorker with a private practice in the Los Angeles area, began noticing an increase” in his homosexual male patients, who were arriving with similar symptoms (1986:36). Weismann in his expertise “was stumped” and recounts how:

“before the great advances in medicine in the later part of this century, doctors were essentially *documentors* of what happened. With this patient, that’s essentially all [he] could do... People had the naive belief that no new killer infectious disease would ever come along... [His] whole generation of physicians up until [that] time had not had to

deal with a disease that could kill the doctor in treatment of the patient. That's why this generation of physicians reacted so terribly" (Black 1986:39-40; emphasis added).

It is important to recognize how now medicine is still expected to solve any biological issue, yet realistically, medicine had been challenged as doctors could only document what was happening.

### **The Effects of the Epidemic on Medicine, the Government, and Religion**

The HIV and AIDS epidemics transformed medicine economically as the epidemic became a source of revenue. The medication that was available to treat Kaposi's sarcoma and *Pneumocystis carinii* pneumonia (PCP) helped provide context as to what exactly the scale of AIDS was as through a "sudden marketed increase in requests for a drug long used to treat PCP, pentamidine" (Jonsen and Stryker 1993:90). Even with "vitamins, holistic therapies, and imported, non-FDA-approved drugs," AIDS "increasingly came to be viewed as an untreatable disease, and medical and lay literature emphasized the need to respect the rights and needs of individual disease of short duration" (Jonsen and Stryker 1993:90). As medical professionals define AIDS as untreatable, it reinforces the anxiety and ambiguity that surrounds the very nature of it. This continue in 1985 as Rock Hudson, a famous movie star at the time, traveled to France for an experimental drug, which was questioned by patients in the United States who "became increasingly aware of the often painfully slow process of drug evaluation and licensing regulated by the FDA" (Jonsen and Stryker 1993:90). The winter in between 1985 and 1986, azidothymidine (AZT), a previously discarded anticancer agent, began to show promise for individuals living with AIDS as it "appeared to increase patient well-being and possibly [slowed the] progression of the disease, although it was not obviously curative" (Jonsen and Stryker 1993:91).

Through advocacy work done by the AIDS Coalition to Unleash Power (ACT-UP), AZT quickly moved from the test tube to pharmacy in 1987 while also increasing the “primary federal mechanism for the conduct of clinical trials, the AIDS Clinical Trials Group of the National Institute of Allergy and Infectious Disease, expanded rapidly” (Jonsen and Stryker 1993:92). The factors for the conduct and nature of clinical research alongside the regulation were changed in response to the AIDS epidemic: First, “AIDS led to a fundamental reconsideration of basic methodologies for establishing the efficacy and safety of pharmaceuticals” as new approaches to experimentation to save time were conducted while also questioning the “legitimacy of randomization” when “loomed large in the context of the epidemic” (Jonsen and Stryker 1993:112). Second, “there has been a dramatic shift in the face of the epidemic from a restrictive ethos for regulating new drugs to a new, less, restrictive environment,” which has been important for other infectious diseases like Ebola (Jonsen and Stryker 1993:112). Third, the relationship between federal research and private industry has questioned how the “public-private cooperation in research and development” in response to the AIDS epidemic (Jonsen and Stryker 1993:112). Finally, AIDS “influenced the nature and meaning of the ethics of human investigation” by forcing the “acceleration of the procedures and processes of clinical investigation, as well as the mechanisms of regulation” and eventually highlighting how effective social and political activism can influence and spark change (Jonsen and Stryker 1993:112-113).

While social and political activism have helped changed how HIV was and currently is being approached, cultural beliefs were also an obstacle in providing effective care. The diversity of religion in the United States lead to two broad patterns during the 1990’s. First:

“religious groups are a ‘restrained’ ally in the fight against the epidemic; this is seen in those churches that have declared the imperative of compassion as the most suitable religious response. Taken seriously by the faithful, this response has mobilized considerable personal and institutional energies in the work of care [while others] restrain their involvement, particularly in education and prevention. (Jonsen and Stryker 1993:152-153).

The second broad pattern focuses on religious groups whose doctrinal commitments, “usually about sexuality, are so strong as to prevent the faithful from engaging in an active program of compassionate care [by continuing] a stance of condemnation of the causes of infection and, in so doing, contribute to what they considered the most, and only morally effective message...” (Jonsen and Stryker 1993:153). While it may be simple to categorize religion into two opposites, both influence how public health for HIV and AIDS are presented. While the first group may have “significant energies and resources.” limitations must be recognized and participants must be aware of limitations set by both another individual and their doctrine. On the other hand, the aggressive opposition in providing care is not ideal either because of the refusal to provide care for all affected communities without judgement. According to Jonsen and Stryker, the best mediation is that “the formulation of policies for HIV/AIDS care, research, education and prevention should be sensitive to the diversity of the response to the epidemic by the U.S. religious community. But how exactly can society and the government achieve removing such discrimination?

As Lawrence Gostin states, “governmental, medical, public health, legal and civil liberties organizations all condemned discrimination” (2004:109). The four justifications for antidiscrimination legislation were based on “justice, economic and social harms, public health,

and the normative and educative functions of civil rights law” (Gostin 2004:109). Focusing primarily on the idea of individual justice, the Supreme Court has recognized that “discrimination on the basis of an infectious condition is just as inequitable as discrimination based on race, gender, or disability” (Gostin 2004:109). Reinforcing this was the case of *School Board of Nassau County v. Arline* (1987), in which Justice William Brennan stated that “society’s *accumulated* myths and fears about disability and disease are just as handicapping as are the physical limitations that flow from actual impairment. Few aspects of handicap gave rise to the same level of public fear and *misapprehension* as contagiousness” (Gostin 2004:109-111; emphasis added). Gostin extends his argument by claiming that “discrimination against persons living with HIV/AIDS has serious economic and social consequences for the nation [as] it renders talented individuals unemployable or uninsurable and impairs their ability to secure housing or receive health care or other services” (Gostin 2004:111). Through discrimination, it “undermines public health efforts to identify persons infected with HIV, prevent transmission, and provide care and treatment...” (Gostin 2004:111). Discrimination, whether it be personal, social and/or economic, will influence individuals to “forego testing, fail to discuss their health and risk behaviors with counselors or health care professionals, and refrain from entering the health care system for treatment” (Gostin 2004:111). With normative and educative functions through civil rights legislation, the government can create expectations of “decent and civilized behavior” like the civil rights movement during the 1990’s in which gay men and lesbian were humanized (Gostin 2004:111). Is it possible to set a law to force other people to be considerate? Will it always be universal and respected? Can it help deconstruct the language of the “difference between ‘us’ and ‘them’” which “exculpates or at least makes irrelevant moral judgements about ‘them’” into something more empathetic? (Sontag 1977:152).

I believe that this is part of the root of the problem as “language is a virus” (Sontag 1977:156). While it may not be biologically affecting the body, it is constructing a social, cultural and political environment for other bodies to participate in. The environment itself is susceptible to not only tone, but intensity as well, allowing for the possibility for the tone of a conversation to change both subtly or dramatically. As Sontag states:

“AIDS marks a turning point in current attitudes towards illness and medicine, as well as towards sexuality and toward catastrophe... Medicine changed mores. Illness is changing them back... Now AIDS obliges people to think of sex as having, possibly, the direst consequences... The fear of AIDS imposes on [sex] whose ideal is an experience of pure presentness (and a creation of the future) a relation to the past to be ignored at one’s peril...” (1977:160).

While this idea of a network may bring together communities, it also places a sense of self-interest that if one were to stumble or suffer, then it is of their “moral prudence” (Sontag 1977:161). The notion of pollution comes back into play here as it implies that an individual living with either HIV or AIDS can change the environment they are in through relations and by interacting with others and so called “polluting” them, they disrupt social norms and relationships. Henceforth, in correlating living with either HIV or AIDS to pollution, it devalues the person.

Within the late 1980s, it was clear that HIV and AIDS were not going to disappear, and attempts at medication, like AZT, emphasized treatment, but its cost challenged who could afford and whether the government would pay for such a medication. The reason that this was raised was the fact that AIDS became a chronic disease that was transmissible, yet other chronic conditions like cardiovascular disease and cancer were not (Fee and Krieger 1993:1479).



Fortunately, the CDC, “revised its diagnostic definition of AIDS in 1991 to include T-Cell counts and, in 1992, to include cervical cancer and pulmonary tuberculosis among HIV-associated diseases” (Fee and Krieger 1993:1480). It becomes interesting to see what information is presented: will it be success rates or rates of incidences. Critiques on the biomedical model are that it is founded on the “ideology of individualism” in which “it considers individuals ‘free’ to ‘choose’ health behaviors” (Fee and Krieger 1993:1481). In that case, what exactly is being targeted: is it the individual, who has the potential to transmit the HIV virus, or rather focus on the social determinants to which it makes it susceptible to do so? (Fee and Krieger 1993:1481). In the end, the biomedical model analyzes disease as a “fundamentally individualistic and sanctions only the physicians’ or scientists’ point of view... [as] it reduce[s] individuality to the very constrained level of genetic constitution and susceptibility” (Fee and Krieger 1993:1481).

Through the efforts of scientists, in 1985, HIV was identified as the virus that caused AIDS and because of this, “scientists tended to lose interest in the social factors accompanying transmission. They instead turned to laboratory studies... that would lead to patents, vaccines, and possibly a cure.” (Fee and Krieger 1993:1478). The first blood test called the enzyme-linked immunosorbent assay (ELISA) became the first commercial test that used color change and the presence of certain antibodies to indicate the presence of certain diseases or infections. ELISA helped create better infection control while removing the “traditional approach” of isolation, quarantine, or other methods of societal means to end any transmission (Fee and Krieger 1993:1479). What is interesting is the fact that it took civilian efforts to be able to convince and educate the government while President Reagan ignored the existence of AIDS, and when he did acknowledge it, he placed a travel ban onto anyone living with HIV or AIDS from entering the

United States in 1987; this was later reinforced by President Clinton (U.S Department of Health & Human Services [HHS] 2016a). Even with the blood supply being screened for HIV and antiretroviral medication being developed, the United States government heightened the paranoia of who could be exposed to HIV and emphasizing it as a threat to national security. This ruling was eventually overturned on January 10<sup>th</sup> 2010, during the Obama Administration, who lifted the HIV travel and immigration ban to the United States (U.S Department of Health & Human Services 2016a).

### **PrEP, PEP, and TasP: Inhibiting the Biological Mechanisms of HIV and AIDS**

The once unknown characteristics and nature of HIV and AIDS were feared as there was no medication to treat either, but it is important now to recognize the advancements that have been made. Currently, if one is diagnosed with HIV, they can “choose among 41 drugs that can treat the [virus]”, and when given the “right combination...at the right time, the drugs can keep HIV levels so low that the person never gets sick” (Park 2017). However, when HIV was first discovered, there was no immediate treatment to help reduce transmission of the virus alongside extending an affected individual’s lifespan. Nevertheless, the first medication that was used in treating HIV was originally developed in the 1960s by a U.S researcher, its initial purpose would later be reworked into a life-saving medication. At first, AZT was intended to thwart cancer as “the compound was supposed to insert itself into the DNA of a cancer cell and mess with its ability to replicate and produce more tumor cells. But it didn’t work when it was tested in mice and was put aside.” (Park 2017). As AIDS became more of an emerging infectious disease, Burroughs Wellcome, a well-known antiviral pharmaceutical company, reworked the original configuration of AZT in a new synthesis called Compound S, and when tested in “a dish with animal cells infected with HIV, it seemed to block the virus’ activity” (Park 2017). On March 19,

1987, in a record 20 months, the FDA approved the first AIDS medication, which was seen as “a breakthrough’ and ‘the light at the end of the tunnel’” (Park 2017). Advancements in antiretroviral medication continued in 1997, when highly active antiretroviral therapy (HAART) becomes the “new standard of HIV care” and as a result of this therapy, “AIDS-related deaths in the U.S decline[d] by 47% compared with the previous year” (U.S. HHS 2016a).

The biological mechanisms of HIV and AIDS are now better understood and are being combatted with new medications. HIV attaches itself to the surface of a CD4 cell, which are cells that are produced by the immune system and help the body fight of any infection (U.S HHS 2016b). Once HIV binds to CD4 cell receptor, the cell membrane of each corresponding cell begin to merge together, and after HIV fully merges with the CD4 well, it undergoes reverse transcription in which HIV “releases and uses reverse transcriptase [an HIV enzyme] to convert its genetic material- HIV RNA- into HIV DNA. The conversion of HIV RNA to HIV DNA allows HIV to enter the CD4 cell nucleus and combine with the [CD4] cell’s genetic material- cell DNA” (Alberts 2013:310; U.S. HHS 2016b). Following reverse transcription, integration takes place in which HIV, which is already in the CD4 nucleus “releases integrase [another HIV enzyme] which allows HIV to insert its viral DNA into the DNA of the CD4 cell” (U.S. HHS 2016b). The fifth step in the HIV lifecycle deals with replication, as HIV uses “the machinery of the CD4 cell to make long chains of HIV proteins... [which] are the building blocks for more HIV” (U.S. HHS 2016b). From this point forward, new HIV proteins and HIV RNA move “to the surface of the cell and assemble into immature (noninfectious) HIV” (U.S. HHS 2016b). Finally, after rising to the surface of the cell, the “newly formed immature HIV... pushes itself out of the host CD4 cell [and also] releases protease [another HIV enzyme] which break[s] up the long protein chains that form the immature virus. The smaller HIV proteins combine to form

mature (infectious) HIV” (U.S. HHS 2016b) and continues the process by infecting more CD4 cells.

While HIV does lead to AIDS, not everyone who has HIV will advance to this stage. AIDS occurs after a significant amount of CD4 cells have been eliminated, thus exposing the immune system to opportunistic infections. One is considered to have progressed to AIDS when the number of CD4 cells “falls below 200 cells per cubic millimeter of blood (200 cell/mm<sup>3</sup>) in comparison to an individual who is not living with HIV as their CD4 cell count ranges from “500 cell/mm<sup>3</sup> to 1,600 cells/mm<sup>3</sup>” (U.S. HHS 2016c). People who are diagnosed with AIDS “typically survive about 3 years without treatment” and about 1 year, should an individual gain a “dangerous opportunistic illness” without treatment (U.S HHS 2016c).

While HIV may be transmitted through semen, vaginal fluids, breast milk and blood, there exist medications prevent the transmission of HIV. There are six major types of drugs called antiretrovirals, as they interfere with the retrovirus HIV by inhibiting, or inactivating, one or more of six stages: entry, fusion, reverse transcriptase, integrase, protease or multi-class combinations (National Institutes of Health [NIH] 2013). On July 12, 2012, the U.S Food and Drug Administration (FDA) approved Truvada (PrEP), which is a combination of two HIV medicines, tenofovir and emtricitabine, for daily use (CDC 2016b). When used daily, PrEP can “lower the risk of getting HIV from sex by more than 90% and from drug use by more than 70%” (CDC 2016b). This medication is revolutionary as it provides a preventative measure for populations that may be at a higher probability in being exposed to HIV. It also recognizes the individual more as a form of preventative care while encouraging one’s health as well. PEP is similar, but different from PrEP. PEP is only used in emergency situations in which one believes that they may have potentially been exposed to HIV (CDC 2016a). PEP consist of taking

antiretroviral medication within 72 hours, and may need to be taken once or twice a day for 28 days (CDC 2016a). Like PrEP, PEP will be the most effective if taken as prescribed and while it will not guarantee that one will not contract HIV, if administered correctly, the chances of preventing HIV increase. Continuing along the lines of prevention, treatment-as-prevention refers to the use of antiretroviral medication to decrease the risk of HIV transmission. It is primarily emphasized to those “who *are* infected with HIV in order to reduce the amount of virus in their blood (and genital fluids) so that they are less likely to infect others” (POZ 2016). In 2011, a study was conducted by the HIV Prevention Trials Network (HPTN 052) in which the use of antiretrovirals by “HIV-positive heterosexual men and women cut the chance that their HIV negative partner would become infected by roughly 96 percent.” (POZ 2016). This study concluded in 2015 and it was found that “no participant with a fully suppressed viral load infected his or her long-term HIV-negative partner” (POZ 2016). Between September 2010 to May 2014, an additional study was conducted by The Jama Network along with PARTNER (Partners of People on ART [antiretroviral therapy]- A New Evaluation of the Risks) in which 1166 HIV serodifferent couples (HIV-positive partner taking suppressive ART) engaged in condomless sexual activity. (Rodger et al. 2016). This study is important as it included both heterosexual and men who have sex with men (MSM) couples and concluded, with “upper 95% confidence”, that there were no cases of within-couple HIV transmission, thus providing “estimates of the risk of HIV transmission through condomless anal and vaginal sex with use of suppressive ART” (Rodger et al. 2016).

Through these new medications and therapies, there has been an improvement in HIV infection rates. By analyzing HIV diagnosis data alongside post-HIV diagnosis CD4 counts that were reported to the National HIV Surveillance System, the CDC presented its estimates at the

Conference on Retroviruses and Opportunistic Infections (CROI) in Seattle (POZ 2017). Having been stagnant at about 45,000 to 50,000 per year since the mid-1990s, the CDC reports that HIV incidence fell from 45,700 to 37,600 between 2008 and 2014, which is an 18% decrease; it is believed that the FDA's approval of PrEP in 2012 attributed to the decline (POZ 2017). The CDC researchers estimated that between 2008 and 2014, HIV infection rates declined: "56 percent among injection drug users, from 3,900 to 1,700; 36 percent among heterosexuals, from 13,400 to 8,600; 19 percent among young MSM ages 13 to 24, from 9,400 to 7,700; 30 percent among MSM ages 35 to 44, from 5,800 to 4,300 and 18 percent among white MSM, from 9,000 to 7,400" (CDC 2017b). While MSM category did not have a dramatic decrease in infection rates, it is still promising to see that HIV infections rates are "falling among gay and bisexual men aged 13-24 and 35 to 44, but [is] rising among those aged 25-34 years" (POZ 2017; CDC 2017b). While progress has been made, it remains uneven, both in populations and statewide.

Amongst the states, the CDC estimates that "HIV rates fell 10 percent annually in Washington, DC, 8 percent annually in Maryland, 7 percent annually in Pennsylvania, 6 percent annually in Georgia, 5 percent annually in both New York and North Carolina, 4 percent annually in Illinois and 2 percent annually in Texas" (POZ 2017). While these states experienced a decline, others states like California and Florida, experienced new HIV infections, 5,100 and 4,700 respectively (CDC 2017a). In total, 35 states were estimated alongside Washington D.C, however, other states were excluded from this report if they had "less than or equal to 100 diagnoses per year" as HIV incidence cannot be estimated in these states (CDC 2017a). Additionally, the study reveals that "Southern states bear the greatest burden of HIV, accounting for 50% of new infections in 2014" (CDC 2017b). In 2014, there were 37,600 new HIV infections in the United States in which gay and bisexual men constituted 70% of the HIV rates

with 26,200 infections; heterosexual individuals were second with 23%, or 8,600 infections; next in line were intravenous drug users with 5%, or 1,700 infections; finally, gay and bisexual intravenous drug users constituted 3%, or 1,100 infections (CDC 2017b). Apart from gay and bisexual men not “experience[ing] a decline in annual HIV infections from 2008 to 2014 [with annual infections remaining stable at 26,000 per year],” it is important to deconstruct the percentages of each respective community to see who is being represented. As previously mentioned, there was an 18 percent decline of HIV rates within white males, however, infections “remain high and stable among black gay and bisexual men from 10,100 to 10,100”, and there was a “20% increase among Latino gay and bisexual men from 6,100 to 7,300” (CDC 2017b). While these statistics may show the biomedical advancements that have been made towards HIV and AIDS, it is essential to question who the statistics are representing, and to see what obstacles, like race and stigmatization, are socially affecting how another individual is depicted.

### **Contemporary Documentation and Visualization of HIV-related Stigma**

While stigma may be documented into certain events, it becomes difficult to truly locate and confront stigma when people may unknowingly participate in reinforcing the stigma either individually or collectively, or in public or private settings. Nevertheless, efforts are being made to take on such a challenge by visualizing stigma and confronting injustice (Davids 2014). Since 2008, the People Living with HIV (PLHIV) Stigma Index “has measured and revealed the shape of stigma and discrimination experienced by people living with HIV” (Davids 2014). This project launched in the United States on World AIDS Day 2013 and is led by Laurel Sprague, who is the national coordinator of the PLHIV Stigma Index in the U.S (Davids 2014).

Sprague reiterates and expands the definition of stigma as:

“a process of devaluing people based on some characteristic of who they are. It is a social construction- by which [she] means that is created by people- that sets up some members of the community as more credible or valuable than others. Stigma works by ‘othering’ groups of people: labeling certain characteristics as different and undesirable, assigning negative stereotypes to people with those characteristics, and then systematically excluding those people from full inclusion in social life.” (Davids 2014).

Sprague elaborates upon the traditional definition of stigma through HIV-related stigma which occurs “when social norms devalue the lives and experiences of people living with HIV. The stigma people face is not only about HIV, but also about racism, homophobia, sexism, transphobia and [more]” (Davids 2014). The effects of HIV-related stigma are well documented and include “missed doses of medication; fear of HIV testing; avoiding medical care; violence at the hands of intimate partners; hiding one’s status to avoid violence, losing employment or housing, and [more]...” (Davids 2014). The PLHIV Stigma Index is not only a research project that is “created and led by and for people living with HIV...[but] it is also a stigma intervention, creating spaces and support for people living with HIV to talk about their experiences, build networks... challenge mistreatment together, and develop a positive shared identity” (Davids 2014). The PLWHIV Stigma Index observed these responses in its pilot study in Detroit, Michigan.

The first wave of the MI PLHIV Stigma Index (MI-SI) Project had 70 diverse PLHIV in metro Detroit (Arnold 2016:1). The goal of the MI-SI was to “document experiences of internalized, social, and institutional stigmas and discriminations among PLHIV in the state, and to increase the capacity of PLHIV and their allies to effectively challenge HIV stigmas and discriminations (Arnold 2016:1). The participants identified as 47% gay/MSM and the rest as



heterosexual (Arnold 2016:10). Although it may be a small number of participants, it is important to recognize that a community is being represented and listened to. When asked “what opportunities, if any, do you see for your community resulting from the HIV epidemic?”, a small number of participants “stated that they were unsure how to respond to this [question, yet] several stated that the barriers of stigma and discrimination were too large to realistically envision feasible opportunities” (Arnold 2016:18). Nevertheless, the primary themes that were emphasized were “increased education and awareness about HIV; greater outreach and access to resources; increased focus on stigma reduction; increased positive community building efforts; getting PLWHIV into positions of leadership and power; and opportunities from health insurance expansion and research” (Arnold 2016:18). The general response amongst the 44 participants towards recently seen HIV prevention campaign, “64% and 59% found the campaign(s) to be encouraging or empowering, respectively” (Arnold 2016:19).

While positive responses towards campaigns are progressive, it still does not solve the idea of stigma itself as previously mentioned. Negative HIV-related feelings among PLHIV manifest themselves into “internalized stigma,” which can be described in eight feelings: “blam[ing the] self, guilt, shame, [having] low esteem, ang[er], blam[ing] others, suicidal, [and feeling] punished” (Arnold 2016:20). Overall, “95% of participants reported feeling at least one of the negative emotions during the prior 12 months; and 74% reported experiencing 3 or more of the 8 emotions” with blaming the self, guilt and shame being the top three at 79%, 66% and 59% respectively (Arnold 2016:20).

In terms of perceiving social support, the participants were asked how often types of support are available to them, which included advice, assistance, care, leisure, affection, and information (Arnold 2016:23). About 80% or more had occasional access to any type of social

support with “informational support rank[ing] the highest, and care and assistance (instrumental supports) rank[ing] the lowest” (Arnold 2016:23). Although one may have resources to be supported, it requires a personal engagement to do so. Building upon internalized stigma, the possibility of social avoidance is likely as described previously with the eight feelings. For these participants, the rates of avoidance were prominent through 12 avoidant behaviors: isolating oneself; not attending social gatherings; choosing to not apply for/quitting work; withdrawing from education/training; deciding to not disclose one’s HIV status; deciding to not engage in sex; avoiding social media; deciding to not have children, and avoiding going to clinics and/or hospitals (Arnold 2016:25). From these twelve scenarios, the highest rates of avoidance were “highest for direct social relationships (avoiding people, events, disclosure, or sex) [with 53%, 41%, 46%, and 36% respectively]” while institutional avoidance was less likely amongst the group; all participants engaged in at least one of the behaviors with a maximum of engaging in 3 to 9 behaviors being engaged (Arnold 2016:25).

Building upon internalized stigma is “anticipated stigma”, which is participants “anticipated being stigmatized, harassed or discriminated against in social interactions” (Arnold 2016:27). This form of stigmatization presents itself in 7 events: sexual rejection, being gossiped, being outed, being verbally and/or physically threatened, being assault and being denied health care (Arnold 2016:27). From these 7 events, 89% of participants reported fearing at least one with sexual rejection and gossip being the most feared at 71% and 69% respectively while also being the most occurring at 44% and 51% respectively. (Arnold 2016:27, 30). Because of these forms of social stigmatization and discrimination, 11 consequences were highlighted by the participants in how they responded: depression, anxiety, leaving one’s family, reducing self-care, avoiding support groups, substance abuse, leaving one’s faith, skipping doses of medication,

income loss, avoiding care and missing work; depression, anxiety, and familial exclusion were the highest with percentages of 59%, 47% and 44% (Arnold 2016:33). It is important to recognize how an individual's responsibility and management of their own life can be transformed and criminalized based on misconceptions.

According to a joint study conducted in 2012 by The Washington Post and the Kaiser Family Foundation (KFF), "Americans' optimism regarding the country's progress against the disease has outweighed pessimism... [yet] despite these feelings of progress, the public acknowledges that there are ongoing challenges in access to treatment... and many still have misconceptions about the disease and how it is transmitted" (KFF 2012:1). Approximately 58% of Americans believe that progress is being made, while 18% believe that the virus itself is winning, with the remaining percentage being unsure or choosing to answer the question (KFF 2012:4). The obstacles that are preventing progress are the belief that there is an "unwillingness of people to change unsafe sexual practices (85 percent), widespread poverty (76 percent), not enough action by developing country governments (74 percent), corruption (71 percent), and lack of effective programs (63 percent)" (KFF 2012:4). The misconceptions that remain are that about 25% of Americans did not know that HIV cannot be transmitted by sharing glass, which is the same percentage as in 1987 (KFF 2012:1). Additionally, 17% of Americans who do not know that HIV cannot be transmitted by touching a toilet, a similar statistic to that of 1987 which was 19 percent (KFF 2012:13). The most recent statistic of 11% of Americans who do not know that HIV cannot be transmitted by swimming in a pool with someone who is HIV positive is the only statistic that has seen a decline from its 2009 statistic of 14% (KFF 2012:13). The simple solution for these statistics would be to educate oneself, however, personal morals still influence the attempt to do so. This is reflected by asking the participants whether they agreed or disagreed

with the following statements: is it one's own fault if they get AIDS, and do they think that AIDS is a punishment for the decline in moral standards (KFF 2012:18). Between 2002 to 2012, there has been a decline regarding the first statement going from 40% agreeing to 32% respectively; the percentage of people who disagreed increased from 55% to 60% respectively; the remaining percentages did not know how to answer or refused to answer the statement (KFF 2012:18). In seeing AIDS as a moral punishment, there has been a decline from 26% to 21% in a decade (KFF 2012:18). Ultimately, it is this slowly progress, that although good, is not transforming quickly enough to change our legislation around HIV and AIDS.

At the early stages of the HIV epidemic, many states implemented many HIV-specific criminal exposure laws which penalized people living with HIV who “know their HIV status and who potentially expose others to HIV” (CDC 2017c). After the passing of the Ryan White Comprehensive AIDS Resource Emergency (CARE) Act in 1990, states were provided with funding for AIDS treatment and care; however, every state had to verify that their criminals were “adequate to prosecute any HIV-infected individual who knowingly exposed another person to HIV” (CDC 2017c). While the White House may have provided some guidance through the National HIV/AIDS Strategy about the issue of criminalization, many of the existing HIV exposure laws need to be re-examined (CDC 2017c). In 2011, the CDC alongside Department of Justice researchers found that “a total of 67 laws explicitly focused on persons living with HIV had been enacted in 33 states” (CDC 2017c). These laws define what behaviors are criminalized alongside what penalty shall be imposed upon violation. Within 24 states, laws may require people “who are aware that they have HIV to disclose their status to sexual partners and 14 states require disclosure to needle-sharing partners” (CDC 2017c). Additionally, 25 states criminalize “one or more behaviors that pose a low or negligible risk for HIV transmission” (CDC 2017c).

Most of the laws that were passed were before antiretroviral therapy was proven to reduce HIV transmission and the laws themselves do not account for HIV prevention measures, and because of this, it is crucial to re-examine and modernize the state laws in tandem with “current evidence regarding HIV transmission risk” to help reduce unjust HIV-specific criminalization (CDC 2017c). In changing the political atmosphere and legislation, it allows for accurate depictions and acknowledgments of people living with either HIV or AIDS.

### **Representations of HIV and AIDS within the Media**

When the first cases of AIDS were reported in 1981, epidemiologists were puzzled to see how previously healthy persons all had Kaposi’s sarcoma and *Pneumocystis carinii* pneumonia after they had disclaimed that they “had no known contact with each other; had no known sexual partners in common...” (Wald 2008:222). In 1982, a break appeared for epidemiologists through “an unconfirmed report of possible associations among cases in southern California,” which presented an “unidentified infectious agent to center stage by demonstrating connections among person, place and time” (Wald 2008:223). In breaking down the testimonies of individuals within the Los Angeles and Orange Counties, it was determined that some individuals had had sexual contact with “1 patient who was not a resident of California” (Wald 2008:223). This supposed finding created an immediate shift in focus going from inquiring about the nature of the disease to the conviction of “an infectious agent”, who “inflected the emerging outbreak narrative” (Wald 2008:223). It is important to see how boundaries were created between the native and the foreigner, and regarding HIV, the non-Californian was targeted and transformed into “Patient Zero” to complete the infectious-agent theory (Wald 2008:223). Altman’s publication of “Clue Found on Homosexual’s Precancer Syndrome” “unleashed the power of the outbreak narrative and, with it, the triumph of virology” as AIDS was described as the “*wily, craftly, sinister*

invader...with [a] particular cruelty, disable[ing] the very defense mechanisms needed for the fight, leaving the body completely susceptible to all of the other marauders responsible for the physical devastation that constituted the syndrome”” (Wald 2008:225). In personifying the syndrome itself, it created a power dynamic between the “elusive killer” and the victim’s natural defenses being eliminated (Wald 2008:225). In describing the virus as the dominant feature from a person living with HIV or AIDS, it strips agency from the individual and allows for a further stigmatization based upon one’s health. It is no longer a person living with HIV or AIDS, but rather a carrier of HIV and AIDS.

Language continued to emphasize the physical aspect of HIV and AIDS as depicted by a 1984 *American Journal of Medicine* piece in which it describes how “AIDS developed in four men in southern California *after* they had sexual contact, with a non-Californian, Patient 0” (Wald 2008:226; emphasis added). By presenting a cause-and-effect model to describe how “Patient 0” interacted with others and in emphasizing the physical characteristics of “chronic swelling of the lymph nodes... [alongside] Kaposi’s sarcoma”, it allows for an unaffected individual to place a physical template as to how to expect a person living with HIV or AIDS will look like, and in what manner they might act in. Descriptions like “*appeared... possible... may... consistent with*” highlight how uncertainty allows for one to fulfill the role of being the ideal target for stigmatization (Wald 2008:227). Wald visualizes how this concept was implemented through a haplotype network to indicate how each “sexual exposure [occurred while also attempting to map out one’s sexual history as well]” (2008:227,229). The minor story of “Patient Zero” soon exploded after the publication of Randy Shilts’s *And the Band Played ON: Politics, People and the AIDS epidemic* in 1987 (Wald 2008:232). Shilts’s book amplified the story by “identifying Patient Zero” as Gaetan Dugas, a Canadian flight attendant who, based

off a simple rumor, was transformed into “the unwitting carrier whose sexual practices and occupation... make him an especially efficient vector, the recalcitrant disseminator who embodies the public-health dilemma and the malevolence of the virus itself” (Wald 2008; 231, 233). Dugas became the human representation for the HIV virus and dealt with being seen as the “Quebecois version of Typhoid Mary” for the entirety of his life, facing the stigmatization of being seen as a promiscuous and reckless vector (Wald 2008:232). Dugas’s name was recently cleared from being labeled “Patient Zero” as scientists screened over 2000 serum samples from the 1970s, which are the earliest archived HIV samples, and when Dugas’s sample was placed on a phylogenetic tree alongside the documented, it showed two main points: Dugas was not the individual who introduced HIV to the United States, and that the HIV group that is present in the United States arrived from the Caribbean (Worobey et al. 2016: 98-99).

An additional representation of HIV occurred in 1993 through Jonathan Demme’s *Philadelphia*, starring Tom Hanks as Andrew Beckett and Denzel Washington as Joe Miller. *Philadelphia* is one of the first mainstream films in Hollywood to acknowledge homosexuality, homophobia, and most importantly, HIV and AIDS. The film begins with Bruce Springsteen’s “Streets of Philadelphia,” which emphasizes Philadelphia as the City of Brotherly Love by depicting shots of diverse communities either smiling amongst themselves or directly acknowledging the camera itself (Demme 1993). The opening scene quickly transition into featuring Beckett and Miller as opposing sides on a case, but eventually focuses on Beckett, who arrives to work at the law firm he is employed at, and is immediately the center of many interactions that praise both his work and being. This soon changes after Beckett is chosen to be senior associate for an important case for the firm; the environment for this bestowing of power is interesting as the firm’s partners are all dressed in suits and smoking cigars while Beckett has

an aura of naivety that is soon vilified by one of the partners, who asked “What’s on your forehead pal?” in reference to the Kaposi’s Sarcoma lesion that is present on Beckett (Demme 1993).

This moment creates the entirety of the plot as Beckett begins to work from home as his lesions worsen, but still effectively produces the work that is necessary. Unfortunately, the physical documents and its electronic counterparts go missing, yet is eventually found. This mishap leads to the partners dismissing Beckett to which he believes that he was wrongfully terminated due to him living with AIDS. Miller is soon reintroduced into the film as his wife is in labor and eventually delivers a baby girl; this environment emphasizes Miller’s heterosexuality while also amplifying his masculinity through the very nature of reproduction. After some time, Beckett and Miller meet again in Miller’s law office in which homosexuality and heterosexuality clash over a two-sentence exchange: “What happened to your face?” “I have AIDS.” (Demme 1993). Soon after Beckett’s truth, Miller becomes fearful of Beckett and distances himself and maintains a watchful eye as to what Beckett touches while also observing his lesions. When Miller begins to listen to Beckett’s recounting of why he believes he was fired, Miller poses the obvious question of why didn’t Beckett inform his employers to which Beckett responded that it doesn’t matter as his duties are to his clients and not the law firm partners. Eventually, Miller refuses to accept the case, and as Beckett is leaving the office, Miller states that he is “sorry about what happened to [Beckett]”; a statement that is quickly contrasted with a Miller panicking about myths around HIV at the doctor’s office (Demme 1993). After witnessing Beckett being discriminated in the library, Miller agrees to represent Beckett in court.

The final court scene addresses the stereotypes of the law firm’s defense team attempted to vilify Beckett. A powerful statement is made by Ms. Benedict, who had disclosed her HIV



status to one of the former law partners, states that “[she] does not consider [herself] different from anyone with [HIV or AIDS]. [She’s] not guilty. [She’s] not innocent. [She’s] just trying to survive” (Demme 1993). This statement addresses all forms of HIV transmission as Ms. Benedict acquired HIV via blood transfusion, and her testimony visualized how the law firm’s strategy was to emphasize promiscuity within Beckett to negate his responsibility and undermine his status by describing him as reckless. Miller eventually proves that the partners knew that Beckett had AIDS after he exposes his lesions that are on his chest; the law firm partner respond with statements like “My god, what a nightmare” to which was responded with “He asked for it” (Demme 1993). Soon, Beckett collapses and is sent to the hospital, and in his time there, the jury rules in his favor, a powerful realization of the discrimination faced by individuals living with HIV and AIDS. The last interaction that Miller has with Beckett is when Andrew is about to pass away, yet Joe, the man that once feared having direct contact with Andrew, sat beside him and aided Andrew’s breathing by placing his mask over his face. A message of empathy and unity was sent through this end; it highlighted that by listening to a person living with HIV or AIDS, one can come to recognize the person first before the virus.

This idea is presented in ABC’s *How to Get Away with Murder* through a homosexual serodiscordant couple named Oliver and Connor. Their relationship began as a one-night stand, but their relationship blossomed over the course of the first season as they interacted more. At one point, they end their relationship and begin seeing other people, until they realize that they still have feelings for each other, and go to a clinic to be tested for STDs. In the season finale, Connor visits Oliver at his apartment in which he finds out that Oliver has tested positive for HIV (D’Elia 2015). Throughout the second season, Oliver shames himself for contracting HIV, representing the stigma that he internalized, yet Connor still accepts him, and goes as far as

moving in with Oliver to help him be comfortable. This lasts until the third season in which Oliver ends the relationship and attempts to date someone new named Thomas. One night, Thomas and Oliver are about to engage in sexual intercourse, but Oliver goes to the bathroom to give himself a pep talk: “There’s no shame in this. [Thomas] can react however he wants to react. The most important thing is that you just got to be you” (Smith 2016). As Oliver builds up his confidence to tell Thomas about his HIV status, Thomas claims that he is listening, yet continues to remove his clothing (Smith 2016). It isn’t until that sense of exposure that Oliver tells him, and Thomas retreats from Oliver and feigns a painful smile throughout Oliver’s attempt to emphasize how responsible he is being, but is being ignored by Thomas. Thomas claims that he is not mad, but later states that he “was just really starting to like [Oliver]” (Smith 2016). He attempts to lighten the weight of his statement, but continues to fumble over his words, describing how he sees dating a person living with HIV as a lot to handle, something that he is not ready for (Smith 2016).

Throughout these works, different variations of acknowledging HIV have been presented. The concept of “Patient Zero” broke the collective narrative of all gay men being equally responsible for the AIDS epidemic as “Patient Zero” threatened the idea of national familiarity with the notion of the foreigner. Promiscuity became associated with any person living with HIV and became a common stereotype to be transformed into a feature that could challenge, weaken and possibly ruin one’s character as portrayed in *Philadelphia*. Nevertheless, in highlighting how sexual orientation did not matter when the law was broken proves that it is possible to move beyond the biological definition of an individual and focus more on justice. The empathy that was depicted in *How to Get Away with Murder* is exactly what is needed to move forward

judgement and achieving a future that is better for all. While it is important to remain optimistic for the future, it is essential to reflect upon the past to effectively progress.

### **“I Lived Through It”: Recounting the Epidemic**

The following testimonies are of people who lived through the HIV and AIDS epidemic. I hope that you read and listen with an open heart and open mind as to how they experienced

The first two interviews that I would like to focus on are from the ACT-UP Oral History Project. These interviews may have been conducted in 2014, but the interviewees were directly affected by the HIV and AIDS epidemic. While I wish I could describe their entire life story, I will be providing a summary of their upbringing and selecting quotes from their interview that I believe best captures their argument; through this method, it is by no means is it the only way to interpret the information, but for this thesis it will be presented in such a manner.

The first interview took place on March 9<sup>th</sup>, 2014 with Cesar Carrasco, a 59-year-old (at the time) Chilean man, who grew up in a Seventh Day Adventist and Catholic household. At 18 and during a Fascist rule, Carrasco came out to his family as gay, an experience he describes as “pretty open...for Chilean standards...” (2014). Carrasco first heard about the HIV and AIDS epidemic through a man he was dating named Bruce, a dermatologist who had seen “strange skin... and respiratory disorders that were becoming more and more prevalent among gay men” (2014). When Carrasco moved to the United States, he began activist work in 1982 within San Francisco by translating how the virus worked into Spanish (2014). Carrasco decided to do bigger activist work and went from working in the GMHC between 1984-1988 to working at ACT-UP between 1988-1990 (2014). He believes he contracted HIV between 1982 and 1984,

but was formally diagnosed in 1988, and used his work at ACT-UP to channel his “frustration...anger, and energy” in a productive and effective manner” (Carrasco 2014).

When asked by Schulman about the “lost generation”, or “[the] generation of people who have suffered the deaths of everyone around them; who’ve had their own personal health crises endlessly; who’ve gone through all the terrible drugs,” Carrasco emphasizes that while the younger generations may have access to medication, it is through “activism, [that people can become] much more aware of what happened” in the past and understanding how relationships developed into the ways they did (2014). This quote is important as it highlights that while there may be an intergenerational shift in perspectives around HIV and AIDS, it allows for the bridging of previous and current work.

The second interview took on September 30<sup>th</sup>, 2014 with Sean Strub, a 56-year-old (at the time) man who grew up in Iowa with a Catholic upbringing in his lifetime. He is also the founder of POZ, a magazine that focuses primarily on the lives of people living with HIV or AIDS. Throughout his interview, Strub discusses how the stigmatization of HIV was so prevalent it was as if “people [were] at totally opposite ends of the spectrum; ...[either] doing horrific things by day [about the stereotype of queer bodies] or doing homophobic things by day” to emphasize how being queer was not accepted at all (2014). He remembers how evangelical churches described how “homosexuals...[were] a type of person who is a threat to you; not just a threat to themselves, but a threat to you and to your family, [emphasizing that] that was a real transition that happened in the public consciousness about homosexuality” as a response to the visibility and political opportunity to target homosexuals (Strub 2014).

Regarding PrEP, Strub believes that it will weaken condom use as people will see it as “the fear that [drove] people to [use] condoms” is as biologically present, yet it doesn’t mean that

individuals should abandon them” (2014). Strub believes that the only way “to deal with stigma effectively is to empower the stigmatized. It’s a real power-transfer...and people don’t like that” (2014). Back then, when individuals were:

“seen as dying, very possibly a horrific death... regardless of whatever moral judgement somebody might make out of homosexuality or drug use, there was some measure of human compassion. Once combination therapy came out, we were no longer seen as dying. We started to be seen through the prism of our survival. We were going to be around longer, therefore we were around longer to infect people longer. So, we increasingly became defined through that potential to infect, as viral vectors, as an inherent threat to society” (Strub 2014).

It is now the task to transform the idea of being solely defined as a vector into one that emphasizes the person first and not being defined by the virus.

Regarding the interviews that I conducted, my participants were asked general questions about HIV and AIDS alongside their feelings about both. They could opt out of a question if they chose to do so, and at times, answered multiple questions through one statement. I encouraged them to ask questions that way it became easier to share their opinions.

The first interview I conducted was in December 2016 with Peter Griffin. Peter is a 39-year-old white man from Ohio; I met him after he came down to visit some friends in California and saw my advertising for my thesis. His knowledge on HIV and AIDS was accurate, so there was no need to clarify how the virus and syndrome worked, only the new antiretroviral medication. When asked about his knowledge about current medications, he immediately spoke of PrEP, yet remained hesitant about addressing the medication entirely. Griffin believes that

“They [researchers] says its 99% effective, and some people will take that chance and not use a condom. I think that they’re just opening the door to HIV even more” (2016). He later elaborates upon how he thinks it’s interesting that “hookup apps”, like Grindr, now allow for one to choose to disclose whether they are on PrEP or not. Griffin thinks that such an option is “shocking because it implies that one person is being more responsible than the other. What if they can’t afford the medication, yet they are still HIV-negative. Do you trust the person who says they are negative, or will a simple four-lettered medication lead you to choose that person?” (2016). I found this to be interesting to see how the medication itself that I have been arguing will change the stigmatization of HIV for the better is creating an additional rift in how responsibility is viewed. After realizing that my curfew is near, I ask Peter to leave on a whatever statement he’d like to which he stated “Let’s not screw up again, let’s learn from the past. Everything we’ve earned we call them rights, but if enough people are against it, then it can go away. Nothing is every truly appreciated, so we’ve got to continue earning our things. Fight for your future, kid and the future of others.” (2016).

I soon leave California to begin my second semester of senior year, and within a week of arriving an individual offers to help with an interview. His name is Bruno, a 55-year-old self-described “loner foodie and oenophile.” Bruno’s knowledge about HIV and AIDS was impressive, and again, I focused primarily on the other questions. His knowledge on the new antiretroviral medications is also impressive, and even corrects me when I used an incorrect statistic. Nevertheless, the heart of Bruno’s interviews lies primarily in his experiences of knowing people living with HIV: “I’ve been in love with three of them” (2017). Bruno begins to recount the time in which he lived in Brazil and how his boyfriend at the time was afraid to tell him because he was uncertain of how Bruno would react. Bruno recounts how his partner “found

out two months before I was supposed to move down there, but I still went. He thought it would change my mind. Since then, I've told all three of them, it doesn't change how I feel about you, just the repertoire of what we can do sexually" (2017). The way Bruno presented this quote was very eloquent as he emphasized how when he was younger, I believed at one point that people contracted the virus because they were "irresponsible," but now that he has matured "I have mellowed out. I don't feel any different to someone whether they be positive or not." (2017). He is a stronger believer in tranquility, and believes that he has no right to judge another person based on their physical descriptions; he does, however, place a significant amount of weight on morals, but not in the manner you would think. He recounts that:

"when in Brazil, there was a strong advertisement campaign about the social stigma around HIV. It was called *figuq saberlo*, meaning in the known. Stay in the knowing literally. And I think, it was important because people didn't want to know, maybe because of their *machismo*, men believe they cannot contract HIV. It doesn't matter who they are as a person, *the virus is indiscriminate, but we are not*" (Bruno 2017).

I thank Bruno for his time, but before I leave he tells me the following: "Here in the States, the campaign is know your status. Knowledge is power. While not everyone may not see eye-to-eye with you, I hope that this interview allows you to use my experience to encourage your generation to get tested and to be more supportive of each other. You can end it you know? It's just all about making the effort, and not taking no for an answer" (2017).

### **Conclusion**

HIV and AIDS hold a global history that goes beyond the scope of my thesis. These entities remain tabooed in the United States even though both are living entities that are

constantly changing. Their sudden beginnings and devastating tolls still echo within our society, legislation, and medical techniques, but we are also evolving and thriving as well.

Through this thesis, I have documented and discussed how the initial stigmatization of HIV and AIDS was created through anxiety and fear. Using literature from the beginnings of the outbreak, it is better understood as to how a social and cultural stigma arose towards individuals living with HIV and AIDS. Nevertheless, it is through this social exiling that HIV and AIDS activism arose and the impetus to challenge both the virus and syndrome began. Now with the inventions of new antiretroviral medications, the biological mechanisms of HIV and AIDS are being inhibited and research continues to dismantle the composition of both HIV and AIDS. It is time to recognize the scientific breakthroughs that are happening, and incorporating those facts into society to better educate others to recognize affected individuals as people that are living *and* thriving with HIV or AIDS, instead of being defined by either one.

This research holds value in academia and in activism. If we can understand and visualize how the stigmatization of HIV and AIDS occurs, then it is possible to one day be able to remove those obstacles. Studies are already being conducted and are depicting how HIV-related stigma takes place and how it is reinforced; nevertheless, it is in these discoveries that the production of support groups, positive networking and strives for justice can take place.

Engaging in this topic, both as a researcher and activist, has allowed me to appreciate the progress that has been made in ending the HIV and AIDS epidemic. It has also allowed me to appreciate the oral histories from my predecessors, providing me with the opportunity of educating others and encouraging empathy through attentive listening and activism. I am optimistic that in understanding the historical roots of HIV and AIDS, more people will be



encouraged to fund research, to participate in activist roles, and to end the misrecognition of affected individuals towards the goal of finding a cure for the *now* incurable HIV and AIDS.

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