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Emily A. Moner
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What Does Silence = Now?
An Analysis of Past and Present Discourse Surrounding HIV/AIDS

by

Emily Moner

Submitted in partial fulfillment
of the requirements for the degree of
Master of Arts in Anthropology, Hunter College
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Thesis Sponsor:

May 9, 2017
Date

Christina Zarcadoolas
Signature

May 9, 2017
Date

Ignasi Clemente
Signature of Second Reader
Dedication

To Dad, Alberto, and Andy

For giving me all of the direction I didn’t know I needed.
Acknowledgements

I would like to extend my heartfelt gratitude to all faculty and staff in the department of Anthropology at Hunter College. In particular, I thank my advisors, Dr. Christina Zarcadoolas and Dr. Ignasi Clemente, the wisdom of which without my thesis would not have been possible.

Secondly, I would like to thank Mom and Dad for their unwavering support, never failing to cheer me on no matter what my goals have been. Additionally, I thank friends both near and far for keeping me sane throughout this arduous process.

Finally, I would not be where I am today without the support of my undergraduate institution of Mount Holyoke College. I would like to thank in particular, Dr. Alberto Sandoval who sparked a passion in me that I could not turn away from and one that fueled this entire endeavor. Last but certainly not least, I thank Dr. Andrew Lass for never failing to provide wisdom and humor and never allowing me to forget my strengths and why it is that I continue to study Anthropology.
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Abstract: Initially, HIV/AIDS was not discussed openly due to the stigmas attached to the disease itself and how it was transmitted. In the present day many view HIV/AIDS as having become a non-issue or, at the very least, under control. Currently, HIV/AIDS is considered a treatable, chronic condition, however, the illness still has the potential to spread rapidly if proper precautions are overlooked or deemed unnecessary due to the misconception that the disease is no longer a threat. Technological advancements like social media have made it easier to connect with others over various topics including healthcare. As a result, HIV/AIDS education and prevention can now be communicated in a variety of new ways. This essay examines how the HIV/AIDS epidemic was first addressed in the context of politics, media and the general public and subsequently how that compares to the ways in which it’s currently being discussed using popular forms of communication such as Facebook and Twitter. The primary goal is to illustrate how the discourse surrounding HIV/AIDS has evolved and what role social media has played in this process of evolution.

Introduction

In Sarah Schulman’s “The Gentrification of The Mind: Witness to a Lost Imagination,” she reflects on her time spent living in New York City during the height of the HIV/AIDS epidemic. She opens by describing her reaction to a radio broadcast heard back in 2001.

“Bizarrely, this very day is the twentieth anniversary of AIDS…the announcer is discussing events that I know intimately…and yet there is a strangely mellow tone to the story. ‘At first America had trouble with People with AIDS’ the announcer says…’but then they came around.’ I almost crashed the car. This? I realize the way one realizes that the oncoming train is unavoidable and I’m stuck on the track. This is going to be the official history of AIDS?.”

Attitudes and declarations like those mentioned by Schulman both concern and fascinate me. I was moved to examine the present discourse surrounding the epidemic for this reason. Schulman goes on to state that, “there are two distinctly different kinds of AIDS that are not over. There is AIDS of the past. There is ongoing AIDS. Neither is over, although they are treated quite differently in the present moment. (Schulman 2012, 42).”
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I recalled Schulman’s frustration at the idea of AIDS being over when I began expressing to friends and family my desire to devote my thesis to examining the epidemic. The responses I received were puzzling. “Isn’t that a bit dated?” “Isn’t the disease considered treatable now?” “Are you sure there’s enough material to compose a thesis on that topic?” to name a few. I began to wonder whether they knew something I didn’t.

 Throughout the first two decades of the epidemic, there was a noticeable silence that accompanied the disease. This silence was so prevalent that in 1987, six years after the AIDS epidemic first began in the U.S., six New York based activists and later members of the AIDS Coalition to Unleash Power (ACT UP), Avram Finklestein, Brian Howard, Oliver Johnston, Charles Kreloff, Chris Lione, and Jorge Soccaras created the “SILENCE=DEATH” campaign (Smith and Gruenfeld 1998). In this essay I will examine the various types of silence that occurred: silence from politicians, silence from the media and silence from the general public.

 The phrase “silence=death” was used to reference the importance of political activism as a way of fighting the disease along with the dangers involved when there is no communication between carriers of the disease and others that may be at risk either through sexual activity or drug use. Silence was also a reference to the lack of attention given to the epidemic by politicians. By the time President Reagan faced the public to address the disease in 1987, 36,058 Americans had been diagnosed with the disease and 20,849 had died (Shilts 1987, 596).

 In 1985, two years prior to the campaign’s creation, James Brady, editor for the Advertising Age, published an editorial stating that,

 “The dead are homosexuals who have contracted and will perish from AIDS…but there is a gentle, loving conspiracy of silence to deny
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reality…Men are dying and we in the press cough politely and draw curtains of discretion across the truth…Protect a name, a family, a reputation. A memory. So we write lies about the cause of death…Can lies be a cause of death? (Shiltz 1987, 544).”

Brady was referring to the pattern that was taking place in the writing of death certificates. Due to the embarrassment that came with contracting what was viewed as a homosexual disease, patients did not want to reveal their status once they were gone. Doctors learned quickly to be accommodating by falsifying these certificates (Shiltz 1987, 544). In these cases, silence was perpetuated by the victims themselves rather than those who refused to acknowledge them. The issue here was not that their positive status would be ignored but rather that it would plague their reputations even after death.

I fail to understand how the HIV/AIDS epidemic can be discussed so little at its most devastating point only to evolve into an illness that is no longer considered a problem and therefore not worth discussing anymore. Given that many no longer view AIDS as a cause for concern, has this translated into a new type of silence surrounding the disease? In this essay I will strive to answer the question, how is the ongoing AIDS of today being addressed both socially and politically? This paper is the product of a literature review and an analysis of social media and health messaging.

I will begin by reviewing literature that was either written within the first two decades of the epidemic (1981-1999) or written to reflect on the events of that time period. The literature being reviewed will chronicle how HIV/AIDS was addressed by politicians, the media, and the general public alike. I will focus on identifying the issues that drove the initial silence surrounding the disease while also providing examples of attempts that were made by advocacy groups such as ACT UP and The Gay Men’s Health Crisis (GMHC) to educate the general public despite receiving little support from
governmental officials. Secondly, I will explore the role that social media is playing in the advocacy and methods of prevention from 2000 to present day. I will aim to construct a picture of what HIV/AIDS discourse and prevention currently looks like from both a political and social perspective and how it compares to prior messages.

**HIV/AIDS and Stigma**

From the very beginning of the HIV/AIDS epidemic in 1981, the illness has been defined medically as a highly infectious disease but also moralized as a stigma (Herek and Glunt 1993; Letteney and LaPorte 2004; Liamputtong 2013, 2). The disease managed to combine “sex, drugs, death and contagion” in such a way that made the disease uniquely problematic in not only a medical sense but also a social one (Liamputtong 2013; Scambler 2003). Additionally, the illness would often disproportionately effect those of already stigmatized groups such as gay men, drug users and sex workers (Liamputtong 2013; Scambler 2003; Parker and Aggleton 2003).

A stigma is defined as an attribute that marks an individual separating them from the wider view of society (Airhihenbuwa and Iwelunmor 2013; Link and Phelan, 2001). Such a marking can refer to an immoral, pathological or disfiguring condition or a quality that the majority consider to be a sign of “deviance” and a break from cultural norms (Airhihenbuwa and Iwelunmor 2013; Link and Phelan, 2001). If a person is stigmatized for whatever reason they risk stereotyping and labeling by others, separation, loss of status and discrimination (Airhihenbuwa and Iwelunmor 2013; Link and Phelan, 2001).

Two attitudes have been identified in the process of forming stigmas: evaluative and expressive (Hosseinzadeh and Hossain 2011, 585). Applying these categories to the stigmas attached to those who suffer from HIV/AIDS, a negative expressive reaction
could stem from the disease’s connection to drug use or homosexuality. Along that same line, a negative evaluative reaction could be connected with the fear of transmission (Hosseinzadeh and Hossain 2011, 585). Both categories of stigma contributed to how the government and general public addressed (or failed to address) the epidemic.

**The Early Years (1981-1999)**

Addressing the spread of AIDS and how to prevent infection proved difficult due to the fact that embedded ideologies of heteronormativity, the belief that heterosexuality is the only acceptable way to identify oneself, made carriers of the disease “the enemy” (Armstrong and Bernstein 2008, 88; McKenzie 2016, 1754). Additionally, promiscuity and engaging in frequent sexual acts were seen as ways of affirming one’s identity in the gay community. As a result, in 1982, when health officials began stressing the need for protection and even abstaining completely from high-risk behaviors, many viewed their warnings as an attack on the foundation of the gay rights movement (McKenzie 2016, 1752). Silence in these cases rested on the shoulders of the gay community rather than those who stigmatized them. The failure to disclose status combined with the resistance to take protective measures helped the disease spread even quicker.

When the AIDS epidemic began, conservatives were establishing themselves as part of the “New Right” and gaining political power (Rimmerman 1998, 1). The New Right gave rise to another movement known as the “Moral Majority” which served as a movement rooted in religious fundamentalism reinforcing the idea that homosexuals were to blame for the epidemic (Rimmerman 1998, 1). The New Right pointed to homosexuality as a sign of moral failing in society and viewed AIDS as a natural punishment for such failing (Rimmerman 1998, 1). Even when politicians (and media)
didn’t necessarily hold such far right views, they still preferred to avoid tackling the subject of AIDS. New York City mayor at the time, Ed Koch along with *The New York Times* serve as an example of this pattern of avoidance.

**Media Inaction**

The Times had a noticeably sluggish start to what was considered by some to be the “biggest health story of the decade (Soffer 2010, 306).” Only one article addressing AIDS was published by The Times between July of 1981 and May of 1982 and it wasn’t reported on routinely until over two years after the epidemic had begun (Soffer 2010, 306). Mayor Koch, who, despite declaring himself an ally of the gay community would be labeled by many New Yorkers as someone whose silence and inaction defined the initial years of the epidemic (Soffer 2010, 306)\(^1\). In 1981, during an interview with the *New York Native*, Koch expressed his discontent with “what it cost him, as a single man, to be vocal on gay rights (Soffer, 306).” In this case, silence was the result of more concern being poured into a political image rather than the growing disaster at hand. It was during this time and in the six years that followed, that New York based non-profits such as ACT UP and private organizations like The GMHC helped to break the silence and hold the mayor accountable, with ACT UP eventually plastering subway cars with photos of Koch bearing the caption, “10,000 NYC AIDS Deaths. How’m I Doin’?” (Soffer, 215).”

On November 6\(^{th}\), 1984, Ronald Reagan was re-elected as President of the United States. Throughout his campaign (as well as his opponent’s) there was never any public

\(^1\) Koch would later acknowledge his mistakes but would claim he had only tiptoed around the issue due to what he believed addressing it would cost him as, “a single man to be vocal on gay rights (Soffer 2010, 306).”
acknowledgment of the increasingly devastating disease that his administration had once called their “number-one health priority (Shiltz 1987, 495).” Additionally, the press treated the issue as unimportant. A survey of news articles from The Wall Street Journal, The New York Times, The Washington Post and USA Today, revealed that the number of AIDS-related stories peaked in 1985 despite the fact that the number of those infected continued to increase for the next six years (Brodie et al. 2004; Baumgartner, Lisa M, 2012). As Reagan declared victory he claimed that, “America’s best days lie ahead.” Later that month, the caseload of AIDS patients in the US surpassed 7,000 (Shiltz 1987, 495).

AIDS Prevention and The Far Right

In March of the following year, Reagan assistant Gary Bauer was questioned as to the reason for the president’s ongoing silence. His response was, “it hasn’t spread to the general population yet (Liclair 2015, 2).” Later that year, Rep. Henry Waxman, D-Los Angeles, stated in the Washington Post that, “it’s surprising the president could remain silent…that he could fail to acknowledge the epidemic’s existence. Perhaps his staff felt he had to, since many of his New Right supporters have raised money by campaigning against homosexuals (DemocracyNow, 2004).” Surgeon General C. Everett Koop, was of the mindset that Bauer and other Reagan affiliates like Pat Buchanan and Rev. Jerry Falwell who referred to AIDS as “God’s punishment,” were the primary influences behind the president’s failure to take action (Berhman 2004, 28). As Reagan turned to them and others from the Moral Majority for advice, they helped to reinforce the idea that AIDS both nationally and globally was, “something over there (Berhman 2004, 28).”
On February 17th, 1986, an editorial was published in The New York Times that attempted to highlight the less obvious forms of suffering that AIDS patients were grappling with. E.R. Shipp stated that, “a Gallup Poll reported…a third of Americans say they have a less than favorable attitude toward homosexuals because of AIDS…most Americans favor some sort of legal discrimination against homosexuals as a result of AIDS (Shipp 1986, 1).” Shipp goes on to clarify that those desiring such discrimination do so because they believe it will contribute to the well being of the public. However, at the time, doctors had already confirmed the virus could only be transmitted through sexual intercourse, exchange of blood by intravenous drug use or otherwise or from mother to fetus (Shipp 1986, 1). Nevertheless, support for such acts of discrimination continued and a month later, came in the form of an additional New York Times editorial.

On March 18th, 1986, political commentator and confidant of President Reagan, William F. Buckley Jr., wrote a piece for The New York Times detailing what he believed should be done to combat the AIDS epidemic.

“If the news is progressively reassuring, public identification would not be necessary. If it turns in the other direction and AIDS develops among, say, children who have merely roughhoused with other children who suffer from AIDS, then more drastic segregation measures would be called for…Everyone detected with AIDS should be tattooed in the upper forearm, to protect common-needle users, and on the buttocks, to prevent the victimization of other homosexuals (Buckley 1986, 2).”

His methods reflected the sinister views that the Moral Majority held in regard to AIDS victims. Instead of trying to combat stigma and promote protection he proposed the idea of involuntary marking that echoed events of the holocaust (Eiselein 1996, 165).
In spring of 1987, President Reagan gave his first speech regarding the AIDS crisis. There was little talk of educating the public and instead the primary focus was on testing techniques. Activist Larry Kramer listened to Reagan’s words backstage and noticed something else his speech was lacking: the word “gay.” He referenced the spouses of intravenous drug users, the struggles faced by hemophiliacs along with anyone who contracted AIDS via blood transfusion but no mention of the demographic that had been advocating tirelessly for their own survival and dying off by the thousands for the past six years (Shiltz 1987, 596). President Reagan, ironically dubbed “The Great Communicator,” had stood by while AIDS attacked the American public and failed to acknowledge the events.

AIDS in a Post-Reagan White House

As Reagan was approaching the end of his term, the House and Senate served as the blockades to any tax dollars being spent on research, treatment, or other AIDS related issues. Republican senator Jesse Helms of North Carolina took the floor on October 14th, 1987 with the goal of passing the “Helms Amendment” that would prohibit the use of tax dollars for AIDS education materials that “promote or encourage, directly or indirectly, homosexual activities (Rimmerman 1998, 2).” The Senate voted favorably and the amendment was established. Progress going into the 1990s was mixed as conflict between President Bush and later, President Clinton and Congress was frequent. In 1990, Congress passed the Ryan White Comprehensive AIDS Resources Emergency Act (CARE) that was intended to ensure federal assistance to urban areas heavily affected by the epidemic. Despite this act being signed into law by President Bush, he consistently opposed the level of funding that Congress requested (Rimmerman 1998, 3).
The year 1992 brought with it the election of Democratic president Bill Clinton along with a Democrat-controlled Congress. The outcome being that the Moral Majority was given less influence leading to significantly less friction surrounding congressional, AIDS-related policies and Clinton kept his campaign promise of increasing federal funding (Rimmerman 1998, 3). In 1994 however, Republicans took control of both the House and Senate for the first time in four decades. As a result, by 1996 conflict between the president and Congress surrounding any AIDS related decisions had resumed (Rimmerman 1998, 3).

To summarize this section of the thesis, I have shown that, the silence surrounding the AIDS epidemic was rooted in stigmas surrounding not only illness and the fear of transmission but also in moral objections to drug use, homosexuality, and the fear victims had of being ostracized should one’s status be known. Given that those stigmas have not been erased from our society, it is conceivable that the disease could still be shrouded in silence for those reasons even though progress has been made in regard to treatment. I will now discuss more recent literature and examine how the discourse surrounding AIDS has evolved up until the present.

**The Later Years (2000-Present)**

In this next section I will aim to paint a picture of what current AIDS discourse looks like. In a written piece for Forbes magazine in 2015, Steve Olenski acknowledged that despite its lack of presence in the news, HIV/AIDS remains a significant danger. He explains that globally, “38.1 million people have been infected with HIV and 25.3 million people have died from AIDS-related illnesses between 2000 and 2014. As of last year, there are 36.9 million people living with HIV and that number includes 2.6 million
children.” Given that HIV/AIDS is still considered a public health risk and that social media has taken on a large role in both the sharing and retrieving of all kinds of information, I wanted to see if it was serving as a tool for advocacy, education and other resources. Primarily, I examined Facebook, Instagram, Twitter and Pinterest and will elaborate on my findings below.

**Social Media and Health Communication**

If one is going to examine the role that social media is currently playing in HIV/AIDS awareness, it’s important to also take into account how these types of online resources are involved in health communication in general. Below I’ve compiled a table of statistics from both PWC Health Industries and Pew Research Center that offer a look into how the internet is currently interacting with healthcare:

<table>
<thead>
<tr>
<th>Percentage</th>
<th>Description</th>
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</thead>
<tbody>
<tr>
<td>42%</td>
<td>Individuals viewing health information on social media look at health-related consumer reviews.</td>
</tr>
<tr>
<td>32%</td>
<td>US users post about their friends and family’s health experiences on social media</td>
</tr>
<tr>
<td>29%</td>
<td>Patients viewing health information through social media are viewing other patients’ experiences with their disease</td>
</tr>
<tr>
<td>24%</td>
<td>Individuals access healthcare information on social media by viewing health-related videos/images posted by patients</td>
</tr>
<tr>
<td>74%</td>
<td>Internet users engaging on social media</td>
</tr>
<tr>
<td>80%</td>
<td>Social media users looking for health information including a specific doctor or health professional</td>
</tr>
</tbody>
</table>

Figure 1: Social Media’s role in Healthcare  

It was also found that, “some of the most engaged and active audiences on social media are individuals coping with a disability or chronic condition (PewResearch, 2011, via referral MD).” Based on these statistics, it would appear as though the increasing popularity of social media is apparent in the ways in which the general public is both accessing and sharing medical information. These media sites can provide information, networking opportunities, access to health professionals, other medical resources and
more. As I will demonstrate below, HIV/AIDS awareness, prevention and education have taken to social media to help get various messages across to the public.

Social Media and HIV/AIDS Prevention

Michelle Betton and Nyaka Mwanza of the Pediatric AIDS Foundation explained that because of social media, it’s relatively easy to reach a broad audience. Additionally, social media can target high-risk populations especially those of a younger age. People living with the disease or those that have lost family and friends to it can find online support communities that have the potential to reduce stigma and provide a lifetime of other resources. Microblogging sites such as Twitter can serve as a source of frequent updates of the latest news surrounding HIV/AIDS. Additionally, sites holding primarily visual information such as Instagram can enhance personal testimonies and stress the importance of certain precautions through the use of imagery (Betton and Mwanza 2013, 2). It was stated that social media is “eliminating the barriers that exist between the people making decisions and the people most affected by these decisions. It unites us and helps amplify our collective voice (Betton and Mwanza 2013, 2).”

Along the same lines as Betton and Mwanza, David Duran of The Body PRO, composed an article titled “Leveraging Social Media for HIV/AIDS Campaigns.” His primary message stressed the importance of choosing the social media platform that would be the most effective based on the type of message being communicated. He stated that, “Facebook is the best platform for medium-length messages …Twitter is minimalistic due to its character constraints…LinkedIn is best for mid-length and long-form information…it's important to research and discover what will work best for you
Duran shed light on the importance of identifying the style and tone of the language most likely to attract attention for your desired audience (Duran 2016, 2). Though there are differences between how each site presents information, they have all managed to address the topic of HIV/AIDS using their specific formats.

**Facebook**

Facebook is ideal for interacting with others and sharing information through groups or chat exchanges. As of 2016, 79% of internet users (68% of all US adults) now use Facebook. While young adults constitute the majority, the rate of usage for adults over the age of 65 is steadily increasing. As the diagram shows below, it continues to be the most widely used social media site available (PewResearch, 2016).

---

**Facebook remains the most popular social media platform**

<table>
<thead>
<tr>
<th>Year</th>
<th>Facebook</th>
<th>Instagram</th>
<th>Pinterest</th>
<th>LinkedIn</th>
<th>Twitter</th>
</tr>
</thead>
<tbody>
<tr>
<td>2012</td>
<td>60%</td>
<td>30%</td>
<td>25%</td>
<td>25%</td>
<td>20%</td>
</tr>
<tr>
<td>2013</td>
<td>65%</td>
<td>35%</td>
<td>30%</td>
<td>30%</td>
<td>25%</td>
</tr>
<tr>
<td>2014</td>
<td>70%</td>
<td>40%</td>
<td>35%</td>
<td>35%</td>
<td>30%</td>
</tr>
<tr>
<td>2015</td>
<td>75%</td>
<td>45%</td>
<td>40%</td>
<td>40%</td>
<td>35%</td>
</tr>
<tr>
<td>2016</td>
<td>79%</td>
<td>50%</td>
<td>45%</td>
<td>45%</td>
<td>40%</td>
</tr>
</tbody>
</table>

Note: 88% of Americans are currently internet users. Survey conducted March 7-April 4, 2016. “Social Media Update 2016”

PEW RESEARCH CENTER

Figure 1: Percentages of Social Media Use
Source: PewResearch Center, 2016
Facebook campaigns such as “Act Against AIDS” serve to raise awareness throughout the general population and work to reduce the rate of infection within the higher risk communities. Launched in 2009, this campaign currently has 156,218 followers and 158,676 likes. Another example, “Start Talking. Stop HIV,” is designed to target gay and bisexual men and to initiate conversation about prevention methods and sexual health. The messages used in this campaign reflect the input of more than 500 men of varying ages, races and ethnic groups across the US. This campaign, launched in May of 2014 has 93,333 followers and 94,397 likes.

**Instagram**

32% of internet users (28% of all US adults) are users of Instagram (PewResearch, 2016). The use of this website is particularly prevalent in young adults (ages 18-29). Nearly six-in-ten of those online (59%) are users of Instagram (PewResearch, 2016). The (originally Facebook) campaign “Act Against AIDS” has created an Instagram platform as well containing 789 posts and 4,150 followers. Another campaign, “Greater Than AIDS,” aims to raise awareness regarding the use of the HIV preventative drug, PrEP. This campaign contains 429 posts and 6,645 followers. Instagram’s primary purpose is to share photos and brief videos. As a result, short but informative campaign ads that help get messages across quickly are ideal for this website.

**Twitter**

24% of internet users (21% of all US adults) use Twitter. 36% of online adults ages 18-29 are present on the website as opposed to the 10% of adults over 65. Additionally, it has been found that the highly educated tend to be drawn towards this platform with 29% holding college degrees compared to 20% with high school diplomas.
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or less (PewResearch, 2016). Campaigns such as “Talk HIV” which serves as the “Act Against AIDS” Twitter account, stress the importance of getting tested regularly and staying informed along with encouraging users to get involved in community outreach. This campaign was launched in March of 2010 and now has 31.6K followers and 1,357 likes. Additionally, the “Greater Than AIDS” Instagram campaign is also garnering support on their Twitter page. After joining the social media site in January of 2010, they now have 24.9K followers and 1,175 likes. Twitter posts are limited to 140 characters so any message posted must be concise. That said, private messaging contains no character limit and the use of hashtags are helpful in starting conversations and organizing various topics.

**Pinterest**

Pinterest, while less widely used than Facebook or Instagram, remains one of the more popular social media sites with 31% of internet users (26% of US adults) having accounts (PewResearch, 2016). Pinterest, like Instagram, is primarily used for the sharing of images and short messages. Additionally, like Twitter, it can provide the user with information as to who else is “pinning” similar topics. The CDC’s pinboard (account), titled “Preventing HIV and STDs,” has currently gained 5.16k followers and 49 pins.

**Social Media and Politics**

Just as social campaigns like ACT UP helped to initiate discussion and action from the public in the early days of the epidemic when politicians were not providing adequate information, social media has taken similar measures to serve as a method of initiating both political dialogue and action. Millennials (born 1980-mid 2000s), are the first generation that came of age when the Internet and other forms of social technology
such as cell phones, smart phones and tablets were commonly available (Kelsh 2015, 1). A study was conducted at the University of Hawaii to try and get a sense as to how social media and the Internet impacts the political leanings of the millennial generation (Kelsh 2015, 1). After surveying 70 students it was found that the majority of them would “stumble upon” political information through social media platforms rather than seek it out and their political opinions were often based on interactions they had both on and offline (Kelsh 2015, 1). It was also found that students who viewed the Facebook pages of political candidates were more likely to form opinions surrounding “community-based cues” (discussions they either read or took part in on those particular pages) in addition to how they felt their candidates interacted with others through these pages (Kelsh 2015, 1).

Along with influencing political decisions, social media has made it possible for HIV/AIDS awareness to continue being discussed in the realm of politics. In 2012, The One Campaign, an international organization focused on poverty and disease, provided a banner on their YouTube page that lead viewers to a petition urging Congress to reverse budget cuts to the AIDS prevention program, PREP.FAR. The petition was able to gather over 40,000 signatures (Crews 2012, 1). Additionally, the role of social media in AIDS awareness was apparent on Twitter on World AIDS Days December 1st, 2015 when presidential hopefuls Hillary Clinton, Bernie Sanders and Martín O’Malley along with New York City Public Advocate, Letitia James and New York City Comptroller, Scott Stringer took to the micro-blogging site to stress the importance of getting tested and staying involved (Szulman 2015, 1).

**Social Media in Action**
In order to demonstrate the effectiveness of social media on HIV/AIDS awareness and prevention, I will summarize two brief case studies that examined events surrounding National Youth HIV & AIDS Awareness Day (NYHAAD). On April 10th 2014 the second annual NYHAAD was held. The day of action was created in an effort to encourage young people to place themselves in the center of the dialogue surrounding HIV/AIDS and to highlight the impact it has on their community as well as what their roles are in responding to it (Cooke and Dixon 2014, 1). Associate Director of Communications, Rachel Cooke and NYHAAD ambassador Wesley Dixon reflected on the role social media played in the organization and effectiveness of the event. 17 youth ambassadors were recruited from all over the country to share their stories and experiences with HIV/AIDS and their work resulted in nationwide events, a multitude of blog posts and recognition of NYHAAD from the mayors of Gainesville, Florida and Seattle, Washington. Dixon stated that, “new forms of media empower young people to insert their voices in conversation that they have historically been left out of (Cooke and Dixon 2014, 1).”

The help promote NYHAAD, a hashtag (#NYHAAD) was created for both Facebook and Twitter while a tracking tool known as TweetReach was used to measure the extent to which the hashtag was promoted (Cooke and Dixon 2014, 1). On April 10th, 2014 alone, #NYHAAD reached over 9 million people while over the course of the month the number rose to 13 million. Edric Figueroa, one of the youth ambassadors responsible for the campaign’s success remarked that, “it takes the online village to build success and capacity in our messaging and movements towards youth executing control over their sexual health and to thwart new HIV infections (Cooke and Dixon 2014, 1).”
In addition to posts launched via Twitter and Facebook, there were infographics designed to highlight the particular ways that youth is impacted by HIV. The infographics were shared over 600 times and reached 36,000 people. Dixon, who additionally created a panel of youth organizers to participate in a Huffington Post Live segment, stated that he felt as though the campaign “demonstrates the ways in which youth work to curate conversations about issues that matter to them (Cooke and Dixon 2014, 2).”

A year later, April 10th, 2015 marked the 3rd national observance of NYHAAD. Advocates for Youth partnered with NYHAAD Founding Partners and NYHAAD Youth Ambassadors to create a social media campaign initiating new dialogues surrounding HIV/AIDS using youth friendly content and highlighting the engagement of the younger generations (McKay 2015, 1). NYHAAD Youth Ambassador Hannah Loeb stated that, “NYHAAD gives us all a platform to share our voices while creating change in our communities (McKay 2015, 1).” Despite reports pointing to Facebook as the platform becoming less popular for younger people, it still holds the highest amount of users compared to any other media site. Facebook combined now with Instagram both demonstrate that gathering an audience via those sites is proving to be one of the most effective strategies at inviting young people to join the conversation (McKay 2015, 1).

The website “What Works in Youth HIV,” stresses the need for social marketing. Social marketing doesn’t necessarily involve traditional social media but rather the end goal is to achieve a level of social good while promoting positive social change. These campaigns can be combined with efforts such as promotional billboards, television ads, public events and other materials to reach a target audience. They stress that a particular outline (product, price, place, promotion) for each campaign can ensure its effectiveness.
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Product refers to what behavior the campaign is looking to change along with the benefits that will likely come about as a result, price refers to the financial, social, emotional and time-related barriers that the desired audience might face, place is meant to emphasize what programs and/or services will be aiding in the process of social change and finally promotion that lists the methods of communication that will be used to carry the campaign. It is through promotion that social media can be used to help drive a particular cause.

Discussion

I began writing this essay with the goal of trying to answer the question, what does HIV/AIDS discourse look like today and how does it compare to the ways in which it was addressed early on? I wanted to get a sense as to whether or not the persistent silence from politicians, the media and parts of the general public that occurred in the early years was still present in today’s current dialogue. The overall theme I’ve gotten from comparing past and present discourse is that social groups and media sites (ACT UP, GMHC, Facebook, Twitter, etc.) can provide a voice to an issue or epidemic when politicians and public figures either fail to address the issue or reinforce stigmas that perpetuate lack of discussion. Additionally, if mainstream media platforms such as newspapers or television aren’t giving adequate time to a particular issue, social groups can provide information where other sources are lacking.

AIDS discourse has gone from an issue that was rarely discussed to one that can easily be researched and addressed if one chooses to seek out information online through social media or otherwise. I would not go so far as to say we are still in a period of silence. Rather, at this point, I believe we run the risk of holding onto a false sense of
security if we assume that because information is online and easily accessible, no more action is required. How we choose to interact with the various social media platforms is highly personalized in the sense that a Facebook, Twitter or Instagram profile can be as public or private as the user chooses and can contain as much or as little information on any given topic as the user sees fit. As a result, the campaigns I’ve outlined that are accessible through these sites are only as effective as the number of views they receive. It seems the question now is, how do we ensure that the stigma-rooted silence that originally surrounded the epidemic doesn’t evolve into a different form of equally volatile inaction rooted in the belief that we needn’t do more due to all the information that’s currently available?

The AIDS Walk is set to take place in New York City on May 21st, 2017. Recently I’ve seen posters advertising the events posted in windows, on subways and other public areas. Each advertisement summarizes the purpose of the walk and the ways one can learn more if they have questions. Additionally, every advertisement contains links to the Facebook, Twitter and Instagram pages for the event. I believe this type of promotion could be the most practical use of social media in the context of AIDS discourse. If the advertisements are publicly visible one can view them regardless of their participation on social media. However, if one does choose to use social media as a tool of research and/or promotion, they’re given the outlets to do so. If we can find ways to combine advocacy through online social media, face-to-face interactions, and publicly viewable posters/advertisements we’ll have the best chance for success at keeping dialogue surrounding HIV/AIDS education and prevention active.

Conclusion
During my undergraduate career I was shown a film that motivated me to examine the HIV/AIDS epidemic in greater detail. Partners Mark Massi and Tom Joslin both contracted AIDS in the early 90s and they decided to make a documentary that chronicled their journey through the illness. The film titled, *Silverlake Life: The View from Here*, is made primarily of raw footage showing the realities that those who suffer from AIDS face. Joslin succumbs to the disease far more rapidly than his partner and there’s a scene that depicts the severity of the stigmas that he’s surrounded by. The two of them decide to vacation at a nearby resort with an outdoor pool. While sitting outside by the water, Joslin removes his shirt exposing his back covered in lesions from Kaposi’s sarcoma. Massi asks him what he’s doing, to which he responds, “I’m being political.” Within minutes, just as expected, he’s asked to cover up or leave as not to “disturb” the other patrons. I think the AIDS epidemic is an example of what happens when a disease becomes both politically contextualized and socially stigmatized.

HIV/AIDS as a social and political issue is what I believe Sarah Schulman was referring to when she stated that AIDS of the past is not over. Currently, AIDS is seen as a treatable, chronic condition and resources like the ones I’ve evaluated serve as a reminder of how far we’ve progressed in HIV/AIDS awareness and prevention. With that said, the stigmas attached to the disease like homosexuality and drug use still persist.

Based on my literature review and analysis of social media and health messaging, I can conclude that the ways in which HIV/AIDS prevention and treatment is communicated appears to have taken on a much different form in the past decade as opposed to a less active one. While I’m optimistic given the amount of information that is now accessible, I’m concerned that social media has become one of the sole outlets of
awareness. A common complaint I hear often is that technology is beginning to define our daily lives and living without internet access or a mobile phone means cutting one’s self out of human interaction almost entirely. HIV/AIDS awareness has made immense progress through the years but not everyone has access to social media or wants to take part in it and as a result other forms of media should not be overlooked. Just as representation across race, class and gender are vital to the cause, ensuring that all communities are given access to information in ways that are accessible to them is just as important.

Just as young adults are taught the dangers of alcohol and drug abuse, education regarding risk reduction in the context of HIV/AIDS should be viewed as just as important. If prevention and education become as easy and as common place as checking Facebook, Instagram or Twitter for the latest updates, I believe there is great potential. We cannot provide resources solely to be utilized after one becomes infected. While we may not currently be experiencing another period of silence there is an overwhelming sense that only those who are already dealing with the disease have the need for resources concerning it. If we want discourse efforts to be successful, we need to see the issue as relevant regardless of one’s status. The conversation regarding HIV/AIDS must remain non-partisan and must begin before one has the need for test results.

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