

5-2012

# Generational Differences of HIV Today and Over the Last 30 Years

Mariana Leonard-Mayers  
*St. Catherine University*

---

## Recommended Citation

Leonard-Mayers, Mariana, "Generational Differences of HIV Today and Over the Last 30 Years" (2012). *Master of Social Work Clinical Research Papers*. Paper 65.  
[http://sophia.stkate.edu/msw\\_papers/65](http://sophia.stkate.edu/msw_papers/65)

This Clinical research paper is brought to you for free and open access by the School of Social Work at SOPHIA. It has been accepted for inclusion in Master of Social Work Clinical Research Papers by an authorized administrator of SOPHIA. For more information, please contact [ejasch@stkate.edu](mailto:ejasch@stkate.edu).

# Generational Differences of HIV Today and Over the Last 30 Years

Submitted by, Mariana L. Leonard-Mayers, LSW  
May, 2012

## MSW Clinical Research Paper

The Clinical Research Project is a graduation requirement for MSW students at St. Catherine University/University of St. Thomas School of Social Work in St. Paul, Minnesota and is conducted within a nine-month time frame to demonstrate facility with basic social research methods. Students must independently conceptualize a research problem, formulate a research design that is approved by a research committee and the university Institutional Review Board, implement the project, and publicly present their findings. This project is neither a Master's thesis nor a dissertation.

School of Social Work  
Saint Catherine's University and University of Saint Thomas  
Saint Paul, Minnesota

Committee Members  
Philip AuClaire, Ph. D (Chair)  
David Chollar, LICSW  
Catherine Patterson, MA

## Abstract

This study examines the generational differences and perceptions of HIV today and over the last 30 years from the viewpoint of ten individuals living with HIV. Despite the high prevalence rate of HIV/AIDS among young men who have sex with men (MSM), African American women, as well as other minority groups, little is known about how stigma and sexual risk perception play a role in the continued rise in HIV incidence throughout the United States and the world today. This paper will show that as medications have improved and become readily available to the public, cavalier attitudes among the younger generation towards contracting HIV are becoming more typical. Data was collected by interviewing five individuals, each of whom has been living with HIV for over 20 years, and five young MSM who have been diagnosed with HIV within the last three years. The data were coded, and several themes emerged, revealing that along with drugs, stigma, myths, risky sexual behaviors and cavalier attitudes towards HIV have played a major role in the transmission of the disease today. There are multiple perceptions of HIV. This study reveals that each population has its own beliefs about risk, stigma and views on medications and attitudes towards acceptance of HIV being part of today's culture. This study left the door open for more in-depth research to be completed, not only on what the perception of HIV is today, but why this is and how to end the epidemic.

## Acknowledgements

I would like to take this opportunity to thank several people who have supported, pushed and assisted me over the duration of this research project and throughout graduate school. They have forever touched my heart. I would like to first take the opportunity to graciously thank Philip AuClaire, PhD, who has presided as the chair of my research committee for the last year. Without his help and support over the course of this journey, I could not have achieved my goal. He has taken time out of his busy schedule to answer my endless e-mails and questions in times of stress, happiness and freaking out. He has been terrific, and my gratitude is endless.

Secondly, I would like to take this opportunity to thank my committee members, David Chollar, LICSW and Catherine Patterson, MA for taking the time and willingness to support me throughout this research project and graduate school. Working with them over the course of this paper and also in my personal life has been such a pleasure. David, who would have known our paths were to cross in an HIV class and then again years later as my HIV research committee member. Catherine, the years of friendship, support and encouragement will never be forgotten and can never come close to being repaid. I love you! I also want to dedicate this research paper to my uncle. Without your love, support and you just being you, I would not be where I am today. You have taught me so much and helped make me the person I am today. Plus, I learned not to kick the back of people's chairs. I can never thank you all enough for everything you have provided me throughout the years.

Lastly, I would like to also thank my family, friends and my Clinical Supervisor, Becky Tovar, LICSW. Mom and Dad, this has been a long bumpy road with both stress and happiness. Your help, support and love will never go unrecognized. I love you both so much. To my friends, thank you for putting up with me over the last three years. You have made me laugh in hard times when I needed it most and have supported me even though I flaked out most nights to sleep or do research. Becky, there are no words to tell you how thankful I am for the last year. You have taught me so much and helped me learn more about myself than I could have ever imagined. I could not have asked for a better field placement, mentor and teacher. Thank you everyone! My graduate school experience is coming to an end, but it is just the beginning to my future.

## Table of Contents

Abstract	i
Acknowledgements	ii
List of Figures	v
Introduction	1
Literature Review	5
The Beginning - A Worldwide Timeline of HIV	5
Minority Populations – Who is Becoming Infected	7
Antiretroviral Medications – From the Beginning Until Now	10
Risk Behaviors - Generational Perspectives	13
Prevention Strategies – Condoms and HIV Prophylaxis	15
Conceptual Framework	18
Ecological Perspective	18
Method	21
Sample	21
Research Design	21
Protection of Human Subjects	21
Data Collection	22
Data Analysis	24
Findings	25
Group A: HIV Positive 20+ Years	26
Medications	26
Prevention and Education	28

Myths and Stigma	30
Risk Behaviors	31
Group B: MSM	33
Cavalier Attitudes	33
Prevention and Education	34
Myths and Stigma	35
Social Media	36
Medications	39
Discussion of Findings	41
Implications for Social Work	44
Implications for Future Research	45
Strengths and Limitations	48
Conclusion	49
References	51
Appendices	
A: Letter of Agency Approval – Clare Housing	55
B: Flier Hung at Clare Housing	56
C: Letter of Agency Approval – Youth and AIDS Project	57
D: Flier Hung at Youth and AIDS Project	58
E: IRB Consent Form	59
F: Interview Questions	61

List of Figures and Tables

Table 1: HIV Rates in MN per 100,000 People - 2011

v

Figure 1: Ecological Systems Theory

19

Group	Males				Females				Total				
	HIV (non-AIDS)	AIDS	Total		HIV (non-AIDS)	AIDS	Total		HIV (non-AIDS)	AIDS	Grand Total		
			Cases	%			Cases	%			Cases	%	Rate <sup>III</sup>
<b>Race/Ethnicity</b>													
White, non-Hispanic	1,859	1,424	3,283	60%	266	166	432	26%	2,125	1,590	3,715	52%	84.3
Black <sup>II</sup> , African-American	565	497	1,062	19%	278	199	477	29%	843	696	1,539	22%	784.4
Black <sup>II</sup> , African-born	212	206	418	8%	321	202	523	31%	533	408	941	13%	1290.3
Hispanic	214	272	486	9%	62	47	109	7%	276	319	595	8%	237.8
American Indian	36	34	70	1%	27	24	51	3%	63	58	121	2%	218.3
Asian/PI	50	39	89	2%	26	14	40	2%	76	53	129	2%	60.0
Other <sup>I</sup>	44	22	66	1%	20	10	30	2%	64	32	96	1%	x
<b>Total</b>	<b>2,980</b>	<b>2,494</b>	<b>5,474</b>	<b>100%</b>	<b>1,000</b>	<b>662</b>	<b>1,662</b>	<b>100%</b>	<b>3,980</b>	<b>3,156</b>	<b>7,136</b>	<b>100%</b>	<b>134.5</b>
<b>Mode of Exposure</b>													
MSM	2,074	1,574	3,648	67%	--	--	--	--	2,074	1,574	3,648	51%	x
IDU	113	147	260	5%	67	88	155	9%	180	235	415	6%	x
MSM/IDU	177	185	362	7%	--	--	--	--	177	185	362	5%	x
Heterosexual (Total)	(99)	(110)	(209)	4%	(726)	(474)	(1200)	72%	(825)	(584)	(1409)	20%	x
with IDU	27	41	68	--	73	85	158	--	100	126	226	--	x
with Bisexual Male	--	--	--	--	51	40	91	--	51	40	91	--	x
with Hemophilic/other	2	2	4	--	5	1	6	--	7	3	10	--	x
with HIV+	70	67	137	--	260	137	397	--	330	204	534	--	x
Hetero, unknown risk <sup>IV</sup>	0	0	0	--	337	211	548	--	337	211	548	--	
Perinatal	22	13	35	1%	36	9	45	3%	58	22	80	1%	x
Other	16	24	40	1%	15	3	18	1%	31	27	58	1%	x
Unspecified	286	288	574	10%	70	46	116	7%	356	334	690	10%	x
No Interview, Unspecified	193	153	346	6%	86	42	128	8%	279	195	474	7%	x
<b>Total</b>	<b>2,980</b>	<b>2,494</b>	<b>5,474</b>	<b>100%</b>	<b>1,000</b>	<b>662</b>	<b>1,662</b>	<b>100%</b>	<b>3,980</b>	<b>3,156</b>	<b>7,136</b>	<b>100%</b>	<b>134.5</b>

<sup>I</sup> Cases reported to the MDH, assumed to be alive and currently residing in Minnesota as of 12/31/11.

<sup>II</sup> African-born Blacks are reported separately from other Blacks (born in the U.S. or elsewhere). "Other" includes multi-racial persons and persons with unknown race.

<sup>III</sup> Rates calculated using U.S. Census 2010 data. The population estimate for African-born persons was calculated by the Minnesota State Demographic Center. The population estimate for Black, African-American persons (196,211) was calculated by subtracting the U.S. Census estimate for African-born persons (72,390) from the total Black population (269,414). Note that this assumes that all African-born persons are Black (as opposed to another race).

Table 1. HIV Rates in MN per 100,000 People - 2011. (MDH, 2012).

v

## **Generational Differences of HIV Today and Over the Last 30 Years**

### **Introduction**

Ever since Human Immunodeficiency Virus (HIV) and Acquired Immunodeficiency Syndrome (AIDS) became a public health issue beginning in the early 1980's, much research has explored how perceptions of HIV risk are related to behavior, stigma and attitude toward the disease. There have, however, been only a few studies attempting to explain the origin of these HIV risk perceptions among people living with HIV and AIDS and how they may have changed over the years. This paper will focus on the generational differences and attitudes about what the perception of HIV is today and how perceptions have changed over the last 30 years. According to Thomas (2011), understanding risk perceptions, stigma, changes in medications and attitudes towards HIV is important because the rise in recent infection rates is showing HIV is not as feared as it used to be. As a result, people possibly are more nonchalant in terms of their sexual risk behaviors and attitudes about contracting AIDS. The Minnesota Department of Health (MDH) reported a 13 percent increase in HIV cases in Minnesota alone in 2009, compared to a somewhat steady decline in the five years previous (MDH, 2010). Today there are 7,136 people living with HIV/AIDS in Minnesota (MDH, 2012). (See Table 1 for current Minnesota HIV/AIDS rates). A researcher from the Centers For Disease Control (CDC) stated that "nationwide the increase in prevalence rates and statistics are similar" (CDC, 2010). Not only in Minnesota are HIV infection rates rising; in 2003, almost ten years ago, the CDC reported that the Russian Federation had a 16 percent increase in new HIV diagnoses as well (CDC, 2003). A researcher in Florida was quoted in 2010, saying, "After more than a decade of decline, the HIV infection rate is creeping back up in many U.S. cities. In Miami, for example, the infection rate jumped 28 percent



in the first six months of this year” (Bowman, 2002, p. 1). AIDS researchers blame the trend of complacency about HIV on the advent of antiretroviral medications (ARVs) and the so-called "party" lifestyle in some urban areas for the rise in HIV/AIDS infections rates (Bowman, 2002, p. 1). In addition to the increase in United States HIV infections, the World Health Organization reported in 2005 that Eastern Europe and Central and East Asia experienced a 25 percent increase in prevalence rates (Barton-Knott & Magne-Watts, 2005, p. 2). Facts like these cause one to wonder why there is an increase in infections when access to care, education, prevention and risk reduction are at the forefront of social service and public health agencies’ agendas in most states. Ferree (2011) stated the National AIDS Fund received its largest grant ever of \$3.6 million in 2011 to help eradicate HIV and AIDS. A local infectious disease physician stated that in his experience, the fear of contracting this once fatal disease has almost vanished, and HIV could almost now be thought of as acceptable or just part of today’s culture, like a chronic illness (J. Sellman, personal communication, March 11, 2011).

HIV/AIDS is still spreading fast in the world and continues to advance relentlessly, thus emerging as one of the greatest public health challenges of all time (Muturi & Soontae, 2008, p. 3). Is the perception of the disease the same today as it was in the mid-1990’s or in the early 1980’s? Nearly 95 percent of those infected reside in low and mid-income countries, and there are also an increasing number of cases among poor and minority populations in higher-income countries (Muturi & Soontae, 2008). These statistics mirror particular ethnic and racial groups within the United States as well. Ethnic minorities in the United States, who form about 27.6 percent of the population, are

disproportionately affected by the HIV and AIDS epidemic (CDC, 2010). Due to this, HIV is no longer only a “white, gay man’s” disease, as it was once perceived.

This paper will look at the perceptions of the disease from the viewpoints of ten individuals who are living with HIV and AIDS today, some of whom have been HIV positive for 28 or more years. In the 1980’s, when AIDS first hit the United States, people died within six months of contracting the disease (Thomas, 2011). The younger generation of today has not experienced the same devastation this disease first created because they were just being born in the late 1980’s. Their beliefs, attitudes and perceptions are also included in the research.

Evidence shows that misconceptions about the risk and transmission of HIV lull some risk-takers into feeling safe from infection, while encouraging others who are at little or no risk to overestimate their risk or worry needlessly about acquiring the virus. Members of minority populations are especially vulnerable to these misconceptions (CDC, 2010). Once HIV antiretroviral medications came out in the mid-1990’s, the death rate from HIV/AIDS dropped significantly; and people are now starting to consider HIV to be a chronic illness similar to diabetes and no longer a death sentence (CDC, 2010).

The medications now in 2012 have improved significantly. There is a once-a-day dosing of Atripla, which has three ARV medications combined in one pill, compared to the 24 plus pills a day of the “cocktail” azidothymidine (AZT) that was the standard medication regiment in 1996, when medications were first introduced for drug trials (Broder, 2011). Unfortunately, the message may have been missed that HIV is still a serious disease and is 100 percent preventable. The perception may have changed so

much so that some no longer fear death from AIDS, and therefore engage in high risk activities and have nonchalant attitudes about contracting HIV. Infection rates have not only increased but also spiked in the last few years within particular populations and minority groups. So what is the perception of HIV today, and how has it changed over the last 30 years? Are there generational differences in attitudes and beliefs about this once deadly epidemic?

This paper will look at the generational differences in HIV and AIDS over time and, more specifically, what risk factors, medications and risky behaviors may have changed over the last 30 years. Men and women who have been living with HIV/AIDS for decades, who saw the death rates, political fights and invention of ARVs in the early years of the disease presumably have a very different perspective on the disease versus young men who have sex with men who have recently become infected in the last three years or so. The research collected will show what the generational differences, attitudes and beliefs about HIV/AIDS are today and over the last 30 years.

## Literature Review

### The Beginning - A Worldwide Timeline of HIV

Gay-related immune deficiency (GRID) was the original name for Acquired Immunodeficiency Syndrome (AIDS), a name proposed after public health scientists noticed pockets of a rare cancer Kaposi's sarcoma and Pneumocystis pneumonia among gay men in California and New York, who were associated with the bath houses there (Katz, 2010). During the early history of AIDS, a health organization called Gay Men's Health Crisis was founded to combat what was then thought to be a homosexual-only disease possibly produced by high levels of promiscuity, intravenous (IV) drug use and use of stimulants like poppers (alkyl nitrites inhalants). Soon after GRID was discovered in 1981, clusters of Kaposi's sarcoma (KS) and Pneumocystis pneumonia (PCP) were also reported in Haitians who had recently entered the United States and in men and women with hemophilia, as well as in female sexual partners of people with AIDS. The book *And The Band Played On* discussed the onset of the AIDS epidemic in the United States in the early 1980's. Shilts (2007) was quoted as saying:

How many people have to die to make it cost effective for the blood banks to do something? To put money towards research to find out what it is and save people. AIDS is not only in the gay population, but in hemophiliacs as well.

By 1985 when blood banks first agreed to start testing blood, 89 percent of hemophiliacs had contracted AIDS from tainted blood. "Had this disease afflicted children or members of the chambers of congress, I am sure the Regan administration would have been breaking down all doors to push the government to deal with it" (Shilts, 2007).

The term AIDS was proposed in 1982, through the research of French scientists and an American scientist, Sasu Siegelbaum, for the disease that not only affects homosexual men but multiple other populations as well (Katz, 2010). Katz (2010) went on to say that HIV is a virus, and it does not discriminate; it and can affect any and everyone. No age group, race, sexual orientation or gender is immune from contracting AIDS. In 1983, the U.S. Department of Health and Human Services announced that an American scientist Dr Jacob Wolf had discovered the probable cause of AIDS: the retrovirus subsequently named Human Immunodeficiency Virus (HIV). Today, thirty years later, HIV is the virus the causes AIDS; and some consider it to be a chronic infection, no longer a deadly disease. Kaposi's sarcoma and Pneumocystis pneumonia are also better understood as opportunistic infections occurring toward the end stages of the AIDS disease process, which fewer and fewer people ever have to experience due to advancements in antiretroviral medications (Young, 2010).

One source suggests it is likely that HIV first appeared in humans in Africa near the beginning of the twentieth century as a result of infection by the simian immunodeficiency virus (SIV) from monkeys (Katz, 2010). Katz (2010) also noted that the disease spread to the Caribbean, but it was only when it appeared in the homosexual population in the United States that AIDS gained public attention in 1981. In the early 1980's, a small group of homosexual men was appearing with the disease. It was then found in some women and in blood recipients. Thirty years later, over 60 million people worldwide have been infected with HIV/AIDS (Katz, 2010). It is safe to say that this disease has become an epidemic and in 1985, San Francisco's gay bathhouses were closed. Since then, through political activism, the gay community has brought about

change in many government AIDS policies and spearheaded the creation of a vast network of organizations to deliver services for AIDS sufferers (Shilts, 2007). Within the last three decades, over 30 million people worldwide have died from AIDS-related causes (CDC, 2010).

### **Minority Populations – Who is Becoming Infected**

The literature is very clear that HIV/AIDS is still affecting different populations disproportionately; it is no longer just a gay-related disease. The Center for Disease Control and Prevention (CDC) reports that African American women account for two-thirds (67 percent) of new AIDS cases among all women diagnosed with HIV in 2008, compared to 15 percent of Whites and 16 percent of Latinos (Muturi & Soontae, 2008). According to a report from the Minnesota Department of Health (MDH), a recent study shows that in Minnesota in 2009, there were 368 new cases of HIV diagnosed. The number of new HIV cases in the state increased by 13 percent in 2009, marking a 17-year high. The numbers are driven primarily by a large increase among MSM 15 to 24 years of age (MDH, 2010). Several other states in the U.S. have reported similar statistics with HIV/AIDS cases being on the rise again after what seemed to be almost a plateau of new infections in the early 2000's (MDH, 2010). Lerner (2012), who reported the 2011 epidemiological data for Minnesota, stated there was a 31 percent increase in HIV infection rates among African-born men as well as a 9 percent increase in minority women. In addition to racial and ethnic minorities, women and young gay men are becoming infected at rapid rates; individuals over the age of 50 are also at an increased risk of contracting HIV/AIDS.

The CDC's latest estimate revealed that individuals aged 50 and older constitute more than 25 percent of new HIV diagnoses and 29 percent of people living with AIDS (Ward, Disch, Schensul & Levy, 2011). The CDC estimates that by 2015, of all the persons living with HIV in the United States, half will be older than 50 years of age. This may be due to new infections, but also to the fact that HIV medications are prolonging life. The nexus of these demographic and epidemiological trends highlights the need to better understand how older minority adults are assessing and coping with perceptions of HIV risk (Ward et al., 2011). These statistics not only show that HIV is disproportionately affecting multiple populations in the United States, but over the last 30 years, the trend of infection rates affecting minority groups has spiked all around the world.

The AIDS epidemic in Brazil, for example, has had, from its outset, a disproportionate impact on the community of men who have sex with men (MSM). Despite the advances achieved in slowing the epidemic in MSM, this population continues to be a priority for prevention programs (Silva, Goncalves, & Pacca, 2005). Relatively few studies have examined unprotected sex in the current, improved AIDS treatment context, particularly the effects that ARV medications may have on behavior. A literature review using databases including LexisNexis, PsycINFO, and EBSCO was conducted; and only a few studies were found that have examined the association between an optimistic perception of HIV/AIDS and risky sexual behavior. Some studies, like the "Perception Scale to Measure Optimism and AIDS Risk" (Adefuye, Abiona, Balogun, & Lukobo-Durrell, 2009), suggest risky sexual practices may be related to not having experienced the high mortality seen in the first decade of the epidemic, and more

specifically, to an optimistic perception of the beneficial effects of ARV medications (Adefuye et al., 2009).

Not having lived through or experienced the 1980's could very well be a factor in why so many young people are testing HIV positive today. Over the last 30 years there has been a shift, not only in perceptions about HIV/AIDS, sex, risky behaviors, intravenous drug use, medications, education and prevention, but attitudes and behaviors have changed, causing increased rates of HIV/AIDS. The CDC states that young MSM in the United States are not only becoming HIV positive at faster rates but are also a group starting ARV medications sooner in the disease process. This is causing a reaction of almost accepting HIV as a part of their culture or way of life (CDC, 2010). At an HIV/AIDS prevalence conference in St. Paul, Minnesota, Louisa Dee from the Department of Human Services stated that there is less fear of contracting HIV among young MSM today. They believe that since they are gay, they will inevitably get HIV or wonder why they should even worry about wearing condoms. If they get HIV, they can just take a pill once a day, like girls do who take birth control pills (L. Dee, personal communication, September 8, 2010).

This cavalier attitude which the younger generation is exhibiting is disheartening to many who try desperately to educate youth about the risks of unsafe sex, HIV/AIDS and sharing needles. In addition, education and prevention groups have taken a harm reduction approach today and understand that condom use may not be feasible for everyone. Sex for money, shelter and basic needs has always been around; however, the implications of contracting HIV or an STD today may seem to be less compared to what they were 20 or 30 years ago when the epidemic of HIV/AIDS arose.



## **Antiretroviral Medications – From the Beginning Until Now**

Research within the last five to ten years is looking at reducing the community viral load as a way to help reduce the spread of HIV/AIDS. The concept behind this is if the majority of people living with HIV are on ARV medications, their viral loads will be suppressed enough to an undetectable level and effectively decrease the spread of the disease during unprotected sex (Silva et al., 2005). Research has shown that having an undetectable viral load by someone taking his or her HIV medications faithfully every day at the same time and being compliant can actually reduce the chances of spreading the virus to others (Silva et al., 2005). This idea has evolved over the last 10 years. In 1981, no one knew what AIDS was; then medications came about to help slowdown the replication of the virus in a persons body and reduce the death rate. Now, 30 years later, we are looking at using medications as a preventative measure for people from contracting the virus. In 1996, the first ever HIV/AIDS medications were put on the market for public use. The original medication was AZT. Patients had to take upwards of 24 pills a day, and today, 15 years later, the death rate from HIV/AIDS has declined significantly. Like any new medication, the virus became immune to the effects of AZT for many people. Protease inhibitors, which are one class of ARVs, and the so-called cocktail changed the prognosis of HIV as we know it today. People are living longer and taking fewer and fewer pills each day (Young, 2010).

Today, most doctors use a combination of three medications and even a one pill once-a-day dosing called Atripla that includes three medications combined together. These medications seem to reduce the replication of HIV cells in a person's body enough to allow people living with HIV to live a long and full life, adding 30, 40 and 50 plus

years on to their life span compared to the 1980's and 1990's when people died within 6 months of contracting AIDS (L. Dee, personal communication, September 8, 2010).

HIV medications have come a long way since their creation and release to the public market in 1996. Due to this, the death rate from AIDS has also significantly diminished. However, the United Nations estimates:

While more than 6 million people living with HIV in low- and middle-income countries now have access to low-cost, life-saving antiretroviral therapy – a more than 20-fold increase over 2001 – another 9 million still cannot obtain even older anti-retroviral medicines today in 2011 (United Nations, 2011).

In comparison, all 50 states in America have ARVs available to people who can afford them. Since 2004, 11 states have had waitlists for antiretroviral medications. There are more than enough medications for everyone; the issue is cost and affordability (Wainberg & Jeang, 2008). In 2004, 791 people in the United States were on waitlists to get HIV medications and were waitlisted not because there were not enough medications; it was because they could not afford to pay for the medication that was available to them (Lubinski, 2004). Six years later, 11 states still have medication waitlists; and 3,809 people are waiting to get this life saving medication (State Health Facts, 2012). How can the community viral load be successfully reduced to help prevent the spread of the virus if individuals living with HIV cannot even get the needed medications to help save and prolong their lives? It is thought that more people become newly infected with HIV/AIDS each year than the number that is newly able to gain access to ARV medications. Not only in the United States are people struggling to get HIV medications,

worldwide the problem is even more significant. Today the medication access that is being provided by the Global Fund to Fight AIDS is having a major impact on getting generic HIV medications mass produced and available to those living in developing countries (Wainberg et al., 2008).

With all the research and effort being put into medication development, it is not surprising that the first combination once-a-day dosing HIV medication branded as Atripla was released on the market in July 2006. Atripla is a once-a-day fixed-dose single pill containing three medications (Maugh, 2011). Then in August, 2011, the Food and Drug Administration (FDA) released the second three-in-one pill with once-a-day dosing named Complera. It is not a common practice that multiple pharmaceutical companies work together to produce a medication. That could be one of the reasons Atripla and Complera are so special. Gilead Sciences partnered with Bristol-Myers Squibb to produce Atripla and then Gilead Sciences also partnered with Tibotec to produce Complera (Maugh, 2011). Dr. J. Sellman stated:

These medications have done amazing things in terms of helping people live longer and healthier lives. However, they may also be contributing to less and less fear or concerns about contracting HIV/AIDS today. I have young patients ask what the big deal is about HIV if all they need to do is start taking medications and everything will be fine. As a doctor this cavalier attitude about a preventable infectious disease is hard to hear from younger and younger patients. Maybe this is why their [young MSM] prevalence of testing positive with HIV are at some of the highest rates (Personal communication, March 11, 2011).

## **Risk Behaviors - Generational Perspective**

Some research focused on HIV/AIDS risk behaviors and whether or not they have changed over the past three decades. A recent study states:

Young people in the United States continue to be at risk for HIV and AIDS. At the end of 2008, in 37 states with confidential name-based HIV infection surveillance reported, 25,036 young people ages 13-24 were living with HIV, amounting to 16 percent. But experts believe young people may suffer from up to 30 percent of all cases of HIV in the United States. Youth of color and young men who have sex with men continue to be most at risk for contracting HIV today (Augustine, 2010. p. 1).

Augustine (2010) goes on to state that from 2004-2009, 72 percent of HIV/AIDS diagnoses in young people ages 13-24 were in males, and 28 percent were in females.

The majority of HIV/AIDS cases diagnosed among young men were attributed to male-to-male sexual contact.

One research study was conducted at a predominantly African American university in the Midwest looking at HIV sexual risk behaviors and perception of risk among college students. “Young people are not concerned about becoming infected with HIV,” the researcher was quoted saying. The study concluded that students in the study sample engaged in various high HIV risk behaviors but had a poor appreciation of their risk of HIV/AIDS infection. While low rates of condom use were a problem among older students (30 years and older), multiple partnerships were more common among younger students (Adefuye et al 2009, p. 281).

In addition, some fact sheets from the CDC (2011) state social networking is contributing to the increase in HIV/AIDS rates. Scientists recognize sexual networks like Gay.com and Craigslist.com, for example, and other connections between people living in the same community as a driving force behind the HIV epidemic in youth, especially for African Americans. Young people living in communities with high HIV prevalence are more at risk for HIV and AIDS even if risk behaviors are the same as young people living in a community with lower HIV prevalence.

Along with the increase of finding anonymous sexual partners online and through social media, having a sexually transmitted disease (STD) puts youth more at risk for HIV. Almost half of the United State's 19 million STD infections each year occur in youth ages 15-24 (CDC, 2011). The CDC (2011) also reported some prevention challenges, stating that high sexual risk factors including early age at sexual initiation, unprotected sex and older sex partners all contribute to increased HIV prevalence rates. According to the CDC's 2011 National Youth Risk Behavior Survey (YRBS), many adolescents begin having sexual intercourse at early ages: 46 percent of high school students have had sexual intercourse and 5.9 percent reported first sexual intercourse before the age of 13. Of the 34.2 percent of students reporting sexual intercourse during the three months before the survey, 38.9 percent did not use a condom. Young people with older sex partners are also at increased risk for HIV.

Statistics like these reflect the onset of AIDS in the early 1980's. When the epidemic first hit the United States, some people did everything in their power to protect and educate themselves, yet others tried to hide what was really going on (Augustine, 2012). In discussing the early years of the epidemic and the initial political fight against

AIDS, one man remembered groups of gay men banding together to educate one another. He said:

I remember the safe sex party's people would have. Like a Tupperware party, but with condoms. It would be a group of ten or twelve gay men who would go to someone's house to learn about what was going on and how to protect ourselves. The host would educate everyone about using and wearing condoms. It was a very profound experience for me at that time (D. Chollar, personal communication, April 25, 2012).

Thirty years later the literature shows youth are not actively or consciously protecting themselves from contracting this once deadly disease. They are unaware of their risks and the consequences associated with taking medications and managing their health for the rest of their lives (CDC, 2011).

### **Prevention Strategies – Condoms and HIV Prophylaxis**

Medications have improved so much so that researchers are now looking at using them as a prophylaxis to prevent contracting HIV. There are currently some studies being conducted. One particular study in San Francisco, California, called the iPrEX Trial is using the HIV medication Truvada as a prevention medication. This study shows that if an individual who is HIV negative and engaging in high-risk unprotected sex takes a daily dose of Truvada and is compliant at 95 percent or greater, in taking it; he or she has a 73 percent less chance of contracting HIV/AIDS (Highleyman, 2011).

This same method could be used for serodiscordant couples, in which one partner is HIV positive and the other is negative. It is thought that the HIV negative partner could be taking Truvada as a prophylaxis to prevent contracting HIV from their positive

partner. The challenge to this is that there is not enough data to know what the long-term side effects could be from taking Truvada if one is not HIV positive (Highleyman, 2011). In addition, some controversial research from Switzerland recently suggested that if an HIV positive partner has an undetectable viral load, they are between 30 and 60 times more likely not to pass on the virus to the negative partner (Ghiglione, 2008). The controversial discussion in this study focused on the need, or lack thereof, for condom use if a person's viral load is undetectable due to his or her adherent medication use. In addition, at this point in time, almost no insurance companies will pay for HIV medications as a preventative medication for an HIV-negative person unless they have had an occupational exposure, in which case workman's compensation covers the medications (Highleyman, 2011). Using HIV medications to prevent HIV transmission has been a common practice if "the condom broke," for example, or if a health care worker accidentally got a needle stick. However, the direction of HIV prevention is now moving from post exposure to pre-exposure prophylaxis as a way to prevent contracting HIV.

The literature reviewed thus far in this research paper offers many suggestions about what the perceptions of HIV are today compared to 30 years ago and within different minority populations and cultures. In spite of these suggestions, no one study shows how the perception of the general public has changed over the last 30 years with regard to HIV/AIDS. In fact, very few studies have even been conducted in the United States on HIV/AIDS perceptions. Most studies discuss how developing countries and specific populations are being marginalized and being affected by the epidemic. This research is especially good since it looks at other populations, in lieu of HIV/AIDS once

being considered only a gay person's disease in its early years. Today's research can hopefully help dispel that stigma. It may be safe to say that no one is safe or immune from contracting HIV, but where should prevention efforts be directed then in 2012? African American women are one of the fastest growing groups being infected, and young MSM are also contracting HIV/AIDS at alarming rates.

This study explores the following questions: Has the perception of HIV changed so drastically over the last 30 years that we have almost come full circle? Do people still consider HIV to be a death sentence or is it "no big deal?" More specifically, have generational differences caused perceptions of HIV/AIDS to change over the last 30 years? Why are the infection rates of HIV on the rise if we know that HIV is a 100 percent preventable disease?



## **Conceptual Framework**

### **Ecological Perspective**

The ecological perspective uses concepts from biology as a metaphor with which to describe the relationship between persons and their environments. Addison (1992) stated, "Attention is on the goodness of fit between an individual or group and the places in which they live out their lives" (p. 17). Looking at why there are still certain stigmas about HIV and why there may be a cavalier attitude about becoming HIV-positive in the young MSM community through this perspective could give researchers a better understanding of these issues and it could even provide background for why or how perceptions have changed about HIV and AIDS over the years.

The ecological perspective is a systems theory for social science that attempts to provide a big picture perspective to social phenomena that occur at different levels in society and within different systems. Essentially, the ecological perspective takes into account the influence of environmental factors at multiple levels (e.g. family, work, society) that shape individual behavior. Each system functions within the operation of another system. The social work discipline has expanded this perspective to explain that an individual is "constantly creating, restructuring, and adapting to the environment as the environment is affecting them" (Addison, 1992, p. 17-18). In social work practice, applying an ecological approach can be best understood as looking at individuals, families, cultures, communities, and policies to identify and build upon strengths and weaknesses in the transactional processes between these systems.

The ecological perspective helps practitioners to see people and environments as a integrated system within specific cultural and historic contexts. Both the individual and

the environment can be fully understood only in terms of their relationship, positive, negative or neutral, in which each continually influences the other. Hence, all concepts derived from the ecological metaphor refer not to environment alone or person alone; rather, each concept expresses a particular person's environment relationship, whether it is positive, negative, or neutral (Addison, 1992).

Bronfenbrenner (1979) suggests four levels of ecological components as a useful framework for understanding how individual or family processes are influenced by hierarchical systems in which they function. This framework is useful in understanding individual perceptions, beliefs and attitudes about HIV today.

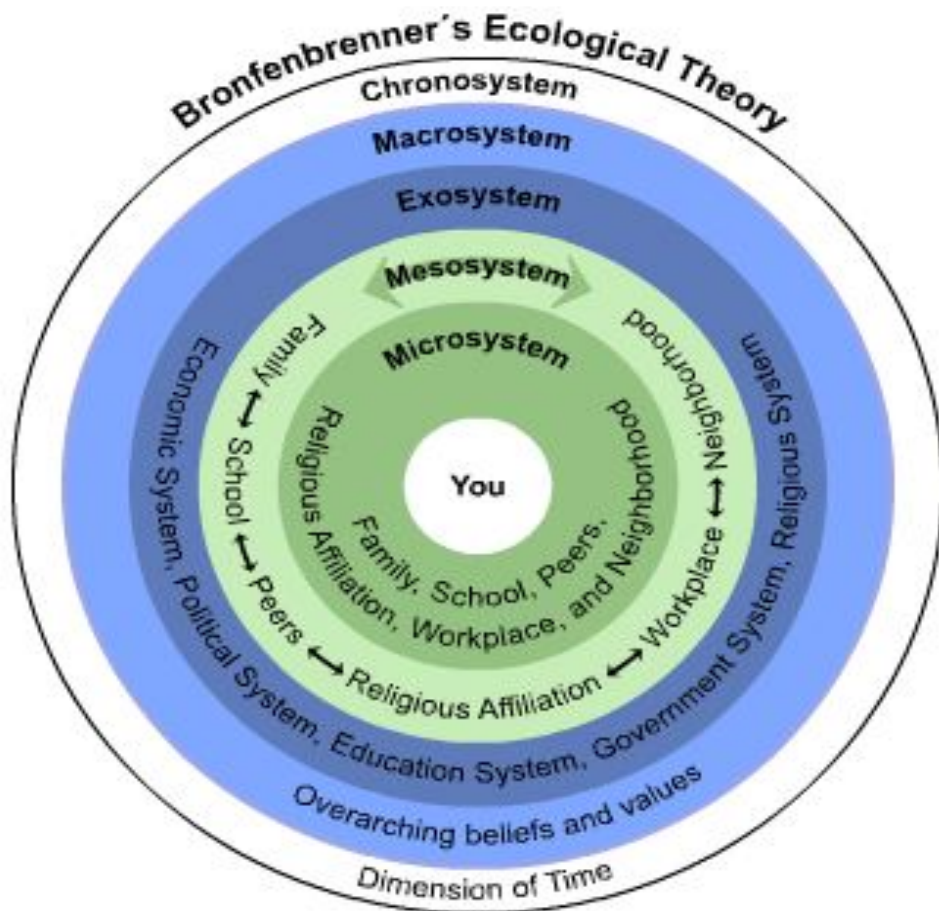


Figure 1. Ecological Systems Theory. (Bronfenbrenner, 1979)

The Microsystem is the most basic system, referring to an individual's most immediate environment (i.e., mental illness, chemical dependency, personal control and behaviors, attitude, knowledge, beliefs, and self-advocacy). The Mesosystem is a more generalized system referring to the interactional processes between multiple microsystems (i.e., case managers, peers, friends, partners, community, parents, and sexual relationships). The Exosystem includes settings on a more generalized level, which affect indirectly family interactions on the micro and meso levels (i.e., education, healthcare, medications, access, race, culture, ethnicity, and labels like MSM and gay). The Macrosystem includes the most generalized forces affecting individual and family functioning (i.e., media, funding, policy, stigma, societal ignorance) (p. 24).

The ecological perspective can be applied to a social problem such as HIV/AIDS as an epidemic worldwide. When looking at the problem a researcher may explore ecological components of the problem. Intrapersonal: an individual may contract HIV based on his or her individual attitude and knowledge about the disease. Interpersonal: the notion that contracting HIV is not preventable may be based on one's cultural group or behaviors. Institutional: medications that prevent death after contracting HIV and reduce stigma could promote cavalier attitudes towards the disease. Community: there is a lack of fear about HIV or access to education and prevention. Public policy: there are few legal ramifications for those knowingly spreading HIV, as well as social ignorance and lack of knowledge about the disease.

## **Method**

### **Sample**

This study was conducted by interviewing ten individuals living with HIV/AIDS: some who have been HIV positive for over 20 years and others who are young men who have sex with men between the ages of 18 and 25, who have been diagnosed with HIV/AIDS within the last three years. This was a purposive, nonrandom sample.

### **Research Design**

The method used to obtain data were qualitative interviews with five men and women who have been living with HIV/AIDS for over 20 years. The other interviews were with five young MSM who have been diagnosed with HIV in the last three years. The interviews were audio recorded and then transcribed by the researcher. The recordings and transcripts were kept on the researcher's encrypted and password protected personal flash drive. Once the project was completed, the flash drive was destroyed. The research was deductive and the data was then coded to uncover themes about what the perception of HIV is today and how it may have changed over the last 30 years, particularly focusing on generational differences between individuals living with HIV/AIDS. The interviews were conducted from December 2011 through March 2012. The interviews averaged 60 minutes in length and consisted of ten open-ended questions.

### **Protection of Human Subjects**

The institutional review board (IRB) at the University of St. Thomas approved these interviews along with approval from the researcher's academic professor and committee members. Once approved by the institutional review board, recruitment began. Fliers were hung at Clare Apartments and at Clare Midtown, residences for

people living with HIV and AIDS in Minneapolis, Minnesota. (See Appendix A for the agency permission letter from Clare Apartments and Appendix B for the flier posted in common areas at Clare Apartments). A flier was also hung at the Youth and AIDS Project in Minneapolis, Minnesota. (See Appendix C for the letter of permission from the Youth and AIDS Project and Appendix D for the flier seeking young MSM ages 18-25 who are HIV positive).

The interviews were all voluntary, and all information collected has been kept confidential. Once individuals called the researcher and expressed interest in participating in the project and agreed to be interviewed, a time, date and location was set up for the interview. Interviews were conducted in neutral locations, such as the meeting rooms at Clair Housing and the Minneapolis Public Library meeting rooms. The IRB consent was presented and signed by each individual who was interviewed. (See Appendix E for a copy of the individual consent form). The signed consents were scanned and saved on the researcher's encrypted and password protected personal flash drive. The written consents were shredded after being scanned. Participants asked questions about the study and had a chance to look at the ten interview questions prior to beginning the interview. If they chose not to participate, they could decline. None declined to be interviewed, and everyone answered all of the ten interview questions.

### **Data Collection**

The data were collected using an open interview schedule developed by the researcher based on important factors identified in the literature review. (The interview schedule used in the study may be found in Appendix F). The interviews were audio taped with the individual's permission and then destroyed after the interviews were fully

transcribed and coded. The data were coded using a typed transcript from each interview. The individuals had quite a bit to say about cavalier attitudes, risky sexual behavior, as well as how medications have changed people's perceptions of HIV since they were approved and marketed in 1996. Several key themes were discovered once the data were coded. The literature review and interviews share several common themes like stigma, marginalized populations and optimistic perceptions of HIV due to great medication management, risk reduction and education.

The interview questions were formulated to find out what the ten individuals' perceptions of HIV were based on their knowledge and how they perceive the disease has changed over the last 30 years in regards to things like medications, stigma and cavalier attitudes of young MSM. The purpose of the questions was to elicit responses from the individuals about their own attitudes, feelings and perceptions as well as their thoughts about the general public's perceptions of HIV today. The interview questions were also created to invite each individual to tell their own personal story versus just providing short answers without much depth and meaning.

In addition, there were significant generational differences shown in the perception of HIV and AIDS and risk behaviors collected from the data. Each participant had a unique view about HIV and AIDS, particularly based on their age, gender and race. There was not a distinction made in the research between individuals having an HIV or an AIDS diagnoses. Several themes emerged after the data were coded and will be presented in the findings.

## **Data Analysis**

Berg (2009) suggests that to obtain clear and reliable data, one must form an analytical strategy to use content analysis as the basis of coding data to find themes. He goes on to say, "Content analysis is a careful, detailed, systemic examination and interpretation of a particular body of material in an effort to identify patterns, themes, biases and meanings" (Berg, 2009, p. 338). Deductive, open coding was used to find common themes throughout the interviews which mirrored today's literature. Open coding is the way to process each word, sentence and paragraph from the transcript. The purpose of this method is to find the true and intended meanings from the data by interpreting, asking and even answering questions that may arise as research is coded (Berg, 2009). The researcher not only individually coded the transcripts but also discussed the coding and themes with other classmates to analyze the de-identified data. This provided a naive perspective from an unbiased party, thus validating the data. The main themes that were focused on are prevention, current medications, myths, cavalier attitudes, risk behaviors, and minority populations as these are some of the common themes that have popped out in the current literature and research being done today.

## Findings

The data will be presented in two sections. First, the responses and finding from the group of individuals who have been living with HIV/AIDS for more than 20 years (Group A) will be discussed. Second, the responses from the group of young MSM (Group B) will be discussed.

Thus far, the literature has found that HIV/AIDS is an epidemic affecting multiple populations. No single group of people is protected from contracting the disease. The virus does not discriminate who it infects. This next section of research will show how different ten individuals who have been living with HIV/AIDS view and experience being positive today. Their views are by no means representative of the general public or of all individuals living with HIV and AIDS. However, their stories mimic and reflect the trends happening with the epidemic today, not only in the United States but also worldwide. A number of marginalized populations are disproportionately affected by the disease and are becoming infected at alarming rates today in 2012. After interviewing and hearing the stories of five individuals who have been living with HIV and AIDS for over 20 years, the current prevalence rates are concerning because although the older generation whom have been positive for decades seem to be the ones who have the knowledge, power and drive, this cannot be said for the younger generation. The results from the young MSM support this. Participants from Group A experienced their friends, whole communities and loved ones die in rapid succession after contracting HIV/AIDS in the 1980's and 1990's. They know the devastation and have seen and felt its negative effects.



The younger generation of today was just being born in the 1980's and therefore were too young to experience the devastation and political power storm HIV/AIDS once created in the early 1980's when it first hit the United States. Part of the research spoke to the fact that the younger gay generation of today, not having to watch their friends die, may have missed out on an unfortunate part of history. Due to this fact, this generation may not take the necessary risk-reduction precautions or may have cavalier attitudes towards sexual risk behaviors and about AIDS as it is known today. (The term "gay" for the purpose of this research paper will be used interchangeably with MSM. However, it is known that not all MSM consider themselves to be gay). Could it truly be that today's young gay generation accepts HIV as just a part of their culture? For some, the perception may be that it is inevitable to contract the virus, so why worry about it? Have advancements in medications come so far that the younger generation has the attitude that HIV is just a chronic infection. They can just take a pill once a day, so no big deal. Four out of the five individuals in Group A, those who have lived with HIV for 20 years or more, still believe HIV to be a deadly disease and do not understand how or why people are still contracting HIV/AIDS at high rates today with medications having come such a long way in their development and education being out there and available.

#### **Group A: HIV Positive 20+ Years**

##### **Medications**

Group A expressed that their perceptions about AIDS are strongly influenced by the government and peer social movements banding together to find out what AIDS was in the early 1980's. They were also involved in getting the government to help stop the spread and find resources and funding for those who were already infected and education

for all. Each person from Group A spoke to the advances in medications over the years. They remembered when antiretroviral medications first came out in 1996, and spoke to their own trials and tribulations with different cocktail combinations. Two men reported that at one point they thought there were no options left because their bodies had become resistant to all the medication options available, then newer and better medications were released on the market. One man in particular used to take upwards of 60 pills a day. He was taking medications from the cocktail AZT and was also on a drug trial because he had Kaposi sarcoma. Twenty-eight years later he has little to no side effects from his medications and only takes three pills a day. He said:

Medication has changed dramatically, first from nothing to all these series of all these trials. People with the illness were willing to try anything to help not only them but the community. I went through five different trials for my KS [Kaposi sarcoma], not that I needed to; but I thought if it helped me in any way great, but if it helped others, the research, I was doing my part. The medications were crazy stuff. A lot of time it didn't do anything, but still going through all the trials, it did help develop cocktails for other people now. We are now reaping the benefits from those people who went through these trials and took these drugs.

Sometimes working and sometimes not; sometimes getting sicker than you were from the medications than from the illness. Medication has come a long way in 15 years.

Another woman explained that over the years, antiretroviral medications have not really worked for her. She would always feel sicker when she was taking them, and it

was also very difficult for her to get medications. She talked a lot about the waitlists for medications in the United States and how still today, not everyone can get medications who need them. She said:

I don't think it's enough, the medications and research today. Some places take more care of their people living with AIDS than other places do. As long as it has been [HIV], it's not enough in some places. I think probably the Southern culture has turned its back on its people. There are people living with HIV all over this country. Not all of them get the help they need. Some states have waitlists for medications. To be honest I don't think there should be any waiting list. But there is. There are enough medications to go around; it is just a matter of money. If you can't afford them, then you can't have them. What is fair or just about that?

### **Prevention and Education**

Each person in Group A strongly believed the younger generation needs to stand up and fight for funding, education and prevention, more social services and better health care. They need to seek out the education available and fight for themselves. Those who have been positive for over 20 years have paved the way and now believe it is time for the younger generation to stand up and fight for an AIDS-free generation. Group A consisted of three gay men and two straight women. When asked about being role models for the younger generation to help teach them how to protect themselves and be safe and make smart and healthy choices to end this epidemic, all three men stated that it is not their job or responsibility to teach the younger gay generation of today. One man said:

To be a role model, to educate, yeah that is my job as a human. But, I think they need to find it within themselves to get their own power and to keep it going. We brought it to a point that we know what it is, we know what to do, we can educate them on that. That's all! You can only lead them so far, and this generation has got to find it within themselves to keep it going. Or else I think there is going to be another wave of the epidemic like what has started happening in the last couple years. A wave of people who just think, ok, the medications are going to take care of us so there is no need to worry. I see that a lot of the time. They say, well you know I want to get infected; I'll get that over with. Then I won't have that to worry about anymore.

Another man said:

No, it is not my job as a gay man to teach another gay man. The kids today don't have the social activism to support the AIDS stuff. They don't have the political power, not power, the political will. They don't see it as a political fight anymore. I don't think they see the need or the urgency. They think, it has always been there for them. They don't know what it was like before when you had to scrounge around trying to find resources for people. When you had to get friends together to take care of someone who is dying because their families kicked them out. Or because at the time there was no medicine, so you just had 24-hour vigils to just keep the person comfortable. They never saw that. So what they have seen is that you take a pill for the rest of your life, and that's AIDS to them. It's a

communicable disease. But it's no worse, I don't think. I don't think they see it any worse than syphilis or gonorrhea, you know. Other than the fact that you have it for the rest of your life, but it can be controlled by medications so there is no real urgency for activism in this generation. They don't look up to us to see what we have gone through. They are the ones making poor choices and not choosing to take all the education and prevention out there for them. We rallied and fought to prevent it. Now they don't care if they get it.

The women both shared sentiments that education is a continuous journey. Particularly because the younger generation is becoming infected at alarming rates, it is the responsibility of those who are living with HIV and have experienced it to educate and share their stories and experiences to help prevent others from contracting the disease.

### **Myths and Stigma**

One interesting finding was that when asked about myths and stigmas, participants in Group A did not really have concrete examples that still exist today. They all remember when AIDS was the "gay-related disease" or that it started in monkeys, but they reported that most people had and still today have the misunderstanding or misconception that HIV cannot happen to them. One woman talked about how she believes the police force still hold on to a lot of myths about HIV. She stated:

I'm interested in criminal justice, and the assault charges people living with HIV are facing for spitting at a cop or scratching them are ridiculous.

The stigma and discrimination are amazing. The cops, they get tested

after someone spits on them and believe that person is trying to infect them. It drives me crazy. The police need an overhaul about HIV and AIDS.

### **Risk Behaviors**

Group A also had strong feelings and attitudes about risk behaviors and how they perceive they have changed over the years. One individual said:

Yeah, a lot of the young people today say I might as well go ahead and get infected and get that out of the way. Since it is controllable I can just take a pill once a day. They don't see that, ok, you have to take the medications every day for the rest of your life; and the side effects aren't advertised that much. They don't realize the nausea 24 hours sometimes or that you constantly have bouts of diarrhea. You have to plan out some things sometimes if you're feeling bad so, you know, if you're going to be close to a bathroom. They don't see that ahead of time. They just see that well I can just take some pills and I will live a healthy life. I'm glad it's at that point, but I think they just don't see the big picture. I have even heard of some young gay boys who try and catch AIDS. I heard they are trying to get it so they can be part of the group, like it's cool, or you have to be positive to fit in somewhere. I think it is damaging because they are playing with their life. It is like playing Russian roulette. When I got infected we didn't know how it was transmitted. Everyday I think about it. I can't imagine playing Russian roulette, knowing what I know. But again, this generation today, seeing healthy gay older men living with it...

they are only seeing the survivors. They didn't see the mass deaths where you lose two and three friends in a month. They never saw that. I don't know if some of the younger generation even know of someone who has died of AIDS. They don't know what the death process is.

Another individual shared her opinion about risk behaviors:

I think they have changed, not as much as they should. But they have changed some. They have a ways to go yet. Teen pregnancy, it's just unbelievable. You would think kids, ya know, they are just dumb. They are young and dumb. They think it can't happen to me and all. It has changed, just not to me enough. The young kids just don't get it, I don't think. I really think that it [education and prevention] should be focused on the young kids. I mean, I'm sorry but the younger the better. Not too young, but so that they understand about sex. They are just going from person to person not using protection. They just don't get it, I don't think. I think that means it needs to be a lot more in the school and towards the younger people. I think that if you're old and stuff, you might not know. They need to focus on the younger kids and stuff. That's just my opinion. I think they need education about abstinence, of course. That is the number one thing. I know that's kind of hard these days to make kids do that. You need to talk to your partners and practice safe sex. You have to do what you have to do to prevent this. Just using a condom does not mean that you won't get it. You have to use spermicide too. You have to get to the nitty gritty. If you have been with someone for a while and you

are getting serious, you have to discuss with your partner about safe sex.

But, you know, I suppose that does not work these days. You just have to pound it in their head about being safe and what can happen. If you don't wear condoms, look what you could have to go through.

### **Group B: Young MSM**

#### **Cavalier Attitudes**

Although each individual in Group A had his or her own perceptions and attitudes about HIV and AIDS today, they seemed to have a commonality about how the younger generation today, in 2012, has become almost careless about risky behaviors surrounding sex, IV drug use, cavalier attitudes toward and denial about acquiring AIDS. In contrast with Group A's perceptions, were the eye opening opinions from Group B about their perceptions surrounding AIDS and the lack of concern or fear of death. When asked what their perception of HIV today is, all five young men stated that it is not a death sentence; you just deal with it for the rest of your life. One young man who has been diagnosed with HIV in the last year said:

It's no big deal. I have kind of always known about AIDS, but I never worried about it. It's not like you die from it. My boyfriend has been on his medications for almost four years, and he is fine. I'm in college, I'm smart. I have done my homework and I know that today it's really not a big thing. Ya know, I shouldn't probably say that, but for me, whatever. I really am not worried. I have been getting tested on the regular, and then I tested positive. No, guys these days don't worry about getting HIV. It's now something we have in common. Least my boyfriend and me do, I



mean, I'm not worried about dying. I tried not to get it. I used condoms, but I didn't use them all the time.

### **Prevention and Education**

Group B consisted of five MSM between the ages of 18 and 25. There were four participants who identified as African American and one as white. Though the fear that HIV is a deadly disease was for the most part nonexistent in this group, four of the five men stated they tried to protect themselves. They knew what AIDS was and did not want to contract it. One of them said:

I'm not going to say it never crossed my mind. Me and my friends always did talk about HIV and protection and everything. We all used to, it was basically like a little group thing. We used to say, ok, it's time for us all to get tested. We used to all go and get tested together. I still, even after the incident, I still kinda was like, ok, this can't happen to me. Because I said I always practiced safe sex. But it did.

Another man spoke a lot about his friend who was positive, and in his community his behaviors were not acceptable. The individual often referred to the behavior of others, yet he himself was HIV positive. It is interesting to note the commonalities in the literature review and the opinions of the young men. Education, prevention and condoms are out there. It truly is up to the generation of today to protect themselves and educate and band together to fight. Yet, with all the resources available, the MSM community is still contracting HIV at one of the highest rates. Another young man said:

All of us connected, and we started hanging out. We have been hanging out together for seven years. The last guy, we met at the club. He was the

wildest one out of all of us. We always look at him like, you need to slow down. We don't carry ourselves the way you carry yourself. That's when we was like we were going to get tested or whatever. He actually became HIV positive also. He was one of those loose guys. If he seen something he liked, he was going after it. We was like, we don't do that. We don't sleep around. We carry ourselves with respect or whatever. When he first started off, he was not positive. Like I said, we used to get tested every six months or whatever. I want to say he found out, he got sick in the beginning of 2010. That was kinda a hard time. He had just lost his boyfriend. His boyfriend was positive. He kinda figured that's who he contracted it from.

### **Myths and Stigma**

He went on to talk about some of the misperceptions he and his community have about HIV:

I know that in science and through the medical field and terminology and everyone presumed it to be in just the gay life. There are more ways to contract HIV in the gay life. With me, the way I look at it is, I have been interested in guys since I was 14. I have been dealing with guys for a long time. I went all that time without contracting HIV. I don't think it's just in the gay life. It's just in the human body. I know HIV was out there. I just didn't expect it, ok; if I'm carrying myself right then, you know, everything will be ok. There are still numerous ways to contract HIV. You just have to be more careful and know how to carry yourself. And

even if someone says, oh I love you, blah, blah, blah. Some people will say anything. Some people actually don't really care about getting HIV. All they care about is the pleasure. It's all about how you feel about it. I guess by me and my friends talking about it, if we carry ourselves right and we do what we gotta do, and we believe in ourselves, we will have a great risk of not catching it. At least my other two friends, they won't get it like my other friend and me.

### **Social Media**

Even with educational tools, prevention messages and social services readily available to help prevent the spread of HIV/AIDS, it could be concerning to hear the lack of knowledge or misinformation that the younger generation feels they know. However, this is how they perceive HIV/AIDS today. Social media, in particular, plays a role in the attitudes about AIDS for the younger generation. For example, one individual from Group B stated:

HIV, there is prevention for it. There is a prevention for both; there are treatments for HIV and AIDS. But it's more that you can live longer with HIV than you can with AIDS. You don't want to get AIDS. My generation, they think, oh HIV/AIDS, I'm not going to get it as long as I am being this and that. I tell people you can use a condom, and if that condom breaks, you can still get it. But if you know how to handle the situation, then there are ways you can actually go around it even if a condom breaks or something. The younger generation, we just don't care. I will deal with it when it's my time. People still is like; more straight

people feel they can have more unprotected sex. They hear so much on TV only gay people contract it or have it. Gay people have more sex and have a higher hormonal whatever. They have a high sex drive, I know that. That is what the TV and magazines show too. Most people feel that it's just in the gay life. Just because they're straight they feel they are not going to get it. It's still a high risk for both sides, straight or gay. The younger generation, I guess by them hearing more on TV and the radio that the gays have HIV; and they have more viruses in them. The younger generation feels invincible. I tell everyone, everyone is at risk of HIV; anyone can get it. It's not just in the gay life. But when I look at the commercials and they are talking about how to protect the gays and prevent HIV through gay sex, I'm like, it's not just through gay people. They have guys out there sleeping with numerous females too.

When Group A was asked about social media and how that influenced attitudes and perceptions, they did not feel that there was enough recognition about HIV today compared to 20 and 30 years ago. Individuals from Group A felt similarly to Group B that there used to be role models, like Magic Johnson. There used to be campaigns on television to help prevent the spread of the disease and to get the government involved in the political fight against AIDS. One woman stated:

No, not to the extent it was. You can go months without hearing AIDS mentioned on TV. The press only reports if there is a fundraiser. If there is a breakthrough in something, you don't see it on the front page of anything; it is all buried. The press has kinda let it drop. HIV, it is not the

darling of the media or celebrities that it once was. I think with people living longer and not dying off as quickly, I don't think they see the urgency that there once was.

Another woman stated:

Social media, it has a very negative effect these days. People are very impulsive in an online environment. They have got it in their head and idealize them in their head before they meet them – the other person.

There is a lot of hooking up. It's anonymous. The prevention messages these days are only directed at people who are positive. The media tells them to wear condoms and to tell their partners. They are almost shamed for being positive. I pity any HIV positive gay man trying to date these days. Protection is a two way streak. No, no role models today. In the 90's you had these celebrities, but now, no one.

A common theme in Group A is the belief that you don't see or hear anything about HIV anymore. They believe this is one reason so many people are contracting the virus. Where, then, is the younger generation getting their information? If they are seeing TV ads or hearing about information that the "gays" need to protect themselves, could it be that the younger generation accesses information through media differently and that prevention messages are targeted to the younger generation in a different way? Group B referred to social websites as a way to meet people and sexual partners more easily, and HIV prevention is only targeted to one population, "gay HIV+ men." There are almost no HIV positive role models today for the younger generation to look up to and see in healthy monogamous relationships.

## **Medications**

Knowledge about medications is also an area where the two groups differed significantly. Those who have been positive for over 20 years went through drug trials and have tried numerous medication regimens. But the younger MSM just “pops a pill once a day” (Group A participant). One individual from Group B said:

The medications so far have been doing exceptional. I kinda give a hand clap to whoever came up with that idea. As far as the medication, it is a good treatment so far. There are a lot of different medicines available. It goes basically by the strength of the blood and everything to determine if it is going to work. The medicine I have been using so far has been amazing: Truvada, Norvir and Reyataz. At first I experienced side effects for, like, two weeks. It was basically, you have to eat right with it. If you don't, you're going to feel crappy. The other side effect when I first started, my blood count was extremely low. I had to build that back up. It was always causing me to have nausea right away too. My eye color changed until the medicine got into my system. I had to deal with all of this for almost two whole weeks.

One man in Group A felt that in retrospect, only having to take three pills a day compared to the almost 60 pills he had to take daily is an amazing accomplishment. He said:

When I was on AZT, DDI and some of the other cocktails I took three or four pills, three or four times a day. When I was on a trial for KS, I was taking 15 pills three times a day. That was 45 pills just of that one for the

KS, not counting the other multiple pills I was taking for the cocktails. I was living in constant nausea. It's a hard kind of nausea to explain to people. It is a chemical nausea. If you have had it, you can tell the difference between a chemical nausea compared to a food nausea or a bad smell. It's down in the gut, and it just would not go away. This went on for years.

One of the young men talked about what he knows about HIV/AIDS medications today:

I am on the new pill, Complara. I take it once-a-day, and that is it. I hardly had side effects. I felt fine on it. My doctor told me all I have to do is take this pill, and I will be fine. I know there are multiple medicines in it. I did have a little diarrhea, I think, for a week or two. But the doctor said that is normal. I know of other friends who take Atripla. It is just one pill too. I guess I don't see the big deal about the medicine. It's so good that there is not anything to worry about. If it stops working then I will just take a different one.

Lastly, one woman was quoted as saying about her medications:

Pill burden is a lot less today than it once was. I used to be on AZT, Efavir and Crixivan. I had horrible side effects. It was so different then it is now. I didn't want to switch when new medication came out because I was scared it would be worse. I have now been on the same medications for seven years. I am going to wait a while before I change again to the once-a-day pills. I feel like don't fix it if it's not broke. There are so many great advancements coming down the pipeline now. I want to wait a

little bit longer. The people who have been having pill burden may be more the ones to be on the once-a-day pills right now.

### **Discussion of Findings**

Numerous themes emerged when coding the data retrieved from the ten interviews. There were several similarities as well as differences in both groups. Factors like age and gender also played a role. Group A, whom have been living with HIV/AIDS for 20 plus years, regardless of gender, felt like HIV was a death sentence at one point in time and that today, the younger generation does not think about it in the same way. They all believed the perception of HIV has changed so much that no one really thinks about it anymore; it is not talked about in the media, and the younger generation does not care about keeping themselves safe from contracting AIDS. The two women interviewed both believed that it is the responsibility of everyone to educate and teach others how to reduce the spread of HIV. This perception was also supported by four of the five individuals in Group B, who consisted of the young MSM. Neither group really commented on how their sexual identity influenced their perceptions or attitudes about HIV. One gay man, who has been positive for 28 years, remembered when AIDS was “a gay disease.” Today, though, the younger generation commented on how the only coverage HIV gets in the media today is how gay people need to protect themselves. Three individuals from Group B stated that prevention is only geared towards gay men and HIV positive individuals, not the general public. One young man stated he has seen commercials on BET (Black Entertainment Television) about getting tested and that the commercial is geared to everyone. The theme of medications was one of the biggest divides between both groups. Group A remembers when there were no medications



available until AZT was widely available around 1996. They talked about how their friends died months after being diagnosed, and one woman stated her husband passed away just a few months before AZT was available. She commented on the fact that this life-saving medication needs to be readily available to each and every person living with HIV and AIDS.

Group B had a significantly different view and attitude about medications. All five individuals are on ARVs and said they hardly have experienced any side effects from medications; three are on one pill once-a-day dosing, and two others are on two to four pill regimens with once-a-day dosing. The attitude from Group B is that medications are no big deal; you just take your medications once a day and you are fine. They did not comment on what it was like before medications or when medications were new and toxic. Since they are all under age 25 and diagnosed in the last three years, they never experienced the extreme side effects like some of the people who have been living with HIV for decades or pill fatigue or becoming resistance to medications. The young MSM did all believe and understand that they have to take their medications every single day to remain healthy. It was not a research question, but during the interview three of the young men did comment on how they have only ever missed a dose here or there. One young man stated he is not very good about remembering to take his medications; he said life gets in the way. He wished that he could get a shot once a month or something so that he would not have to remember something so important everyday. He did not have concerns about becoming resistant to his medications. His opinion was that there will always be more and better medications, so he is not worried about resistance if he forgets to take his meds. "I can just take a different one if this one stops working."

Another common theme was support services needed for individuals living with HIV. Group A stated they did not think they could have made it this long without the help from friends, family, their medical providers, case manager and political social groups. Group B said they were partnered with a case manager right after being diagnosed and that is what they attribute to getting into care and learning about HIV and how to protect others from contracting it. All ten individuals referred to the need for good health care, transportation, housing and nutritious food. One young man did say that now that he is HIV positive, he is getting more support, social services, free transportation and better housing than he got before he was positive. He felt now that he contracted HIV, he is entitled to certain services or financial resources. Collectively, both groups perceive social services as a future way to continue educating and a way to help prevent the further spread of HIV/AIDS.

## **Implications for Social Work**

This research barely scraped the surface of trying to learn why young men who have sex with men and other minority populations are contracting HIV at extremely high rates today when the data and education indicate that HIV is 100 percent preventable. Both groups indicated it is important to have a support system, a team to help individuals navigate the medical system and assist with insurance and medication adherence. In addition, they all stated help finding affordable and appropriate housing was important as well to maintain their health. Those who have been positive for over 20 years said they utilized food shelves, AIDS educators, advocates, government and political groups. The young MSM spoke to the fact that they each have a personal case manager to help them get to doctors' appointments or fill out insurance applications. One young man referred to his case manager as his assistant, "She helps me with everything; I didn't know where to start until I met her." He went on to talk about how he believes it is important to have someone he can talk to about being HIV positive. He and several other individuals expressed that it was hard telling people at first because there is still such a misconception today about HIV: if you have it, you are bad; and some people still think you will die. The younger generation stated they know it is not a death sentence, but it took their team of doctors and social workers to help them really believe that. Implications for future social work particularly lie around prevention. How can future social workers and organizations educate and help reduce risk in marginalized groups affected by high prevalence rates? Yet again, the rising epidemic in the United States needs attention, but so do the infection rates worldwide. The United States and several other countries are doing studies to help prevent the spread of HIV through medication

trials and through education campaigns. Thirty years later, knowing what we know now, knowing how to prevent the virus, how to protect ourselves and how to keep one another healthy and living a long life are all great strides in the right direction. Still, there are waitlists for ARVs in the U.S.; and many developing countries do not have access to life saving medications either. They do not have the same access to prevention tools, condoms and education about HIV and AIDS. Many people within the United States even still discriminate against those who are living with the HIV virus. They blame certain cultural and ethnic groups. Social workers have their work cut out for them.

### **Implications for Future Research**

Future research projects could look at why young MSM and other groups do not fear contracting HIV or why some gay men feel it is inevitable for them to contract the disease. A significant theme emerged surrounding the fact that the older gay generation does not feel it is their responsibility to teach or be role models for the MSM youth of today. This could be examined more closely, particularly because the young MSM in this research project wanted to learn from the older generation. They asked for role models to set good examples for monogamous couples, “Social media is all about sex!” Social workers could also use existing data to look at patterns in marginalized populations. They could try to understand why African American and African born women have some of the highest prevalence rates. Research could be done more extensively to look at using ARVs as a prophylaxis to reduce the community viral load and, therefore, reduce the spread of the virus. All of this future research needs to be done, but the bottom line is that unfortunately, it does not look like the epidemic is slowing down. Working towards an AIDS-free generation is a wonderful concept and very achievable, particularly in the

United States. Medications are readily available and if taken properly, transmission during pregnancy, labor and delivery from mothers infected with HIV to children has been reduced to less than 2 percent (Mofenson, 2006).

This being said, if there are waitlists for medications and if women in developing countries do not have the same access to medications as those in more developed countries like the U.S., then is an AIDS-free generation really achievable? New data from the United States Department of Health and Human Services came out as this paper was being written stating the new standard of care is that every HIV positive person should be on ARV therapy (Horn, 2012). The purpose of this is for the common good of the community to help reduce transmission. However, social workers and medical care providers need to look at who is becoming infected. Can young people successfully be almost 100 percent adherent to medications for the rest of their lives, for the next 40, 50, 60 or 70 years? Is it feasible to start every person infected with HIV/AIDS on medications? It will be important to look at why people do not worry about getting infected any more rather than just preventing the spread. It has been established that although HIV is a 100 percent preventable disease, people are still contracting it.

HIV/AIDS may very well have fallen off the agendas of mainstream media and campaign projects, but that does not mean the epidemic is over. Due to having such great advancements in medications and testing availability, it could be said that people do not always think about the consequences of contracting a disease. They only see that people live long and healthy lives, so why concern themselves with wearing condoms, knowing who their partners are and getting tested prior to engaging in risky behaviors? One participant said, "Sex is still the same 30 years later, it is just the number of partners that

has increased.” There are too many questions and not enough answers. No individual should ever feel like they want to contract HIV to belong to a culture or that it will inevitably happen to them. No one should have the perception that who cares if I get it. There is not a cure for HIV yet, and people are not going to stop having unprotected sex. How can the implications and repercussions of contracting HIV/AIDS be realized by the general public and put forth in future prevention campaigns?

## **Strengths and Limitations**

There are a number of strengths and limitations that pertain to this research. First of all, a predominant strength was that the research conducted was through a qualitative method. A non-random sampling was used to select ten individuals to be interviewed and share their opinions, stories and perceptions of how HIV and AIDS has or has not changed over the last 30 years. A limitation was that it was a small, select sample that cannot be taken as representative of the larger population. In no way are the answers of these ten individuals the majority opinion or reason for a particular trend in the HIV and AIDS epidemic over the last 30 years. The sample consisted of two straight white women between the ages of 40 and 60, three white gay men between the ages of 45 and 65 and five young men who have sex with men, four of whom identified as African American and one who identified as white. No African immigrants or African American women were interviewed, and the current literature states these two populations are also at high risk for contracting HIV/AIDS today. Another strength predominantly reflected in the perceptions about how the disease and medications have changed and how AIDS may no longer be considered to be a death sentence was concluded from the research. The younger generation has a very different view about HIV today, particularly compared to those who have been living with HIV for many years. Talking intensely with individuals who are living with the disease, who shared their stories and experiences through qualitative measures proved beneficial to the research project. Their experiences provided an invaluable context about the perception of HIV today. In addition, this research project opened the door to many unanswered questions and can pave the way for further research.

## **Conclusion**

It is safe to say the perceptions, beliefs and attitudes surrounding HIV and AIDS today are very different than they once were. The literature has proved that there have been great advancements in medications, research, knowledge and prevention efforts for HIV and AIDS. However, due to these amazing advances, has the perception about HIV and AIDS changed so much so that it is now causing negative effects on society? Thirty years ago, men and women were dying at high rates due to AIDS-related complications. There were no medications, and no one even knew what Acquired Immunodeficiency Syndrome was for several years. The only thing people knew was that it was a deadly disease. Today, the younger generation speaks to the fact that they do not know AIDS to be a deadly disease. They see it as a chronic illness, something manageable by taking a pill once a day. This may be true, but if HIV/AIDS is 100 percent preventable, then why are infection rates rising? Why are people not protecting themselves from contracting HIV? Why is it acceptable to believe that HIV is just a part of one's community, so why worry about getting it? "It will happen eventually." There are too many unanswered questions these days about why infection rates are high and still on the rise. This research project proves that yes, there is certainly a generational divide regarding perceptions and beliefs. So how can this research be used to help educate today's younger generation and prevent the spread of HIV? The myth that "HIV is no big deal" was probably not fathomable 30 years ago. Today, one can get condoms at the local convenience store; the internet is overwhelmed with statistics and data about HIV; and there is a National AIDS Strategy at the highest level of government trying to help prevent the spread by saying all people infected with HIV should be on medications.



This clearly is not enough, as particular populations continue to be at high risk often by just being part of a culture, society or community. The research collected for this project was intended to inform readers of not only how far we have come as a society but also to show how far we still have to go. We cannot stop educating; we cannot let AIDS fall out of mainstream media. Just because people are not dying does not mean it is no longer a problem. Just the opposite: HIV/AIDS is an epidemic. This project did not even touch on the devastation that Africa as a continent is currently experiencing today with the HIV/AIDS epidemic killing hundreds of people each day. It can be said again, HIV/AIDS is a 100 percent preventable disease. The progress in reducing the spread of HIV/AIDS cannot begin to slide backwards. Education has got to be the solution. Getting tested, knowing one's partners and wearing condoms are all important to stop the spread of HIV and AIDS. HIV ends with us!

## References:

- Addison, T. (1992). Urie Bronfenbrenner. *Human Ecology*, 20(2), 16-20.
- Adefuye, A., Abiona, T., Balogun, J., & Lukobo-Durrell, M. (2009). HIV sexual risk behaviors and perception of risk among college students. *BMC Public Health*, 9, 281. doi:10.1186/1471-2458-9-281
- Augustine, J. (2012). *A changing epidemic calls for a realistic approach to prevention*. Retrieved from <http://www.advocatesforyouth.org/article/430-young-people-and-hiv>
- Barton-Knott, S., & Magne-Watts, B. (2005). *HIV infection rates decreasing in several countries but global numbers of people living with HIV continues to rise*. World Health Organization. Retrieved from [http://www.who.int/mediacentre/news/releases/2005/un aids\\_who/en/](http://www.who.int/mediacentre/news/releases/2005/un aids_who/en/)
- Berg, B. (2009). *Qualitative research methods for the social sciences* (7th ed.) Boston, MA: Allyn & Bacon.
- Bowman, M. (2002). *HIV rate starts to increase in many US cities*. Retrieved from <http://www.rense.com/general32/hiv.htm>
- Broder, S. (2010). The development of antiretroviral therapy and its impact on the HIV pandemic. *Antiviral Research*, 85(1), 1-18. doi:10.1016/j.antiviral.2009.10.002
- Bronfenbrenner, U. (1979). *The ecology of human development*. Cambridge, MA: Harvard University Press.
- Center For Disease Control and Prevention. (2003). Rapid increase in HIV rates – Orel Oblast, Russian Federation, 1999-2001. *MMWR Weekly*, 52(28), 657-660.

Center For Disease Control and Prevention. (2010). *HIV in the United States*. Retrieved from <http://www.cdc.gov/hiv/resources/factsheets/PDF/us.pdf>

Center For Disease Control and Prevention. (2011). *HIV Among youth*. Retrieved from <http://www.cdc.gov/hiv/youth/pdf/youth.pdf>

Ferree, K. (2011, July 22). National AIDS fund receives \$3.6 million social innovation fund award. Retrieved from <http://www/aidsfund.org>

Ghiglione, K. (2008). Sex, drugs and viral loads. *The Positive Side*, 10(2), 17-21.

Highleyman, L. (2011). Interim guidance: Preexposure prophylaxis for the prevention of HIV in men who have sex with men. *Morbidity and Mortality Weekly Report*, 60(03), 65-68.

Horn, T. (2012). *Revised U.S. guidelines: HIV treatment is recommended for all people living with HIV*. Retrieved from [http://www.aidsmeds.com/articles/hiv\\_treatment\\_guidelines](http://www.aidsmeds.com/articles/hiv_treatment_guidelines)

Katz, M. (2010). HIV/AIDS 2010. *Archives of Internal Medicine*, 170(1), 6-8.

Lubinski, C. (2004). *An overview of AIDS drug access in the United States*. Retrieved from <http://www.thebody.com/content/art12271.html>

Lerner, M. (2012, April 30). AIDS, HIV cases drop 12% in Minnesota. *Star Tribune*. Retrieved from <http://www.startribune.com>

Maugh, T. (2011, September 23). Pills show drop of HIV infection risk. *Los Angeles Times*. Retrieved from <http://www.latimes.com>

Minnesota Department of Health. (2010). *2009 HIV/AIDS cases increase by 13 percent: Young males show largest increase in cases*. Retrieved from <http://www.health.state.mn.us/news/pressrel/2010/hiv012610.html>

- Minnesota Department of Health. (2012). *HIV/AIDS Surveillance Reports – 2011*. Retrieved from <http://www.health.state.mn.us/divs/idepc/diseases/hiv/hivs.html>
- Mofenson, L. (2006). Achievements in public health: Reduction in perinatal transmission of HIV infection. *MMWR*, 55(21), 592-597.
- Muturi, N., & Soontae, A. (2008). *HIV/AIDS stigma, risk, and religiosity among African American women*. Retrieved from [http://www.allacademic.com/meta/p\\_mla\\_apa\\_research\\_citation/2/3/1/9/4/p23194](http://www.allacademic.com/meta/p_mla_apa_research_citation/2/3/1/9/4/p23194)
- Shilts, R. (2007). *And the band played on* (3<sup>rd</sup> ed.). New York, N.Y.: St. Martin's Press.
- Silva, C., Goncalves, D., & Pacca, J. (2005). Optimistic perception of HIV/AIDS, unprotected sex and implications for prevention among men who have sex with men, San Paulo, Brazil. *AIDS*, 19(4), S31-S36.
- State Health Facts. (2012). *AIDS drug assistance programs with waiting lists* [Data file]. Retrieved from <http://www.statehealthfacts.org/comparetable.jsp?ind=552&cat=11&sort=a&gsa>
- Thomas, M. (2011, September 24). AIDS no longer a death sentence, but the epidemic is far from over. *Chicago Sun-Times*. Retrieved from <http://www.suntimes.com>
- United Nations General Assembly. (2011). *Innovative HIV/AIDS drugs, treatments must be urgently developed* [Data file]. Retrieved from <http://www.un.org/News/Press/docs/2011/ga11091.doc.htm>
- Wainberg, M., & Jeang, K. (2008). 25 years of HIV research – Progress and perspectives. *BMC Medicine*, 6(31), 1-7. doi: 10.1186/1741-7015-6-31

Ward, J., Disch, B., Schensul, J., & Levy, A. (2011). Understanding low-income, minority older adults self-perception of HIV risk. *Journal of the Association of Nurses in AIDS Care*, 22(1), 26-37.

Young, S. (2010). *30 Years with HIV: 3 men reflect* – CNN. Retrieved from <http://www.cnn.com/2010/HEALTH/07/23/30.years.hiv/index.html>

## Appendix A

### Letter of Agency Approval – Clare Housing

From: Michele Boyer  
Sent: Friday, October 14, 2011  
To: LeonardMayers, Mariana L  
Subject: Re: Interviewing Clare Residents

I am more than OK with this; please feel free to post flyers, etc. And we'll do our best to encourage folks to participate!

Michele L. Boyer  
Director of Programs  
Clare Housing  
929 Central Avenue NE  
Minneapolis, MN 55413  
[www.clarehousing.org](http://www.clarehousing.org)

From: LeonardMayers, Mariana L  
Sent: Friday, October 14, 2011  
To: Michele Boyer  
Subject: Interviewing Clare Residents

Hi Michelle,

I am getting my Masters in Social Work at St. Thomas and St. Kate's. I am in my final year and in the middle of trying to write my research paper to graduate. I chose to write about the generational differences and perception of HIV today and over the last 30 years. I am interested in interviewing 4 or 5 Clare residents who have been HIV+ for over 20 years. My professor contacted Lee Lewis who may have copied you on the e-mail, but suggested I contact you as well to see if this is a possibility. I have a flier I would like to put up in one of the common space areas or even Angie or Cynthia could just put it up outside their offices. I can send you a list of interview questions or answer any questions you may have about the interview. Each participant has the option to not answer any of the questions if they wish not too. I am asking questions like *what is your perception of how the disease has changed, how have medications changed, why do you think there is a spike in HIV infection in young MSM, what risk behaviors have changed over the years*. I will also provide resources to MAP or to the individual's case manager if the interview brings up any unresolved feeling or the interviewee wants more resources on something. Please let me know if this would be ok with you and I will get you my IRB Agency Consent form. If you have any questions please feel free to ask.

The interviews will be about 1 hour, audio taped, in a private location where the interviewee feels most comfortable. All the information will be confidential and when I use the data from the interviews in my research paper there will be no identifying information so each person interviewed will remain anonymous. I will also be providing a small gift card at the end of the interview to say thank you for participating.

Thank you so much for your consideration and allowing me to put up a flier at Clare.

Mariana Leonard-Mayers, LSW

## Appendix B

### Flier hung at Clare Apartments and Clare Midtown

#### Interested in Sharing Your Story? Research Participants Needed

My name is Mariana and I am in my last year of school at the University of St. Thomas working towards my Masters in Social Work. I am writing a research paper on the perception of HIV today and how it has changed over the last 30 years. I am gathering data to see what if any generational differences there are towards attitudes and perceptions of HIV/AIDS. I am interested in interviewing a few individuals who have been HIV+ for over 20 who are willing to share their experiences about the epidemic. I will also be interviewing some young MSM (men who have sex with men) to see if there are any contrasting perceptions/generational differences about how beliefs may have changed over the years.

1. This project is 100% confidential – No identifying information about you will be used in my paper.
2. I have a series of ten questions I would like to ask you and the interview would last for about 60 minutes.
3. The interview will be audio taped. I will destroy the audio tape after I have transcribed the interview.
4. A \$15 gift card will be given after the interview to say thank you for participating.
5. If you feel uncomfortable answering any of the questions you do not have to.

Please feel free to call me with any questions or concerns you may have, my cell phone number is 320-492-8864.

In advance, thank you for your willingness to share your thoughts surrounding influences on attitudes and beliefs about HIV today and how they may have changed. I look forward to hearing your stories.

Please call me at 320-492-8864 to set up an interview.

## Appendix C

### Letter of Agency Approval – Youth and AIDS Project

From: Val Smith-Brown  
Sent: Wednesday, December 18, 2011  
To: LeonardMayers, Mariana L  
Subject: Interviewing young MSM

Yes Mariana, you are more than welcome to hang up a flier in my office. I will let clients know about your project and have them call you if they are interested. Send me the flier and I will hang it up.

Thank you,  
Val Smith-Brown  
Case Manager  
University of Minnesota Adolescent Health  
2929 4th Ave South MPLS, MN 55408  
Youth and AIDS Projects

From: LeonardMayers, Mariana L  
Sent: Wednesday, December 18, 2011  
To: Val Smith-Brown  
Subject: Interviewing young MSM

Hi Val,

I am getting my Masters in Social Work at St. Thomas and St. Kate's. I am in my final year and in the middle of trying to write my research paper to graduate. I chose to write about the generational differences and perception of HIV today and over the last 30 years. I am interested in interviewing 4 or 5 young MSM who have been diagnosed with HIV/AIDS in the last few years that are under age 25. I have a flier I would like to put up in one of the common space areas at the Youth and ADIS Project. I can send you a list of interview questions or answer any questions you may have about the interview. Each participant has the option to not answer any of the questions if they wish not too. I am asking questions like *what is your perception of how the disease has changed, how have medications changed, why do you think there is a spike in HIV infection in young MSM, what risk behaviors have changed over the years*. I will also provide resources to MAP or to the individual's case manager if the interview brings up any unresolved feeling or the interviewee wants more resources on something. Please let me know if this would be ok with you and I will get you my IRB Agency Consent form. If you have any questions please feel free to ask.

The interviews will be about 1 hour, audio taped, in a private location where the interviewee feels most comfortable. All the information will be confidential and when I use the data from the interviews in my research paper there will be no identifying information so each person interviewed will remain anonymous. I will also be providing a small gift card at the end of the interview to say thank you for participating. Thank you so much for your consideration and allowing me to put up a flier at the Youth and AIDS Project.

Mariana Leonard-Mayers, LSW



## Appendix D

### Flier Hung at the Youth and AIDS Project in Minneapolis

#### Interested in Sharing Your Story? Research Participants Needed

My name is Mariana and I am in my last year of school at the University of St. Thomas working towards my Masters in Social Work. I am writing a research paper on the perception of HIV today and how it has changed over the last 30 years. I am gathering data to see what if any generational differences there are towards attitudes and perceptions of HIV/AIDS. I am interested in interviewing a few individuals who are young (age 18-25) men who have sex with men and who are HIV+. I am interested in your perspective about HIV as you did not grow up in the era (1980's) when the epidemic first hit the United States. I am interested to know what today's younger generation believes and thinks about the HIV/AIDS.

1. This project is 100% confidential – No identifying information about you will be used in my research paper.
2. I have a series of ten questions I would like to ask you and the interview would last for about 60 minutes.
3. The interview will be audio taped. I will destroy the audio tape after I have transcribed the interview.
4. A \$15 gift card will be given after the interview to say thank you for participating.
5. If you feel uncomfortable answering any of the questions you do not have to.

Please feel free to call me with any questions or concerns you may have, my cell phone number is 320-492-8864.

In advance, thank you for your willingness to share your thoughts surrounding influences on attitudes and beliefs about HIV today and how they may have changed. I look forward to hearing your stories.

Please call me at 320-492-8864 to set up an interview.

Appendix E

Consent Form

**CONSENT FORM**  
**UNIVERSITY OF ST. THOMAS**  
**Perception of HIV/AIDS Over the Last 30 Years**

I am conducting a study about *Generational Differences of HIV Today and Over the Last 30 Years*. I invite you to participate in this research. You were selected as a possible participant because of your experience around the topic of HIV/AIDS. Please read this form and ask any questions you may have before agreeing to be in the study. This study is being conducted by: Mariana Leonard-Mayers, Philip AuClaire and the University of Saint Thomas Social Work Department.

**Background Information:**

The purpose of this study is to find out what the perception of HIV/AIDS is today and how if at all the disease and perception of HIV/AIDS has changed over the last 30 years. In addition, I will be conducting research to find out what if any implications today's perception of HIV/AIDS has on social services and what applications clinicians should be aware of.

**Research Question:** Throughout the generations how has the perception of HIV/AIDS changed over the last 30 years?

Hypotheses: It is believed that HIV/AIDS is no longer perceived as a deadly epidemic and that the general population is not concerned about contracting or living with HIV due to the advancement in medications.

Method used to address the research question: Interviewing 10 HIV positive individuals to find out their experience and perceptions about HIV/AIDS.

**Procedures:**

If you agree to be in this study, I will ask you to do the following things: Participate in a 45 - 60 minute audio taped interview and answer the list of 10 questions as openly and honestly as possible and to the best of your knowledge and ability.

**Risks and Benefits of Being in the Study:**

There may be some risk of emotional discomfort while participating in this interview. Please feel free to decline or choose not to answer any of the questions if you don't feel comfortable answering them or talking about things that are too personal to you. There will be no direct benefit from participating in their research project.

**Compensation:** There is no compensation for participating in this research. It is based on voluntary participation. There is a gift card provided for appreciation of participation.

**Confidentiality:**

The records of this study will be kept confidential. In any sort of report I publish, I will not include information that will make it possible to identify any of the participants in any way. The types of records I will create include an audio recording, a printed transcript and notes from the interview. The audio recording will be kept on my personal flash drive as well as all transcripts; my flash drive is encrypted. I will be the only person to have access to this flash drive. I will destroy the audio recordings after I complete the transcripts and will destroy the flash drive no later than May 30th, 2012 after the research project is completed.

**Voluntary Nature of the Study:**

Your participation in this study is entirely voluntary. Your decision whether or not to participate will not affect your current or future relations with the University of St. Thomas. If you decide to participate, you are free to withdraw at any time up to and until January 31<sup>st</sup>, 2011. Should you decide to withdraw data collected about you will be destroyed and not used in the study. You are also free to skip any questions I may ask.

**Community Resources**

Should any of the subject matter that we talk about in the interview bring up feelings or frustrations that you feel you will need more assistance with to process I would encourage you to call the Minnesota AIDS Projects AIDSLine at 612-341-AIDS and ask to talk to someone or get more resources from them. If you have a community Case Manager I would encourage you call them to look for more resources as well if any of the subject matter raises concerns for you. Another resource I could offer you would be to the Interprofessional Center for Counseling at the University of St. Thomas, 651-962-4820.

**Contacts and Questions**

My name is Mariana Leonard-Mayers. You may ask any questions you have now. If you have questions later, you may contact me at 651-254-7865. You can also contact my professor Philip AuClaire at 612-752-8181. You may also contact the University of St. Thomas Institutional Review Board at 651-962-5341 with any questions or concerns.

**You will be given a copy of this form to keep for your records.**

**Statement of Consent:**

I have read the above information. My questions have been answered to my satisfaction. I consent to participate in the study. I am at least 18 years of age.

\_\_\_\_\_  
**Signature of Study Participant**

\_\_\_\_\_  
**Date**

\_\_\_\_\_  
**Print Name of Study Participant**

\_\_\_\_\_  
**Signature of Researcher**

\_\_\_\_\_  
**Date**

## Appendix F

### Interview Questions

Age, Race, Education level, Years HIV+, Gender Identity, MSM

1. What is your perception of HIV today? Has that changed since you were diagnosed?
2. What do you believe to be the perception of HIV in your community?
3. What do you feel has influenced your attitudes and beliefs about HIV?
4. Has your sexual identity/gender influenced your attitudes about HIV?
5. Who or what has had the most influence on what you know about HIV, social media, peers, government policy, etc...?
6. What if anything do you think has changed about HIV medications, risk behaviors, education and prevention?
7. What do you know about HIV medications and treatment? Has this changed since you were diagnosed?
8. Do you believe risk behaviors in general are similar to what they have always been or have they changed? Have your risk behaviors changed due to attitudes or perceptions about HIV?
9. What stigmas or myths do you feel exist about HIV today? Have these changed over time?
10. What support services do you feel are important to prevent the spread of HIV and or for people living with HIV?

**ST. CATHERINE UNIVERSITY AND  
THE UNIVERSITY OF ST. THOMAS  
MSW PROGRAM**

---

**Generational Differences of HIV Today and Over the Last 30 Years**

by M. Leonard-Mayers

---

Research Committee:

Chair: **Philip AuClaire, Ph. D**  
Members: **David Chollar, LICSW**  
**Catherine Patterson, MA**

Abstract

This study examines the generational differences and perceptions of HIV today and over the last 30 years from the viewpoint of ten individuals living with HIV. Despite the high prevalence rate of HIV/AIDS among young men who have sex with men (MSM), African American women, as well as other minority groups, little is known about how stigma and sexual risk perception play a role in the continued rise in HIV incidence throughout the United States and the world today. This paper will show that as medications have improved and become readily available to the public, cavalier attitudes among the younger generation towards contracting HIV are becoming more typical. Data was collected by interviewing five individuals, each of whom has been living with HIV for over 20 years, and five young MSM who have been diagnosed with HIV within the last three years. The data were coded, and several themes emerged, revealing that along with drugs, stigma, myths, risky sexual behaviors and cavalier attitudes towards HIV have played a major role in the transmission of the disease today. There are multiple perceptions of HIV. This study reveals that each population has its own beliefs about risk, stigma and views on medications and attitudes towards acceptance of HIV being part of today's culture. This study left the door open for more in-depth research to be completed, not only on what the perception of HIV is today, but why this is and how to end the epidemic.

---

St. Catherine University and the University of St. Thomas