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Mariah Twigg
Choosing to Live: The Decision to
Take Anti Retroviral Medications
from the Perspective of HIV+ People
Who Take These Medications
Consistently

Abstract

This study was qualitative in design and explored how people who are HIV+ and prescribed Antiretroviral Treatment (ART) are able to take their medication every day as prescribed. Ten individuals who had an HIV VL of <78 (undetectable), were fairly stable in other areas of their lives were interviewed. These individuals had at one point not been able to take their medications as prescribed, but had later been able to commit to taking the HIV treatment regimen as prescribed, for at least six months. Mixed methods were used and participants completed a short written demographic form and a likert scale survey about previously researched boundaries. Respondents also participated in a short interview with open ended questions. All interviews were conducted in person. Findings showed that all participants agreed with at least one barrier identified from the previous research. Findings also showed that people struggled with substance use, pre-existing depression, low self-efficacy and shame or hopelessness about being HIV+. Interviewees all reported having a moment when they decided that they wanted to live. Some of these decisions were motivated by supportive communities, some by therapeutic interventions, and some by critical events. Providers were helpful, especially when direct, honest and caring. But overall, participants expressed that they were only able to commit to taking ART, when they were able to integrate their HIV+ selves (selves doomed to death), with their selves that could live full lives.

**Choosing to Live: The Decision to Take Anti Retroviral Medications from the Perspective
of HIV+ People Who Take These Medications Consistently**

A project based upon an independent investigation,
Submitted in partial fulfillment of the requirements
For the degree of Master of Social Work.

Mariah Twigg
2012

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This thesis is dedicated to all people living with HIV. Your voices matter.

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TABLE OF CONTENTS

ACKNOWLEDGEMENTS	ii
TABLE OF CONTENTS	iii

CHAPTERS

I INTRODUCTION	1
II LITERATURE REVIEW	4
III METHODOLOGY	21
IV FINDINGS	31
V DISCUSSION	50
REFERENCES	59

APPENDICES

Appendix A: Semi Structured Interview Protocol.....	76
Appendix B: Brief Demographics Questionnaire & Likert Scale Survey.....	77
Appendix C: Resource List.....	79
Appendix D: Pre-screening Questions.....	84
Appendix E: Informed Consent.....	85
Appendix F: HSR Approval Letter.....	87
Appendix G: Flyer.....	88

CHAPTER I

Introduction

HIV has been a highly political disease, both in the United States, and world-wide, since it began to appear in 1979, until it was identified in 1984, and now in 2012. HIV continues to be a serious illness in the US. “CDC estimates that approximately 50,000 people are newly infected with HIV each year in the United States. In 2009 (the most recent year that data are available), there were an estimated 48,100 new HIV infections” (CDC, <http://www.cdc.gov/HIV/topics/surveillance/basic.htm#plwha>). Although HIV/AIDS continues to plague populations all over the country, one thing has changed. Medical research has produced miracle, life-saving medications have changed the possibilities for life and health for those who have access to treatment. According to the World Health Report from 2004, antiretroviral treatment, although it is not a cure or a vaccine, can “reverse the inexorable progress of the HIV/AIDS epidemics, offering the worst affected countries and populations, their best hope of survival.” (p.XV)

However, although Highly Active Anti-retroviral Treatment or HAART medications can be successful in increasing life span and quality of life, Many people with access to these medications struggle with taking them consistently enough to improve health outcomes. The research question for the current study is: How do HIV positive individuals, who have successfully improved medication adherence, perceive motivating factors and effective interventions.

HAART, Highly Active Anti-retroviral Treatment or HAART, the Anti Retroviral Treatment (ART) most commonly used today, was discovered in 1996. Throughout this report,

this treatment will be referred to as HAART, ART and ARV (Anti Retroviral) treatment. These all describe Highly Active Anti Retroviral Treatments most commonly used today.

(<http://www.cdc.gov/media/pressrel/aids-d1.htm>). Since that time, the medication itself has proved to be highly effective if taken 90-95% of the time (Farzadegan, Grant, Gourevitch, Buono, Schoenbaum, Arnsten, Demas, Chang, Eckholdt & Howard 2001). Complicating the fact that a high level of adherence is needed in order for HAART to prevent the replication of the HIV virus, is the fact that the HIV virus quickly becomes resistant to ARV medications, if it is taken inconsistently (Miller, Hays, 2000). While the way that HIV medications work is a medical issue, adherence is a social issue. Barbara Turner (2002) states, "...the importance of social support, mental health, and substance abuse cannot be overlooked..." (p.149). These factors play an integral role in the ability of individuals to sustain the high adherence to medication needed for HAART to be successful in treating HIV (Chesney, Morin & Sherr, 2000)). Thus adherence becomes not only a medical concern, but a social work concern.

Although, there has been a great deal of research that shows that psycho-social factors play a significant role in maintained adherence, the most effective way to assist individuals in the areas of social support, mental health etc. remains elusive. Many highly monitored studies attain good short term results. However, for many participants, these interventions fail in the long run, once the high level of support offered by the context of the study, is removed (Kalichman, Cherry, Kalichman, Amaral, White, Pope, Swetzes, Eaton, Macy & Cain, 2011).

Yet some individuals do succeed in improving their adherence to ARV medications, and live healthy lives with HIV. This study aims to explore a client-based perspective on adherence, asking the question: How and why do individuals become and remain adherent? What are their

personal narratives around adherence? How do people who are HIV+ make sense of the experience of choosing adherence over non-adherence?

According to the NASW code of ethics, social workers strive to “promote social justice and social change with and on behalf of clients.” Many studies have researched possible interventions and strived to make objective observations of and on behalf of HIV clients. However, although patient narratives are complex and difficult to weave into simple interventions, these narratives can be highly compelling in assisting other patients to succeed (Lees, 2011). This study will provide information about how and why individuals succeed, specifically with ARV adherence. This information will be valuable to health care providers, outreach workers and case managers working with at risk HIV + clients, both newly diagnosed and non-adherent , so that they may deliver more effective, supportive and lasting interventions.

CHAPTER II

Literature Review

Since the first documented cases in 1979 to the cases documented yesterday, Human Immunodeficiency Virus HIV/Acquired Immune Deficiency Syndrome (HIV/AIDS) has been and continues to be a highly politicized and stigmatized disease. HIV/AIDS also continues to be deadly and incurable. However, over the last 30 years significant strides have been made in terms of education, acceptance and medical treatment. As HIV/AIDS moves from a death sentence to a chronic but treatable illness, new issues have begun to arise for those affected by the disease, specifically medication adherence. This study explores the question: How do HIV positive individuals, who have successfully improved medication adherence, perceive motivating factors and effective interventions.

First, literature will be reviewed to show HIV/AIDS as a serious issue today and more specifically the need for Anti-Retroviral (ARV) drug adherence for HIV+ individuals. Then current research will be reviewed regarding previously identified barriers for medication adherence, particularly ARV medications. Finally, commonly used interventions for ARV medication adherence will be discussed in the context of recent studies.

Overview of HIV/AIDS

The year, 1981, is usually dated as the beginning of the HIV/AIDS epidemic. Over the course of the 14 years following 1981, 512,000 cases of HIV were reported to the CDC. Of those cases reported, 73% had died from HIV related opportunistic infection (Fan, Conner & Villarreal, 1998). In the early 1980s, HIV spread quickly and mysteriously through the gay male

community and IV drug users (Shilts, 1988). Also in the early years, 1981 the CDC published the first official notice regarding the outbreak that would later come to be known as *HIV*. This CDC report was published in the Morbidity and Mortality weekly report (MMWR). The report provided case studies of 5 gay men who, previously healthy, had become sick with *Pneumocystis carinii* pneumonia (PCP pneumonia)

(http://www.cdc.gov/mmwr/preview/mmwrhtml/june_5.htm). PCP pneumonia is usually fought off by the immune system and is generally only seen with individuals taking medications that suppress immune function, as for organ transplant, or in people who have congenital immune-deficiency disorders (Shilts, 1988). Thus, these five cases were quite alarming, especially since 2 of the patients had died in less than a 6 month period.

It was not until a year later, May 11th, 1982 that the New York Times first reported on the emerging disease. The title of this article called this disease a “new homosexual disorder” (Altman, 1982). However, by 1982, hospitals were also seeing cases among IV drug users, heterosexual women, and newborn children (Altman, 1982) (Marantz Henig, 1983).

Several incarnations of names for the disease appeared between 1981 and 1983, including Kaposi’s Sarcoma and Opportunistic Infection (KS/OI), Gay Related Immunodeficiency Syndrome (GRIDS), and “gay cancer” (Begg, 2001). Finally, in July, 1982, after a number of cases were confirmed among heterosexual Haitian immigrants, the disease was more accurately named Acquired Immunodeficiency Disorder Syndrome (AIDS), by the CDC (<http://www.advocate.com/AIDSThe30YearsWar/>).

By 1983, the disease had a name; but its exact infectious agent continued to elude doctors and epidemiologists. More and more patients fell ill and died of strange cancers and infections. In 1982, diagnosed cases had tripled. Of all individuals diagnosed, 75% of all diagnosed cases to date had died (Marantz Henig, 1983).

In the early years of the epidemic, in spite of the alarming symptoms and high mortality rate, the National Institute for Health refused to provide significant funding for AIDS research and clinics (Shilts, 1988). The Centers for Disease Control (CDC) quickly recognized this strange illness as a public health emergency and assembled a task force to investigate. However, the Reagan administration would not approve significant funds for research, palliative clinics, or public health education (Shilts, 1988). Additionally, the National Institute for Health, which is usually where most funding for research and response comes from, continued to withhold funds, even as the death count rose (New York Times editorial staff, May 13th 1983).

The stigma associated with HIV/AIDS

AIDS quickly developed a deep and painful stigma that sufferers continue to bear today. Goffman (1963) defined *stigma* as the public opinion of an attribute of an individual that falls short of general expectation. As a result, the person is considered less than a whole person by the general public. Goffman states “He [the stigmatized person] is thus reduced in our minds from a whole and usual person to a tainted, discounted one. Such an attribute is a stigma, especially when the discrediting effect is extensive; sometimes it is also called a failing, a shortcoming, a handicap.” “The word stigma then will be used to refer to an attribute that is deeply discrediting...” (p.3) Stigma is thus a reaction of the public or society which deeply affects the way that individuals associated with that stigma are perceived and interacted with socially. HIV

infection, from its first case, is and has been a condition that is highly stigmatized. This is manifested in public opinion of individuals who are HIV +. They are considered to have made poor “moral decisions” in their lives, and were responsible for their own illness. The public also showed a high level of fear towards the disease itself, causing further desire for the public to take distance from it and those who are infected (Herek, 1999). A community already in crisis became subject to rejection and isolation at a time when they needed support and compassion most. This stigma increased for HIV as the first groups suffer from AIDS were groups that were already stigmatized and isolated (i.e. IV drug users, people of color, and homosexual men) (Herek, 1999).

Stigma against individuals with HIV/AIDS continued to be high, even after there was a bulk of medical research showing that HIV and AIDS was spread through blood contact and sexual contact and could not be spread by saliva, or sweat, by tongue kissing or shaking hands. In a study published by Herek and Capitano (1999), they found that one third of the people interviewed would stop shopping at a local grocery store if they discovered that it was owned by a person with AIDS. Findings also showed that 50% of people believed that they could catch AIDS if someone who had AIDS coughed or sneezed near them. Herek and Capitano also found that 55% of individuals surveyed believed that “People with AIDS are responsible for having their illness.”(p.1135) Thus, it follows that individuals shunned by a community will have a difficult time seeking treatment and talking about their illness. Individuals who are HIV+ often experience an elevated risk for violent encounters and develop a sense of powerlessness and hopelessness, making them more vulnerable to psychological distress (Vlahov, Wientge, Moore, Flynn, Schuman, Schoenbaum & Zierler, 1998). Many individuals who are at a high risk for HIV infection are already in a marginalized group, such as women, IV drug users, gay men and lower

income individuals with less access to education. Thus, they are often already stigmatized. HIV adds another level of stigma as well as a high risk of death and serious illness (Herek, 1999; Zierler & Krieger, 1997; Latkin, Vlahov, 1998).

Thus, the development of HIV stigma in the United States grew from multiple points, from the government, from affected populations, and from less affected populations. No one wanted to associate themselves with a disease so deadly and so enigmatic (Shilts, 1998). Initially, there was a terror response within affected communities and then a denial response from national organizations and funders (such that they refused funding and downplayed the seriousness of the illness). Then, in 1983, 1984, 1985 as more and more articles were published in the New York Times and other newspapers, fear spread to the general public. However, even though medical researchers now knew that AIDS was spread by a pathogen, information was not provided to the public assisting fearful rumors to conjure up a stigma among the general public and indeed internalized by those who are at risk. Then and now, AIDS was viewed as a “gay disease” and a “Black disease” - a disease brought down as punishment. This public attitude seriously impedes individuals at highest risk, from lowering risk behaviors, getting tested, getting information, and seeking treatment (Bogart, Wagner, Galvan, Klein, 2010; Chesney & Smith, 1999; Lipinski, Braz, & Maloney, 2010).

Many studies have shown that addressing stigma is positively associated with improvement of long term health care outcomes. Thus, events and people that help to restore self-worth or value help people with HIV, disprove HIV stigma that they may feel that they have been labeled (Nguyen, Rasch, Bygbjerg, Mogensen, 2011; Stevens, Hildebrandt, 2009).

Medication Development

In 1987, Zidovudine , more widely known as AZT, was approved by the FDA. This was the first treatment that was successful in alleviating the progression of HIV and AIDS (Young , 1988). In 1995, the first *protease inhibitor anti-retroviral treatments* (ARTs) were approved by the FDA. These medications were intended for use in combination with the already existing AZT (Baker, 1995). These advances were so significantly better at treating HIV than AZT alone, that advocates were able speed up the process by which new protease inhibitors were approved by the FDA (Sondik, 1996). As a result of treatment advances, a dramatic decrease was seen in AIDS deaths between 1996 and 1999 (<http://www.kff.org/HIVaids/upload/Fact-Sheet-The-HIV-AIDS-Epidemic-in-the-United-States.pdf>). Since 1995, medical researchers have developed more successful, stronger ARV drugs. Scientists have been able to produce ARV medications with fewer side effects, available with smaller, more convenient dosing options (Clay, Taylor, Glaros, McRae, Williams, McCandless, & Oelklaus , 2008; http://aidsinfo.nih.gov/contentfiles/HIVandItsTreatment_cbrochure_en.pdf).

Current State of ARV Medication

Currently, there are a wide range of anti-retroviral medications which help to provide treatment that keeps people alive. The doses are small enough with few side effects that people can reasonably take it as prescribed. However, last year, worldwide, there were an estimated 1.8 million deaths from AIDS related opportunistic infection, compared with 1.9 million deaths in 2001. In the United States, 20,000 deaths occurred last year as compared with 19,000 deaths in 2001. So, people are still dying in large numbers from AIDS. It is important to note that although 1,000 more people died from AIDS in 2011 in the US, there are also 7.5 million more

people living with HIV than there were in 2001 (compare 34 million to 26.6 million respectively) (UN World AIDS Day Report, 2011). Additionally, in the United States hospitalization costs associated with poor medication adherence totaled approximately \$100 billion per year in 2004 (Osterberg & Blaschke, 2005). According to the 2011 UN World AIDS Day Report:

The HIV epidemic in North America and Western and Central Europe remains stubbornly steady, despite universal access to treatment, care and support and widespread awareness of the epidemic and the causes of HIV infection. HIV incidence has changed little since 2004. (p.11)

Access to Medication

In the United States, advocates have fought hard over the last 30 years for people diagnosed with HIV and AIDS to have access to ARV drug treatments (AIDS Policy Law, 2006). From 1987, when AZT first emerged onto the market, funds were first earmarked for AIDS Drug Assistance Program (ADAP). In 1990, after the death of Ryan White, the Ryan White Care Act (Ryan White HIV/AIDS Treatment Extension Act of 2009) was drafted and signed into law for the first time (<http://hab.hrsa.gov/about/hab/legislation.html>, 2012). This law has been re-drafted four times since then – in 1996 after the first protease inhibitors were approved and then again in 2000, 2006, and 2009. To date, state health care covers HIV medications at 100% for Medicaid recipients. ADAP is available to cover medications for people who are uninsured, do not qualify for Medicaid and/or are illegal immigrants (http://www.kff.org/HIVaids/upload/1584_10.pdf). A 2011 study showed that being enrolled in ADAP significantly improved chances that women in the United States would take ARV medications (Yi, Cocohoba , Cohen , Anastos , DeHovitz , Kono , Hanna, & Hessol, 2011).

In the early years of HIV/AIDS, thousands of people died because of a failure to identify and treat the disease. After AZT, people continued to die because the medications were cumbersome and the side effects debilitating (Moyle, Nelson, Hawkin, & Gazzard , 1993). When effective treatment finally emerged, people continued to die because they did not have adequate access to ARV medications. Today, in 2012, medications are available and covered by stated Medicaid and private insurance, as well as for individuals who are completely uninsured, via ADAP. Medications are numerous and side effects vastly reduced. But still, people in the United States die of AIDS, because they do not take the ARV medications.

Adherence to ARV Medications

The decision to adhere to medication is a crucial, lifesaving one for all individuals who suffer from chronic illness, whether it is diabetes or heart failure or cystic fibrosis, or HIV. And studies have shown that long term compliance with medication regimens is almost always very challenging (Christensen & Johnson, 2002). Adherence to ARV medications is complicated by the fact that if individuals do not consistently take their medications at the right time, the HIV virus will “learn” the medication, and will become resistant to that particular medication. Once the HIV virus has learned a medication and has become resistant, that medication will never again work on that virus strain (Turner, 2002).

Highly Active Anti-Retroviral Therapy or HAART, is the form of ARV treatment used to treat HIV today. This treatment combines three different medications from at least two different classes of ARV drugs. This “cocktail” interrupts the virus at several stages during its replication. Thus, the virus is kept at an “undetectable” level in the blood and prevents the virus from attacking more and more T-cells, which helps people to stay healthy and not to succumb to

opportunistic infections, or OI. Many different medications are available in each class, so that doctors can find appropriate combinations that will control the virus in their patients (Dau, Holodniy, 2009; Kolber, Campo & Dickenson, 2004; Torti, Bono, Gargiulo, Uccelli, Quiros-Roldan, Paraninfo, Tirelli, Manca, De Francesco, Perandin, & Carosi, 2004).

In order for individuals who are HIV + to be successful with HAART, they must commit to taking the medications on time, every time, as prescribed, at least 90% of the time. If they do not take the medications with at least 90% adherence, according to clinical trials, not only will the medications not work at controlling that person's HIV virus, but those medications will never work again on that patient's strain of HIV (<http://aidsinfo.nih.gov/guidelines/html/1/adult-and-adolescent-treatment-guidelines/0/>).

Fortunately, there are many classes of ARV medications and within those classes there are many different types of medications, so someone who is resistant, or becomes resistant to a medication has a much higher chance of successfully finding another regimen, than they would have had 7 years ago (<http://aidsinfo.nih.gov/contentfiles/lvguidelines/adultandadolescentgl.pdf>) (Kober et al 2004).

Barriers to Adherence

Unfortunately, there are many barriers that prevent people who are HIV+ from adhering to their ARV medications. The most common of these include socioeconomic factors, health care system related factors, condition related factors, and regimen related factors and psycho-social/patient related factors (Vervoort, Borleffs, Hoepelman & Grpdonck, 2006).

Socioeconomic factors refer to risk factors related to race, age, sexual orientation, income level and education level. Studies have shown that individuals with lower income and lower education are at much higher risk for non-adherence (Waite, Paasche-Orlow, Rintamaki, Davis & Wolf, 2007). Individuals who are homeless have a lower chance of being adherent (Vervoort et al, 2006). Research overwhelmingly links social support positively with adherence. (Haynes, McDonald & Garg, 2012) Efforts to educate a patient can also be more effective when the family and support systems are educated as well (Ostenberg & Blaschke, 2005).

Many studies link African American and Latino communities with higher risk of contracting HIV (http://www.cdc.gov/HIV/resources/factsheets/PDF/HIV_at_a_glance.pdf). However, this higher level of infection is not due to genetic susceptibility but to the complex social stigma that continues to exist in African American and Latino communities (Kaul, Cohen, Chege, Yi, Tharao, McKinnon, Remis, Anzala & Kimani, 2011; O'Leary, Jammott, Suarez-Al-Adam, Fernandez, & AlRoy, 1993; Raffaelli, Suarez-Al-Adam, 1998). As national statistics show an increase of HIV infected African American women, studies also show that these same women are less likely to seek and adhere to medical treatment (Lillie-Blanton, Stone, Snow Jones, Levi, Golub, Cohen, Hessol & Wilson, 2010; Turner, Fleishman, 2006). In addition, there are several studies that have shown that some women taking care of children report more difficulties than their male counterparts (Deschamps, Graeve, Van Wijngaerden, De Saar, Vandamme, Vaerenbergh, Ceunen, Bobbaers, Peetermans, De Vleeschouwer & De Geest, 2004; http://whqlibdoc.who.int/publications/2011/9789241502986_eng.pdf; Vervoort, Borleffs, Hoepelman, Mieke & Grypdonck, 2006)

Homosexual men continue to make up the highest percentage of HIV infected population in the US (61%) in 2009 according to the CDC data. However, worldwide, the 2009 UN AIDS report states that heterosexual contact accounted for the majority of infections in Sub Saharan Africa and Asia. Gay men may be adversely influenced by social stigma related to being gay and related to being HIV+ (Herek, 1999).

Health care system related factors refer to how the health care system responds the people who are HIV+. Studies show that one reason for non-adherence is a lack of trust in health care providers (Schilder, Kennedy, Goldstone, Ogden, Hogg & O'Shaughnessy, 2001). A number of studies have found that providers who are perceived to be caring, non-judgmental, direct, responsive and willing to take sufficient time to listen to patients had a positive relationship with long term adherence (Vervoort et al, 2006). Although positive patient-provider relationships overall encourage adherence, there are also instances where a patient fails at Anti-retroviral Therapy (ART), in spite of a long term positive relationship with her/his provider (Ammassari, Trotta, Murri, Castelli, Narciso & Noto , 2002; Mutchler, Wagner, Cowgill, McKay, Risley & Bogart, 2011).

Condition related factors refer to factors related to actually being HIV+. This includes symptoms, treatment effects and side effects, social image and feelings about disclosure of HIV status. One 2007 study found that individuals who were symptomatic with HIV symptoms, often blamed the symptoms of the illness on the ARV medications (Gonzalez, Penedo, Liabre, Duran, Antoni, Schneiderman & Horne, 2007). Findings in the same study showed a significant positive relationship with general negative mood states and negative feelings about medications with non-adherence to HAART. Another study found that positive feelings about ARV medications were

the top predictor of long term ART adherence (Parkes-Ratanshi, Leonard Bufumbo, Nyanzi-Wakholi, Levin, Grosskurth, Lalloo & Kamali, 2010). Also, providing education about how to cope with side effects does not, in and of itself, necessarily encourage adherence. However, there is evidence that individuals who are successful for 24 months and over actually seek out education about how to cope with side effects (Johnson, Dilworth, Taylor & Neilands, 2011). Additionally, people who are HIV+ frequently associate taking HAART with being HIV+ which is negatively associated with adherence (Erlen & Mellors, 1999; Powell-Cope, White, Henkelman & Turner, 2003).

Regimen related factors are factors related to HAART itself. For example, some regimens cause serious side effects which may alter the way in which a person may go about her daily activities. These side effects may decrease long-term adherence >90% (Cooper, Buick, Horne, Lamberta, Gellaitrya, Leakeb, & Fisher, 2002). HAART regimens are known for strict scheduling guidelines, large number of pills and large size of pills, which make the pill difficult to take and take on time (Abel & Painter, 2003). Also, some of the ARV medications need to be taken with food and are more effective when taken with food. If a person misses a meal, that may also mean missing a dose of medication (Vervoort, 2006). One Atlanta study linked food insufficiency with a lack HIV medication adherence in urban areas (Kalichman, Pellowski, Kalichman, Cherry, Mervi, Detorio, Caliendo & Schinazi, 2011). Another California study showed that the strongest factor in predicting non-adherence was “unmet sustenance needs,” including food, and shelter (Riley, Moore, Sorensen, Tulsy, Bangsberg, Neilands & Torsten, 2011).

Finally, *psychosocial or patient related factors* include factors that have to do with a patient's own internal self. These factors include religious beliefs, alcohol or drug consumption, behavioral styles, mental health diagnoses, angry or depressive feelings, ability to remember to take medications and to stick to a routine, and other life influences (children, work, family issues etc.). According to Ostenberg and Blaschke (2005), these issues heavily affect a person's ability to adhere to medications. In their 2005 article, they explain:

...typical reasons cited by patients...included forgetfulness (30%), other priorities (16%), decision to omit doses (11%) lack of information (9%), and emotional factors (7%). 27% of respondents did not provide a reason for poor adherence to a regimen. Physicians contribute patients' poor adherence to complex regimens, failing to explain the benefits and side effects of a medication adequately and not giving consideration to the patient's lifestyle or the cost of the medications and having poor therapeutic relationships with their clients/ (p.490)

According to this quotation, patients attribute most of their barriers to *patient related factors*. Only 9% actually cited lack of information from providers as a reason for being non-adherent. However, nearly all of the providers stated barriers had to do with factors related to health care providers and systems. In order to truly assist people who are HIV+ with being adherent to ARV medications, and ultimately living healthier lives, more attention may need to be paid to these patient related factors.

Self-Efficacy

Self-efficacy has been well linked to medication adherence, stigma and medication literacy in individuals who are HIV positive. People who believe that HIV medications will work and believe that they can do well at taking them correctly, are consistently more adherent (Glass, Sabina, Rainer, Vernazza, Rickenback, Furrer, Bernasconi, Cavassini, Hirschel, Battegay, Heiner, Bucher, 2006; Johnson, Chesney, Goldstein, Remien, Catz, Gore-Felton, Charlebois & Morin, 2006; Li, Huang, Wang, Fennie & Williams, 2011; Waite, Paasche-Orlow, Rintamaki, Davis, Wolf, 2007; Wolf, Davis, Osborn, Skripkauskas, Bennet & Makous, 2007; Colodro, Godoy-Izquierdo, Godoy, 2010). In the health care research field, there is a strong desire to place the onus of healing the sick on health education and provider patient relationship (Kalichman, Pellowski, Kalichman, Cherry, Detorio, Caliendo & Schinazi, 2011). However, an individual's own self-efficacy and belief in treatment mediates all factors related to how care is internalized (Cha, Erlen, Kimc, Sereika & Caruthers, 2008)

Wolf et al (2007) point out that overall literacy necessarily effects health literacy . Self-efficacy has been shown to mediate the application of health education and the ability to sustain behavioral change (Leganger & Kraft, 2003). Self-efficacy often predicts initiating communication with health care providers and adjusting health behaviors (Hogben, Ledsky, Middlestadt, Vandevanter, Messeri, Merzel, Bleakley, Malotte, Sionean, & St. Lawrence, 2005). It can be deduced that increasing health literacy increases self-efficacy and self-efficacy increases adherence over time.

Perceived social stigma mediates literacy and health literacy. In a 2008 study by Waite et al (2007). The effect of literacy on medication adherence was reduced nearly 40% after social

stigma concern was included” (p.1370). Stigma decreases the likelihood that health literacy efforts will succeed. In a more recent study conducted in 2010, Colodro et al state explicitly, “They [people who need to cope effectively] require self-efficacy for coping with stress.”(p.12) Findings in this same study showed that healthy people demonstrate better self-efficacy as do individuals with better self-support.

The HIV community is highly vulnerable to low self-efficacy, because of the stigma of the disease itself and because of the racial and sexual orientation based stigma already existing in these hardest hit communities. Stigma has an active and negative effect on self-efficacy. Low self-efficacy is a widely referenced mediator of adherence behaviors to ARV treatment for HIV.

Research has logically shown that events and people that create an alternative narrative to the stigmatized narrative, assist individuals in developing higher self-efficacy and improve long term ART outcomes (French, Tesoriero, Agins, 2011; Nguyen et al, 2011). Berkeley-Patton, Goggin, Liston, Bradley-Ewign, Neville (2009) conducted a study with people with HIV who had chosen to adhere to medications. They found that people who had become adherent had benefited greatly from drawing on community members and HIV+ role models. Interviewees expressed that it was important to arrive at a “new normal” for living with HIV:

All of the participants were very hopeful about their futures and had a strong desire to stay healthy. Many had overcome issues such as finding a physician they could trust, coping with HIV medications side effects, disclosing their disease to others, and seeking employment. They had developed a “new normal” for living and a strong desire to live... (Berkeley-Patton et al, 2009, p.204)

People who have experiences that help them rediscover a desire to live, and provide positive reinforcement in the ability to be successful, are key predictors for ART adherence.

There are many studies that discuss the importance of an individual's own insight and agency in deciding to make change in their lives. For example, Levitt, Frankel, Hiestand, Ware, Bretz, Kelly, McGhee, Nordtevedt & Raina (2004) explored the experience of insight, how it happens and what inspires it. They noted that insight usually comes about based on an event that arouses "pain or uncertainty." The current study proposes that individuals are catapulted into creating "healing stories," by these events. These authors also noted that the creation of healing stories is based in "identity transformation." (p.21). Levitt et al state that, "insights offer the promise of personal awareness and growth" and "an increased sense of self-reliance in client's lives." (p.22)

Narrative therapists also draw on the idea that healing stories and self-reliance are key factors in long term behavior changes. Davey, Foster, Milton and Duncan (2009) stress the value of family support because it comes from within an individual's own community. They show that patients benefit from providers who draw on family support and encourage the agency of young people in their communities (p.49). Carey, Walther & Russell (2009) discuss the importance of creating narratives that "to steer our lives in directions that work for us and that fit with what matters to us in life." (p.320). These authors express that improvements in quality of life can be predicted by "how people understand their lived experience and how they can be invited into a sense of personal agency in relation to responding to the problem situations that they encounter." (p. 320). This article suggests that by inquiring into the "absent but implicit," people can begin

to open up self-stories built on stigma and marginalization, and transform them into stories that encourage self-agency.

Thus, the current study was an attempt to explore a client based perspective by gathering narrative responses from the clients themselves about how they story their decision to adhere to HIV medications. How do they, or even do they, discuss their own self-efficacy. As providers we may use this information to help HIV+ individuals to help themselves in improving their adherence to medication and their health for the rest of their lives.

CHAPTER III

Methodology

The design for this study was qualitative and exploratory using flexible methods to gather information on how HIV positive individuals, who have successfully improved medication adherence, perceive motivating factors and effective interventions, in the process of becoming fully successful in consistent adherence to HIV medication regimens. A qualitative design was chosen because the intent was client centered, lending weight to individuals' own perceptions of their unique experience of healing. Qualitative designs allow for rich descriptions of salient interventions not previously predicted. By using this design, participants were able to share their own conclusions, based on their own perceptions and personal narratives. Data collection took the form of a short interview consisting of open ended questions (Appendix A) (Anastas, 1999). The literature review noted several general barriers to medication adherence. These barriers included HIV related stigma, lack of self-efficacy, medication regimen related issues, social system related issues, substance use, forgetfulness, side effects and complicated pill regimens. People who took part in the study also completed a brief survey with demographic questions and likert scale ratings of these predicted barriers (Appendix B) . This part of the study was designed to see how clients assess themselves against the frequently assessed barriers found in previous research and to see if they self-assess in the same categories as researchers have predicted in past studies.

Sample

Participants were selected from of Housing Works Inc. Headquarters of this agency are located at 57 Willoughby Street 2nd floor, Brooklyn, NY 10201. Housing Works Inc. “is a healing community of people living with and affected by HIV/AIDS. Our mission is to end the dual crises of homelessness and AIDS.” (www.housingworks.org) This agency is a non-profit agency located in New York City. The agency has four medical clinics in Brooklyn and Manhattan, a dental clinic and 5 sites in Brooklyn, Manhattan and The Bronx, providing targeted medical case management and advocacy to HIV+ individuals in the NYC area. Clients were recruited from case management and adult day health center sites at Housing Works. All participants were low income, Medicaid recipients. All were, at one point, non-adherent to medication and have since become adherent to ARV medications. *Adherence to medication* was defined as taking all medications and all doses as prescribed by HIV physician at least 90% of the time, or 9 days out of every 10 days. Medical adherence was also tracked by client report of undetectable HIV viral load for at least 6 months. *Non-adherence* was defined as taking HIV medications less than 90% or less than 9 days out of 10 days. Patients who are adherent and stable most likely know their viral load, as this is the tool that physicians use to monitor people infected with HIV. Clinics and case management agencies regularly provide education on CD4 and viral load meaning. If clients are adherent and aware of their health, then they will also know their HIV viral load, and they will be familiar with the vocabulary “undetectable.” All individuals who participated in the study were reasonably stable in terms of housing, mental status and medical status.

Participants were clients of any sexual orientation, race, ethnicity and gender, including transgender and intersex individuals. In order to reduce potential risk to sensitive populations, all participants were over the age of 18 and were capable of giving informed consent. Also, because the researcher is English speaking and did not have ready access to translation services, all interviewees spoke fluent English. Individuals interested in being interviewed for the study were responsible for initiating contact with the researcher if he/she was interested in participating.

Ethics and Safeguards

Risks to Participants

The risks of participating in this study were minimal. The participants may have experienced some emotional disturbance related to the re-telling of potentially emotionally laden experiences related to HIV status stigma, HIV diagnosis, life threatening illness and risk behavior. The researcher distributed a list of additional counseling and support referrals (Appendix C). This listing included low cost, sliding scales and Medicaid providers. Names, phone numbers, websites and email information was included for each provider as applicable. Participants were clearly informed of their right to withdraw from the study.

All participants were 18 years old or older and were English speaking. All participants were determined by the researcher to be relatively stable in other areas of their life, such as housing, substance use and mental health. Potential participants were given a quick screening interview over the phone so that the researcher may confirm that they were appropriate for the study (Appendix D).

Benefits to the Participants

Participants may also have benefited from being in the study. They may feel more positively about themselves because their story may help people who have HIV to take and keep taking medications that may vastly improve their health. People who were involved in the interviews may also feel a sense of success, because they have reflected on their own story of success. Respondents were also given \$20.00 cash compensation. This compensation was meant to thank participants for their time and effort towards this interview. Individuals received this compensation even if she/he did was unable to complete the interview, or if she/he ultimately decided to withdraw her/his information from the study.

Informed Consent Procedure

Individuals who contacted the researcher and were appropriate for the study, and who agreed to participate, met with the researcher in person to collect the data. Two copies of the consent form (Appendix E) were provided to the participant to be signed, one copy for the client to keep and one for the study records. The researcher reviewed the informed consent orally with all participants to ensure that they understood the confidentiality policies and procedures, scope and purpose of the study and their right to withdraw from the study. Once the client gave verbal and signed consent, the researcher proceeded with the interview and distribution of demographic survey. All participants were provided a list of counseling resources in all five New York City boroughs. Before engaging in any research related activities, the researcher reviewed these resources with all individuals in the study so that they understood how to get in touch with these resources. Data collection was begun after the receipt of the Smith College School for Social Work Human Subjects Review approval letter (Appendix F).

Confidentiality

Participants' confidentiality was and will be protected. All identifying information regarding demographic data collected or in the researcher's records was removed. Participants were not asked to state their full names on recorded interviews. Signed informed consents were not stored with the interviews and transcripts of the same individual. The researcher will remain the primary handler of all the data and transcripts. Only the primary researcher had access to identifying information linked to interviews, transcripts and demographic survey. A research advisor reviewed the data, but only after all identifying information was removed. Any quotations used in the text were appropriately disguised so that the identity of the individual would not be exposed.

The transcripts will be kept for three years in compliance with federal regulations. During this time, questionnaires and transcripts will be kept in a locked cabinet. After the three years, all material will be destroyed.

Any data reported will be presented in summary form in future publications and in presentations as a part of the entire study. If quotations were used, they were not linked to identifying information.

Participants were given the option to withdraw from the study at any time, during or after the completion of the interview without any negative consequences. They had the option to withdraw from the study until April 1, 2012. If an individual wished to withdraw, that person was given the option to contact the researcher via phone or email, and inform her that they wish to be withdrawn from the study. The researcher would have immediately omitted the participant's data from the written report and all materials related to that participant would have been destroyed in accordance to federal regulations.

Data Collection

The sample for this qualitative study was comprised of 10 Housing Works Inc. clients at any site except the Bronx site. The Bronx site was excluded to prevent a conflict of interest, as the researcher works with clients at that site. However, individuals who live in the Bronx were not excluded based on borough of residence.

The researcher contacted clinical case manager supervisors and program directors at Housing Works Cobra Programs and Job Training Program, in Brooklyn and Manhattan. The researcher explained the study verbally and then provided managers and directors with flyers (Appendix G). Program directors and other supervisory staff were asked to tack these flyers on bulletin boards, and make them readily available at front desks, flyer tables and reception areas available to client flow. All clients had equal access to flyers at all times and no one was approached independently. The researcher visited the sites personally to print and place flyers in prominent locations at Brooklyn and Manhattan offices. No client was individually asked to participate by any case manager, clinic manager or program director. Flyers were made equally available to all qualifying individuals. Clients independently and privately responded if they wished to be in the study. Their case managers and anyone else involved in client contact had no part in individual recruitment. In this way clients at the agency were made aware of the study, but not coerced to participate.

As previously stated, clients at the Bronx site were excluded because they may have had contact with the researcher in a supervisory or therapeutic context. Manhattan and Brooklyn site clients will not be acquainted with the researcher as a provider.

When a client contacted the researcher, a quick screening was conducted over the phone to be sure that the individual is appropriate for the study (Appendix D). If the potential

participant meet the selection criteria and agreed to participate, a housing works site and time were arranged.

When meeting with each participant, the investigator verbally reviewed the informed consent and referral list. Then the participant was provided with the demographic survey, requesting general demographic information such as “How do you identify your sexual orientation?” and “Do you consider yourself to be religious?” This questionnaire also included several questions with likert scale responses. These questions were related to common barriers listed in previous literature. Some of the questions were, “At any time in my life living with HIV has seemed so terrible that I didn’t take my medications because I wished it would just kill me already.” And “At any time in my life I have not trusted my doctor or been treated in a judgmental or discriminatory way and this has made it so I do/did not want to take my HIV medications as directed by my doctor.” The questions in this section were drawn from common barriers noted in the previous literature (Appendix B).

Finally, as the primary part of the study, the researcher asked a series of open-ended questions, designed to elicit the participant’s personal narrative of interventions and events (Appendix A) These questions were open ended in order to allow participants to bring up their own motivations and struggles. The goal of asking these questions was that participant narratives would illustrate transformative aspects of the participants’ experiences becoming adherent to HIV medications, and how they make sense of this experience in their lives. Some examples of the questions asked are, “Thinking back to when you first started taking your HIV medications more regularly, Was there something that happened that made you change your mind about taking medications?” and “Was there a person who helped you, kept you going or inspired you in deciding to take your HIV medications more regularly and in continuing to take the medication?”

Ultimately this kind of rich description is sought in order that providers may gain a better understanding of their clients/patients own experiences of what helped and when it was helpful.

The questions in the interview guide were self-developed by discussing the issue of non-adherence and adherence with 2 licensed clinicians in the field of HIV/AIDS, who have been in the field for at least 2 years. In these discussions, the researcher focused on the topics of how best to isolate individuals' narratives of transformation and healing. The researcher also discussed these questions with research advisor and Human Subjects Review Committee before finalizing the interview guide.

Data Analysis

This study had 3 sets of data that included: demographic information, a brief written survey with likert scale responses and narrative responses. The demographic data is presented in Table 1 of the findings section.

The Likert scale data was analyzed by viewing and separating answers into sections *agree*, *neutral* and *disagree*. The participants' names were changed to numerical codes by the researcher. The questions in the survey were numbered 1-9 in the order that they appeared on the survey completed during the study. A chart was then created with question numbers and each participant. The researcher then calculated how many people agreed with each question, and how many questions were agreed with, by each participant.

The narrative data was organized by creating one document for each question with every participant's response listed under that question. Participants' designated numerical codes from the previous section were used to keep the identity of the respondents disguised. The participant responses were listed in the same order for each question. The interview questions were formatted in bold text. This document was then printed out. The researcher used a highlighter to

mark common themes in all of the responses. Responses that stood out from the others were marked in black pen.

Then, an Excel spreadsheet was created, containing a separate chart for each interview question. In these charts common themes were listed in one column, and then which participants included this theme in their answers were listed in the next column. Another column was created for notes to include any exceptions or important demonstrative quote. In a separate notes section for each question, responses that directly contradicted or differed from the other answers were noted.

Limitations and Biases

This study had some limitations and biases. First of all the sample size (n=10) was quite small thus compromising the possibility to make generalizable conclusions. Also, all of the participants were selected from Housing Works Inc. This agency is a strong advocate of peer education and client centered services. As a result, it is likely that most of the potential participants with access to survey flyers would view peer education as a valuable service, and may not be an accurate representation of how widely effective this activity is outside of the Housing Works community. The research sample was fairly diverse in terms of sexual orientation and race. However, only male and female genders were represented, there were no transgender/gender-queer/intersex respondents in this study. Finally, the interview relied on the participant's self-report of undetectable viral load. Without obtaining blood work, there is no way to rule out false self-reports of medication adherence.

The interview questions were created independently by the researcher 1) after having reviewed relevant literature and 2) with the assistance of licensed clinicians working with individuals who are HIV+ in NYC. However, these self-developed questions were not based on

a pre-existing or previously tested standardized instrument. Thus, they may be subject to individual biases of the researcher.

Additionally, a part of qualitative research is the role of the researcher. The interviews were conducted in person. It is unavoidable that the interviewer's race, gender presentation, size and body language may have affected the responses of the participants.

CHAPTER IV

Findings

Table 1

Questions	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	TOTALS
How old are you?	58	42	34	55	41	57	45	54	47	56	Age range: 34-58
What borough do you live in?	Brooklyn	Bronx	Brooklyn	Brooklyn	Brooklyn	New Jersey	Bronx	Bronx	Brooklyn	Manhattan	Bk 5/10 50% Bx 3/10 30% Mn 1/10 10% NJ 1/10 10%
How do you identify your race?	African American/Black	White	African American	Black	White	Black	Black	Spanish	Black	Caucasian	Black 3/10 30% AA 2/10 20% White 2/10 20% Cauc 1/10 10% Spanish 1/10 10%
How do you identify your ethnicity?	African American/Black	Non-hispanic	No answer	African American	Italian	Caribbean	African American	No answer	No answer	Non-hispanic	AA 3/10 30% None 3/10 30% Non Hispanic 2/10 20% Italian 1/10 10% Caribbean 1/10 10%
How do you identify your sexual orientation?	Heterosexual	Heterosexual	Homosexual	Straight	Bisexual	Heterosexual	Gay	No answer	Straight	Gay	Heterosexual 3/10 30% Gay 2/10 20% Straight 2/10 20% Homosexual 1/10 10% Bisexual 1/10 10% None 1/10 10%
How do you identify your gender?	Male	Female	Male	Female	Female	Female	Male	Female	Female	Male	F 5/10 50% M 5/10 50%
Do you consider yourself religious?	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	yes	Yes	Y 9/10 90% N 1/10 10%
Do you belong to a particular congregation or church?	Baptist	No	No	No	Spiritual/catholic	No	Catholic/pentecostal	Catholic	Baptist	Episcopalian	No 4/10 40%
Does anyone live with you at home?	No	Yes	No	Yes	Yes	Yes	No	no	No	No	N 6/10 60% Y 4/10 40%
If yes, who lives with you?	n/a	My husband	n/a	3 daughters	My husband and my daughter	Husband	n/a	n/a	n/a	n/a	Husband – 2/4 Husband and daughter ¼ Daughter ¼
When were you diagnosed with HIV?	1984	1991	2003	1995	2000	1991	2005	1993	1989	2003	1984-2005
Do you know how you contracted HIV?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Y 9/10 N 1/10
If yes, how did you contract HIV?	IV drug use	Heterosexual sex	From my ex-boyfriend	Sex with men	Sodomized/raped by a man	Sexual contact with my partner	Sexual contact	Unprotected heterosexual sex	Sex with men	Unprotected sex	MSM 4/10 30%
											WSM 5/10 50%
											IDU 1/10 10%

* note - P1,P2,P3 etc. refer to the interview subjects who given arbitrary numbers by the researcher to protect their identities

Table 2

	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	TOTAL percents agreed, disagreed, neutral and n/a
Question1	4	4	n/a	5	5	n/a	1	2	5	1	agree: 5/10 50% disagree: 3/10 30% N/A: 20/10 20%
Question2	2	2	n/a	1	2	n/a	n/a	n/a	1	n/a	agree: 0/10 0% disagree: 5/10 50% N/A: 5/10 50%
Question3	1	2	4	4	3	n/a	5	4	1	2	agree: 4/10 40% disagree 4/10 40% N/A 1/10 10%
Question4	3	2	1	1	2	4	5	5	1	4	agree: 4/10 40% disagree: 5/10 50% N/A 1/10 10%
Question5	2	2	4	3	4	n/a	3	2	2	2	agree: 2/10 20% neutral: 2/10 20% disagree 5/10 50% N/A: 1/10 10%
Question6	2	2	2	1	2	n/a	1	2	1	1	agree: 0/10 0% disagree 9/10 90% N/A: 1/10 10%
Question7	2	2	1	5	2	n/a	4	2	5	1	agree: 3/10 30% Disagree: 6/10 60% N/A: 1/10 10%
Question8	2	2	1	5	4	n/a	2	2	5	1	agree: 3/10 30% disagree 6/10 60% N/A: 1/10 10%
Question9	1	2	4	5	4	n/a	4	2	1	1	agree: 4/10 40% disagree 5/10 50% N/A: 1/10 10%
Total # questions marked agreed	1	1	3	5	4	1	3	2	3	1	
* note - P1,P2,P3 etc. refer to the interview subjects who given arbitrary numbers by the researcher to protect their identities											
*note - Likert scale answer options were 1-5, from strongly disagree-strongly agree (See Apendix). In order to get a clearer picture from the results, answers 1&2 are considered <i>disagree</i> , answer 3 is considered <i>neutral</i> , answers 4&5 are considered agree. Not Applicable is shown as n/a											

Question Key:

1. Now or at any time in my life using drugs or alcohol has made it difficult for me to take all doses of my HIV medications as directed by my doctor.
2. Now or at one time in my life, taking care of my children or others in my home made it difficult for me to take my all my HIV medications as directed by my doctor.
3. At any time in my life, including now, I have worried about people in my life finding out about my HIV status. I worry that friends and loved ones will judge me for being HIV + and this made or makes it hard for me to take my medication every day as directed by my doctor.
4. Any time in my life, including now, My HIV medications have been a daily reminder of my HIV status and this has or does make me not want to take my HIV medications every day, as directed by my doctor.
5. At any time in my life, including now, I have disliked taking medications because I feel like they are bad for, so this has made it hard for me to take my medications every day, as directed by my doctor.
6. At any time in my life I have not trusted my doctor or been treated in a judgmental or discriminatory way and this has made it so I do/did not want to take my HIV medications as directed by my doctor.
7. At any time in my life, including now, I have been on a complicated medication cocktail and this has made it difficult for me to remember when and how to take my medications consistently.
8. At any time in my life, including now, side effects from HIV medications have seemed unbearable and have made it difficult for me to take my medications every day as directed by my doctor.

At any time in my life living with HIV has seemed so terrible that I didn't take my medications because I wished it would just kill me already.

This chapter presents the findings of this study. The findings include demographic information obtained from a written survey, nine likert scale questions based on non-adherence findings from the literature reviewed, and information gathered from an in person open ended question interview.

The likert scale ranged from one to five. One was defined as “do not agree at all,” and five was defined as “strongly agree.” These questions asked if the participant had experienced certain barriers identified by researchers in the literature. For example, “Now or any time in my life, using drugs or alcohol has made it difficult for me to take all doses of my HIV medications as directed by my doctor.”

The interview questions were designed to illicit the key factors in the experience of the participant’s decision to take the HIV medication. Respondents were asked about barriers, providers, support systems, critical events, things that were not helpful, and then how more broadly how did they make sense of their experience of taking medication and living with HIV.

First I will discuss the participant demographic findings, followed by the results of the likert scale survey. Finally, the face-to-face interviews are presented in terms of major themes that emerged.. The data will be analyzed focusing on shared themes and outlying answers.

Overall, the findings showed that a majority of individuals experience a shift in thinking from expecting to die to wanting to live. Nearly all participants were immediately able to state a specific event that happened that had them start to reconsider taking medications. Additionally, most interviewees reported that they needed to come to terms with their diagnosis of HIV, and needed to make some kind of peace with how they had contracted the virus. A majority of participants explained that coming to terms with HIV forced them to deal with other issues that had already existed in their lives prior to becoming infected with HIV.

Demographics

The demographic survey showed the following results: The age range was from 34-58 years old. Fifty-percent (n=5) of the individuals interviewed reported that they live in Brooklyn, NY. Thirty-percent (n=3) of the participants reported that they lived in the Bronx, NY, 10% lived in Manhattan and 10% lived in New Jersey.

The next question asked participants to identify their race. Forty-percent (n=3) of the participants identified their race as “black”, 20% (n=2) as “African American.” Of the interviewees, 20% identified as “white,” and 10% (n=1) identified as “Caucasian.” Finally, 10% (n=1) of the participants self- identified as “Spanish.”

The demographic survey also asked about ethnicity. Of the 10 respondents, 30% or (n=3) answered “African American,” and 30% (n=3) gave no answer to this question. Twenty percent (n=2) of the interviewees responded with “non-Hispanic.” These two participants identified their race as white/Caucasian. One person self- identified as Caribbean, and one person identified as Italian.

People were then asked to identify their sexual orientation. Thirty percent (n=3) people said “heterosexual,” 20% (n=2) respondents identified as “straight.” Twenty percent (n=2) people interviewed identified as “gay,” and one person as “homosexual.” One person gave no response and one participant identified as bisexual. All of the respondents that gave the answer “gay” or “homosexual” also identified as male. The participant that identified as “bisexual” identified as female.

The gender demographics were exactly equal parts male and female. Fifty percent (n=5) answered “M” or Male, and 50% answered “F” or Female. None of the participants identified as transgender, genderqueer or intersex.

Individuals taking the survey were next asked two questions related to their spirituality. They were asked if they considered themselves religious or spiritual and if they belonged to a particular church. Ninety- percent of respondents considered themselves to be spiritual. Only one person answered “no” to this question. Forty percent (n=4) individuals reported that they did not identify with a particular church or congregation. Thirty percent (n=3) of participants identified as Catholic, and 20% (n=2) identified themselves as Baptist. One person simply identified his church by name. I have omitted this answer to protect the privacy of this individual.

Interviewees were then asked if they lived with anyone. Sixty percent (n=6) of respondents answered that they did not live with anyone. The remaining 40% (n=4) of the respondents stated that they did live with someone. Of those four people two reported that they live with a “husband.” One person stated that she lives with her husband and her daughter and one person answered that she lives with her three daughters.

The next and last set of questions inquired about when and how individuals participating in the study had contracted HIV. Dates of diagnosis ranged from 1984 to 2005. The mean date of HIV diagnosis for the interviewees was 1995. See Table 1 for full range of dates. All 10 respondents answered the question “How did you contract HIV,” including the person who answered that she did not know how she contracted. Eighty percent (n=8) reported that they had gotten HIV via unprotected sex. One female participant specified that she had been raped and sodomized. The only heterosexual male in the study stated that he contracted HIV from IV drug use.

Likert Scale Survey

The likert scale survey consisted of nine questions. The responses will be reported as affirmative and negative. The responses “1” and “2” will be reported as negative and “4” and “5” will be reported as affirmative “3” will be reported as neutral. Participants were also given the options of N/A and no answer for all questions. Less than 50% (n=5) agreed with any one of the statements. For two of the statements, all the participants either disagreed or expressed that the statement did not apply. However, everyone taking the survey agreed with at least one of the statements, with the majority 70% (n=7) agreeing with more than one statement.

Statement 1 was “Now or at any time in my life using drugs or alcohol has made it difficult for me to take all doses of my HIV medications as directed by my doctor.” Twenty percent (n=2) of the participants circled that this statement did not apply to them. Of the remaining 8 respondents, 63% n=5 responded affirmatively, while the remaining 37% (n=3) responded negatively to this statement.

Statement 2 was “Now or at one time in my life taking care of my children or others in my life has made it difficult for me to take all doses of my HIV medication as directed by my doctor.” Most people completing the survey, 60% (n=6) answered that they did not agree with this statement. The rest of the responses 40% (n=4) were that the question did not apply.

Statement 3 was “At any time in my life, including now, I have worried about people in my life finding out about my HIV. Worrying that friends and loved ones will judge me for being HIV+ made or makes it hard to take my medications every day, as directed by my doctor.” One person stated that this statement did not apply. Out of the majority of the remaining 9 participants, 5 agreed with this statement while 4 of the participants did not agree with this statement.

Statement 4 was “At any time in my life, including now, my HIV medications have been a daily reminder of my HIV status and this has made me not want to take my HIV medications.” One male responded that he was neutral to this statement. Fifty percent (n=5) of the interviewees responded negatively. And 40% (n=4) answered affirmatively that this statement did apply.

Statement 5 was “At any time in my life, including now, I have disliked taking medications because I feel like they are bad for me, so this has made it hard to take my medications as directed by my doctor.” One participant stated that experience did not apply to her. Fifty percent (n=5) people taking the survey, disagreed with this statement. Twenty per (n=2) of them answered affirmatively and 20% stated that they were neutral.

Statement 6 was “At any time in my life I have not trusted my doctor or have been treated in a judgmental or discriminatory way and this has made it so I did not want to take my HIV medication as directed by my doctor” One participant stated that this did not apply to her and the remaining 9 people completing the survey disagreed.

Statement 7 was “At any time in my life, including now, I have been on a complicated medication cocktail, and this has made it difficult to remember when and how to take my medication consistently.” One participant circled the not applicable answer. Sixty percent (n=6) interviewees responded that they did not agree. The rest, 30% or n=3, felt that this statement applied .

Statement 8 was “At any time in my life, including now, side effects from HIV medications have seemed unbearable and have made it difficult for me to take my medications as directed by my doctor.” One person stated that this statement did not apply to her. The majority

of respondents, n=6 expressed disagreement with this statement. The rest of the respondents 30% (n=3) agreed with this statement.

Statement 9 was “At any time in my life, living with HIV has seemed so terrible that I didn’t take my medications because I wished it would just kill me already.” One person circled that this statement did not apply to her. Of the remaining respondents, the majority, n=5 did not agree, while 40% (n=4) individuals agreed .

Narrative Interview

Questions in the narrative interview section were designed to illicit responses which illustrated participants’ understanding of their own experience regarding their choice to take medication for HIV. The first three questions asked about barriers. The next four questions asked about people and events that may have helped or not helped in the process of deciding and continuing to be adherent to ARV treatment. The last two questions were more open ended. These questions were meant to put the interviewee in the role of experts on their own lives. These inquiries requested information about 1) how the individuals participating in the study have made sense of the experience of deciding to take medication and living with HIV and 2) if there were additional comments. It is of note that many participants gave layered answers to these questions. In other words, people in the study did not just give one answer or theme for each inquiry. Many noted multiple issues in each answer.

The results will be presented by describing commonalities and differences that showed up in response to each question, organized in the order they were asked. The first 3 questions about barriers will be presented first followed by each of the 4 questions about people and events. Finally, responses to the last two questions will be presented.

Barriers

The initial questions on the interview guide asked “Did you find deciding to take your medication to be a difficult thing to do?” “Why or why not?” and “What were some barriers to taking your medications? Explain.” “Why or why not” and “What were some barriers” have been combined as while reviewing the transcripts these questions are essentially asking for the same information.

Of the 10 people being interviewed, 8 answered affirmatively. Two people answered negatively, but both of them explained that the decision was difficult later in the interview. One participant, who answered negatively, identified himself as a heterosexual male, stated that he contracted HIV from IV drug use. This participant answered, “Well, now no, because I take a simple regimen...” However, later he stated, “When I first started [trying to take medications] I was using drugs at the time and it interfered with my...well, I wasn’t really worried about taking it. I was selling my medications. I was conscious of the fact that it was harmful to me, but my concern at the time was getting and using the drug. Eventually it caught up with me...”

There were several themes that came up for the subjects when they were asked about barriers. Eighty percent or 8 out of the 10 subjects reported that taking the ARV medications reminded them that they were HIV+ and this made them reluctant to take the medications. One female respondent who stated that she contracted HIV from heterosexual intercourse with a male partner, explained, “Initially...it was a little bit difficult because I did not fully accept the fact that I was positive, and so taking medication for that, it reminded me every time of the reason why I was taking it [ARV medications].” Similarly, two of these people also recalled not even believing that they were HIV+. Another woman, who also reported contracting HIV from unprotected heterosexual intercourse said, “But there were times when I didn’t believe what the

doctors were telling me because, um, I didn't want to hear the fact that I had to take medicine the rest of my life. I didn't believe at one point, that I was HIV+”

A majority of respondents also reported that feeling judged by others was a barrier - sixty percent (n=6) of the interviewees. A male participant identifying as gay who contracted HIV from sexual intercourse with his boyfriend, discussed this issue when explaining what was not helpful.

And that was what got me over that incident. But what was really most awkward, is we would be at like Thanksgiving, or Christmas, normally, I'm the one who does all the cooking., well, a bulk of the cooking, and now I've got people looking at me funny when I'm in the kitchen. Like it was just really, really, really not a pleasant feeling. Not a pleasant feeling at all. So, that was really, really terrible.

A female respondent who contracted HIV via unprotected heterosexual intercourse, stated, “You know, I ran into people who were like, you're AIDS, you're a drug addict, and threw all this stuff up in my face, and sometimes that made me think, why bother?” One additional participant, the only IV drug user did not directly state that stigma was a barrier for him. However, later in the interview he did refer to feeling stigmatized by the people who were in the HIV support groups and not wanting to be associated with them. He remembered, “...but I hadn't been ready to deal with it, I was looking outside of myself and at the transgenders and people in the residential and the harm reduction program, with using [drugs]...but they sick...I didn't want to be in groups with those people.”

Six subjects reported drug or alcohol use. All of them discussed their substance use as a barrier. For example one person stated “Um, I guess doing drugs could be considered a barrier

because...on top of doing the drugs, and being hung over the next day, and I would forget..."

Another remembered, "I was drinking and smoking crack. I first got diagnosed in prison, and I took the medications, cuz I was clean, but then back out on the street I, ya know, I relapsed, so then all that was out the window."

Half of the individuals in the study (n=5), noted that issues with the pills themselves, (i.e. size, quantity, not liking pills etc.) made it hard for them to take the ARV treatments. One woman recalled, "So I started taking medications in 1995, I believe. That was really hard because back then it was like a whole lot more pills than it is now, so I had to do the drink which was absolutely disgusting, really nasty, and like the pills were giant..." Another stated, "At first it was [hard], because I don't like taking pills, you know?" It may be meaningful to notice that all of the participants reporting this as a major barrier contracted HIV before 1995.

Forty percent (n=4) of the participants explained that they had concerns about side effects, both that they had experienced, and those that they had seen others experience. The same four people who described being apprehensive about symptoms that they saw in others, also indicated that side effects that they had experienced themselves made it difficult to commit to taking the HIV medications. One subject told the researcher,

...there was a lot of bad side effects. Like the first regimen they had me on, it contained Sustiva, so I had lots of bad dreams and, I don't know, it was just really, really, really not working for me. But eventually we got to a regimen that didn't give me a many side effects and that made it easier to take the medication

Another person recounted, "...just the way I looked [was a barrier]...the AZT, it took out my hair, it made spots and stuff on me and it gave me diarrhea, constantly..." Another man explained,

I read somewhere that when you start taking meds, you start losing body fat, so that was one of the reasons that I didn't want to take meds, cuz I didn't want to look sick. You know, I see people with like the skinny legs, or wasting or sunken features, or the small arms and the big bellies... lipodystrophy, I think it is. So I had never really had that look, so I was really reluctant for a long time [to take HIV medications].

People and events that helped

The first of this series of questions asked about an event that may have helped people to change their minds about taking ARV medications. Only one participant did not cite a specific event. She stated, "Well, I saw a lot of people dying. Some of them were friends and family. It really made me open my eyes." Of the rest of the 9 respondents, 4 people named a drop in their CD 4 count as a key motivating factor. For example, one subject replied, "The fact that I fell below 200 [CD 4 Tcell count], and I had the official AIDS diagnosis...I was mortified to have that stapled onto me." Four people also attributed certain loved ones as helping to change their minds about wanting to take HAART. Two of the interviewees reported that their decision was related to a child, one person to family in general, and one person to his partner. A woman who had been very sick and refused to take ARV medications remembered,

Well, my daughter, in like 1999, she caught cancer. Course I wasn't in a good state. My T cells was 2, my viral load was off the chart. I was like a toothpick, I wore 100 pounds, and I made up my mind, when I saw my daughter... And I figured she's dying...she was 9 years old and I looked at my little baby and...I had to make up my mind. Either I'm gonna die, or take care of my child, so I took care of my child.

The next question asked if there was any one who helped to keep participants motivated/inspired to continue to be committed to medication therapy. Three people answered that no specific person had helped. Throughout the interview, these 3 people consistently attributed their success to their own internal process and decision to keep taking the medications. Seventy percent (n=7) did state that someone had helped keep them inspired. One woman responded, "In a word, my daughter." One woman explained, "I had a partner who was positive. He's very sick now, in a nursing home now...Well, I know I need to be strong. I need to be there for him." One person immediately stated that her doctor had been helpful.

The subjects were then asked if their providers had done or said something that changed the way that subjects thought about medications, or assisted them in continuing to commit to taking the medications. None of the participants stated that it was only the doctor or provider who helped. Every one mentioned either 1) no other person or 2) way of thinking that helped them. However, all 10 participants replied that there had been a provider who had helped. Sixty percent (n=6) mentioned that a provider had been helpful because they were caring or compassionate. For example, one man explained,

Well, I used to go to _____, there were a lot of interns and every time I'd go, it'd be another doctor. But then I went to Brookdale in 1990. And the doctor there, he's a caring and sensitive doctor. And you know, he was more encouraging. You know, the first doctor that I had come in contact with, they just gave me my diagnosis, and that was that. But when I went to Brookdale, my doctor was very sensitive.

One woman smiled, remembering, "Yes, my doctor...she always celebrated my birthday. Every time, and she would bring a piece of cake to me. She really encouraged me to live. She would

just keep telling me, you have to keep taking the medication, if you want to get better.” Yet another participant told the researcher, “When you go into his [the doctor] office, his whole staff is smiling, you know, everyone is friendly and smiling...even if people are nasty outside, when you come into the office, everyone has a smile. That’s a lot.”

Just under half of the participants, (n=4) stated that going over blood work and explaining drug resistance was helpful. One woman stated, “After he [the doctor] did the blood work...he basically said, you know, he gave me a little bit of education, like, you know, you can’t really stop medication. You need to take it at the same time every day because if you don’t, you leave a window period for the virus to become resistant. That was all I needed to hear.” Another woman explained, “...but once I started going, I had this doctor, he really educated me and he helped me to learn about my lab results and what my blood work means, and that really helped me too.”

Forty percent of the subjects also expressed that having a doctor who made time to listen was a source of encouragement. For example an interviewee stated, “This doctor was just, like, he was a super expert...but he’s gay, he’s been in New York a long time, he had a manner that was just completely non-judgmental and easy to deal with. He was patient in answering my questions.”

Thirty percent (n=3) stated that they had gone to see a therapist and that had been helpful. One participant stated, “I’ve been in therapy. So that’s helping. I do therapy once a week.”

Thirty percent of the respondents also expressed that having a doctor who worked with them to find a regimen that worked helped stay committed. “Well my doctor, she pretty much, we tweaked my medication together. She really listened when I said, I don’t like this one, it

makes me feel this way. It may have been a good 2 or 3 months before we got to a place where, ok, I'm not having any side effects."

The people participating in the study were also asked to reflect on things people did or said that were directly not helpful. Initially, half of the respondents (n=5) denied that there was anything anyone did or said that was not helpful. However, all 10 of the interviewees, did end up stating that there was at least one thing that was directly counter-productive. All participants also hesitated before answering this question. Fifty percent of the interviewees noted that HIV related stigma was directly not helpful. Forty percent expressed that pre-existing shame played a role. One of the women told the researcher,

The fact that I am HIV+ is directly related to my low self-esteem., So as I built my self-esteem...the more I built my self-esteem, the more I knew I needed to take the medications. When I look back at my history growing up and at that time everything I did was as a result of my lack of self-esteem. Cuz I grew up in a culture that did not value women. I grew up in a culture that says a woman should do whatever a man says. I'm, you know, and I found myself in an abusive relationship, and that's one of the reasons I ended up being positive.

Thirty percent mentioned that the prison system or being incarcerated had made the process of continuing ongoing HIV treatment more difficult. One man remembered, "When I was locked up initially, we had to petition the court to force the bureau of prisons to test me on a regular basis...so it was more of an institutional barrier than one or two people putting me off in a negative direction."

Twenty-percent mentioned medication related barriers previously accounted for in the findings as their response to this question. For example one response was, "No, Some of the

medication was difficult to take because of the size of it, but um, no, I can't think of anything anyone did or said that made me not want to take it."

Additionally, one man who identified as gay linked trying to fit into the gay male community with risk behavior. He stated, "So this is a difficult thing I think, coming out in New York's complicated gay community, where you can easily feel isolated, you do all kinds of crazy things to belong..."

The participant's own process

The last two questions of the interview were less specific than the others. These questions asked about how the participants made sense of their diagnoses and what if any wisdom they took away from their experience living with HIV and taking medications every day.

All 10 of the participants referred to their making a choice to live to live at some point during the interview. All 10 participants referred back to that in this section. One man stated, "And I just started thinkin, I still have time to do stuff with myself, like I really do. Like I've always been able to work, I've always kept a job, I've always been really really outgoing. So, I just got to a point where I had to really get spiritual with myself and just know that this was not the end for me." Another answered, "Um, well, I definitely know, if I want to live, I have to take it (ART)."

Seventy percent, or 7 out of the 10 participants, made sense of their process by integrating how they contracted HIV and the stigma of that with choosing to live. These responses incorporated making sense of the stigma the individuals had experienced not just related to HIV, but to their mode of infection. For instance, a woman stated, "

For many years, I used drugs, I became spiritually dead. What I mean is that I didn't care, I was like, well, I'm HIV+ I'm just going to get high. I had like this

'fuck it' attitude. Um but you know I know I'm going to die, but I'm hoping that before I die, I can have a little more of this life and togetherness. I have this beautiful person inside, and I'm not just going to sit here and die.

One additional respondent linked the stigma without discussing his experience of contracting HIV. He told the interviewer, "I never really felt sick, so I hesitated in taking the meds. Once you start taking them you have to think about the fact that you are taking these medications for a reason. And it's not just like diabetes or something, it's like, for this sickness that has a stigma..."

Seventy percent of people interviewed reiterated that their family or loved ones helped them to make sense of why they should continue to live. As part of a response to the last question one person stated, "She [my doctor] had a rapport with my sister and basically got into my whole person...to make me realize that when you leave your people behind, they miss you. They love you. Like, why would you want to do that to them?" A mother responded to how she made sense of her experience by saying

I think it was a test, to see what I can do or how I can work through things. Ya know, I'm not religious or nothing, but I sit back and look, because I'm a mother of nine children. I took care of most of them myself, they father is a piece of crap, so I figured with all this stuff I have to go through dealing with the virus and all...I think it was I test...to show me that there was people that wanted me.

Of the 10 participants, 60% discussed faith or spirituality when making sense of choosing to live. A respondent explained, "I think God has a purpose for all of us and he gave me this baby girl, so that I could live. I mean, I might still be out there in the street..." Another

interviewee stated, “There’s nothing that you can feel or sense, in my case, you know, you have no symptoms, nothing that could make you or anyone else know you, other than a blood test...and by the way you have to take this handful of chemicals every day for the rest of your life, to save your life. So there’s a little bit...there’s a bit of a leap of faith in that.”

Six participants expressed that incorporating the community by sharing their experience with others, was an important part of continuing to choose to take medication. For example, the oldest respondent clarified, “So, I didn’t think I had anything to give. But then talking to people, I realize that we can all use each other’s experiences. You know, and I know that.” Also, one person shared, “I talk to other people who are positive, and I have been interviewed for a magazine and like that. My life has been hard, but I feel like I’ve learned something.”

Forty percent (n=4) of the individuals in the study shared that they still sometimes struggle with the decision to adhere to ARV treatment, but they just take the medication anyway. One woman expressed this by saying, “The fact is that I am [HIV+] and there is a reason why. Sometimes I think I know what it is, and it is exactly what I am doing with my life right now, and sometimes I’m a little bit lost, thinking, why me? Of all people in the world, why was I one of those who got infected? But it is what it is and at the end of the day, I can’t change that.”

Forty percent of respondents also mentioned valuing themselves as a pivotal part of making sense of choosing to live with HIV. One woman exemplifies this stating, “I learned to really love myself and really accept myself and , you know, I’m not really being punished by God” another reflected, “When I came to the US, I became infected here, but ironically, this is also where I learned how to value myself.”

Finally, 60% of participants spontaneously urged others to see the HIV medications as a way of living instead of evidence that they are dying. For example one person told the

researcher, “Either you want to live, or you want to die. If you don’t take the medication, then you are just waiting to die. Honestly, you are, if you take it, you are striving to live.” A woman shared her insight that,

I would like to see some of my peers go the straight and narrow. I don’t want to see them die...I wish they would just wise up, I don’t wanna see none of em fall down and die, or go through this bad experience, when we could save our lives. It ain’t the medicine that’s killing them, it’s not taking the medicine.

Summary

The findings showed that most people were negatively influenced by stigma and by pre-existing issues such as substance use, shame, and low self-esteem. The participants all made sense of their experiences by finding a way to integrate their identity of being HIV+ into their identity as being a “normal” person, who is living, instead of dying. People interviewed in this study found that their faith, connection with others who are HIV +, critical events, family (especially children and partners) and encouraging providers helped them to integrate these experiences and choose to take the ARV medications in spite of its side effects.

CHAPTER V

Discussion

This study was a qualitative, explorative study. It was designed to explore the process of choosing to take ARV medications from the perspective of people who are HIV+ and have been prescribed HAART by their doctors. The findings confirmed the barriers and strengths mentioned in the literature reviewed. As predicted, participants put a greater amount of weight onto their own decision to live and coming to terms with being HIV+, than they did on their experience of the quality of their provider. However, the findings showed people did benefit from certain approaches from their providers. These approaches matched up with those mentioned in a number of previous studies. The respondents in this interview all commented on the decision to live being integral in the ability to take ARV medications as prescribed. This particular experience was more strongly emphasized in this study than in previous literature.

This chapter is presented in three major sections. The first section is *Barriers*. This section will discuss the implications of the findings from the likert scale survey and the narrative responses related to barriers. The next section is *People and Events that Helped or Hurt*. This section explores the findings from the narrative responses regarding who helped and why, in the process of choosing to take and continuing to take ARV medications. The third section is *The Participants' Own Process*. This section will take a deeper look into the findings related to how interviewees integrated their selves that are HIV+ and their selves that want to live and be healthy.

Barriers

Five major barriers surfaced in the narrative interview. These five barriers were the same as five of the barriers listed on the likert scale survey. Those 5 barriers confirm the previous research, but there were also 2 barrier statements that the respondents did not agree with, contradicting previous research. The last of the likert scale survey statements was, “At any time in my life living with HIV has seemed so terrible that I didn’t take my medications because I wished it would just kill me already.” Forty percent of participants agreed with this on the written survey. However, a larger percentage mentioned some experience similar to this in their narrative responses. However, they addressed this issue when discussing their processes, not their barriers, so statement 9 will be discussed in the process section of the discussion.

There is a large body of research that shows that substance use is a barrier to ARV medication adherence (Ostenberg et al, 2005). The findings of this study supports and aligns with Osterberg et al’s findings. All but one participant who reported using drugs reported on the likert scale survey that their use was a barrier. Additionally in the narrative interview, all interviewees who mentioned drug use mentioned it as a barrier to being adherent.

The likert scale results showed that 40% of the participants reported feeling judged because of their HIV status, as being a barrier. In the narrative interview, 60% agreed with this statement. Both findings confirm the literature reviewed which has showed in many studies that stigma can reduce self-efficacy, which decreases likelihood of ARV therapy success (Colorado et al, 2010; Ford, 20011)

Related to the effect of stigma, the findings also corroborated the previous research, showing that the act of taking the medication itself is a reminder of being HIV +, which makes people not want to take the medication because they don’t want to associate themselves with

being HIV+. On the likert scale survey, 40% agreed, but in the narrative interview 80% reported that this was a serious barrier in choosing to take ARV medications. This barrier continued to be a theme through-out the narrative findings, with all of the participants bringing up their HIV status or the way that they contracted HIV as being something that they had needed to integrate into their identities. This confirms research that social stigma greatly effects peoples willingness to adhere to medications. (Wolff et al, 2007).

The likert scale survey and the narrative interview showed that participants found the medications themselves to be a barrier. It should be noted that participants who have been diagnosed for a longer period of time and suffered through more difficult regimens in the 1990s, were more likely to consider side effects/size/quantity of medications to be a serious deterrent from taking ART. This finding also confirms research that medications are much more accessible an easier to take then they have been in the past (Holdniy et al, 2009; Kolber et al, 2004). The findings of this study also confirmed that even as mediations have improved, taking them still presents challenges.

However, participants primarily noted having to overcome psychosocial barriers, and once they overcame those barriers, they were then able to deal with side effects and medication schedules. In other words, although issues with the medications themselves are a highly referenced issue with being fully adherent, the findings in this study show that it is not a primary barrier.

The findings contradicted the previous research in two areas (Deschamps, Graeve, Van Wijngaerden, De Saar, Vandamme, Van Vaerenbergh Ceunen, Bobbaers, Peetermans, de Vleschouwer & de Geest , 2004; Schluder et al, 2001). One likert scale statement described care taking responsibilities getting in the way of adherence. None of the participants rated this as a

barrier, and none of them discussed it in their interview, rather they discussed the opposite. They expressed that care taking responsibilities for a child or loved one kept them inspired.

Also, none of the participants agreed with the statement “At any time in my life I have not trusted my doctor or been treated in a judgmental or discriminatory way and this has made it so I do/did not want to take my HIV medications as directed by my doctor.” which contradict previous studies showing that insensitive, judgmental or non-personalized health care decreases the likelihood of adherence (Schlider et al, 2001). However, although none of the people interviewed mentioned poor provider care as a reason for non-adherence, all of the people interviewed did note that there had been a doctor or provider who did or said something that helped participants continue to be adherent. This finding confirms Marcus et al’s (2003) study showing that self-efficacy is the strongest factor in seeking health care providers and changing health related behavior. However, once self-efficacy is increased, caring providers who take sufficient time with their patients, are a critical positive support in continuing the process of staying committed to being adherent.

Two participants provided a detailed discussion of how providers did not meet their needs. Both mentioned that they felt judged and written off. However, both individuals denied that their negative experiences were direct barriers to seeking health care. Both of these individuals attributed their non-adherence at this time to their own behaviors such as using substances and feeling hopeless. The findings of this study confirm that non-caring, judgmental, rushed providers do not help, and that caring, listening providers who take time and build individual relationships with their patients do help. However, stigma, family support and self-efficacy, substance use and depression are important mediating factors. This supports a number of studies reviewed, that showed that these mediating factors may actually play a larger role in

encouraging or discouraging adherence to ARV treatment than provider quality does (Colorado et al, 2010; Berkeley-Patton, 2009; Waite et al, 2007).

People and Events that Helped or Hurt

Providers were mentioned as people who helped, as were family and HIV+ community members. A majority of participants mentioned that going to groups or seeing others who had been successful with the medication, helped them to start taking it. They explained that seeing other people like them succeed with the medications helped them see that they could do it too. Again, this confirms the importance of self-efficacy, specifically in believing that the ARV medications will work (Glass et al 2006; Li et al 2011; Wolfe et al 2007).

Not all, but a majority of participants mentioned a family member or child who kept them going. These findings confirm Hayes et al (2012) and Ostenberg et al, (2005), whose results showed that social support is positively linked with adherence. Berkeley-Patton et al (2009) also stated that social supports can help individuals to re-narrate their lives in a more positive way, directly improving their health outcomes. The respondents in this study corroborate Berkeley-Patton et al findings by relating that people and times in their lives that helped them re-assess their own self-worth and decide to fight for their lives were the most significant events and interventions. It is of value to note that for 30% of the people in this study reported that it was providers (therapists and doctors) who played a large role in assisting their patients to change their views about self-worth and help enable them to seek out their own health care and engage in healthy living behaviors. In other words, the findings of this study show that the most important shift is the shift in an individual's own way of thinking about her/his own value in the world and the community, and their own ability to succeed. These findings align with those of Li et al (2011) and Glass et al. (2006).

The Participant's Own Perspective

This study's findings showed that when respondents reflected on their own experiences, they cited access to care, caring doctors, family support as being important, but they also expressed that their own process of learning to live with HIV instead of allowing themselves to die of AIDS was integral.

In keeping with Levitt et al (2004), 90% of the participants in this study identified a specific event that inspired a change in how they perceived themselves and their value and the possibility of their survival. The events mentioned were often painful, such as a child being ill, or finding one's-self sick and incarcerated and pregnant, or being labeled with a full blown AIDS diagnosis. When reflecting upon their experiences, respondents viewed these events as forcefully causing them to re-evaluate their preconceptions and jump-start them into the construction of healing stories.

All of the interviewees in re-told the stories of their contracting HIV, or being HIV+ as stories of success and survival rather than suffering and imminent demise. This finding corroborates Carey et al (2009), Carr et al (2010) and White (2007), who noted that by locating another more efficacious story within oneself, one is able to gain not only insight, but sustain long term changes in health/mental health because agency itself has been discovered and proved correct. Participants in this study commented on how they had a change in perception and compared the post change self to the pre change self. Respondents not only named this as being key for themselves, but also encouraged other that this was the most important intervention. One woman explicitly stated,

I think the word needs to get out there, because a lot of people are in denial, they're scared, and they see these pills as death. They aren't looking at these pills as life, and they need to. They need to. I saw life. I looked at them and I saw my life. If I don't take the pills, I'm dead, and then what's my daughter going to do. Right? So, they have to be aware. You know they (the pills) represent life. They're aggravating, but they do represent life...

The findings of this study shows that people who succeed do so because they have built up a structure that supports their own self efficacy. They have found a way to retell their story. This story is then re-enforced by social supports, providers and perceivable changes in health. According to the people interviewed in this study, there are many factors that can assist with medication adherence, but long term adherence must draw one's own agency and ability to change and improve one's life. Notably, 40% of participants expressed that they still had doubts about their stories of success or health, but that they privilege the story of self-efficacy enough to "just take it anyway."

Summary

In conclusion, there are a number of factors that weigh in when examining a shift from non-adherence to adherence to ARV medications in individuals who are HIV+. Family and social support, access to care, substance use, pre-existing depression and shame, and internalization of HIV stigma all effect ART adherence. However, from a client centered perspective, it is an individual's own story of change and decision to live instead of die that is the most important in long term positive changes in health care behaviors. Providers can most support this by including community and family support, and taking sufficient time and

individual care with their patients, directly addressing dangers to health and reinforcing self-worth.

Implications for Social Work Practice

The findings of this study indicate several implications for social work practice with people who are HIV+. Some recommendations include the importance that providers (1) continue to encourage healthy behaviors and self-care, even when a client is not following these directives, (2) maintain a supportive and non-judgmental environment in clinics, (3) educate and discuss self-efficacy and self-worth with clients, (4) provide accessible peer resources in clinics (5) include family members when family social supports are present and to respect confidentiality and if family is not supportive, (5) keep supporting and encouraging clients without taking away their agency in their own recovery (6) remain active in local communities and educate not only those who are HIV+, but also the general public about the current facts about HIV. Providers can stand up against the stigmatization of people living with HIV, and continue to advocate for their rights and their safety. By helping to reduce the negative associations with HIV infections, providers may improve their client's chances of integrating being HIV+ with living, and thus improve their chances for effective ARV treatment, especially those clients at highest risk.

Recommendations for Future Research

This section will describe the limitations and biases in the study. Implications for future areas of research will also be discussed.

The major limitation in this study was time constraint and as a result, sample size. The sample size was very small (n=10). Thus, generalizability of the study cannot be assumed. Also, most of the literature reviewed was comprised of research regarding specific barriers and

interventions related to HIV adherence, in the medical field. However, the results of this study showed that while these issues are significant predictors of adherence, interviewees themselves privileged their own shift in narrative from “existing” or “dying,” to being someone who lives. More narrative therapy related studies and literature may have improved the development of the interview guide itself.

The participants were all recruited from Housing Works Inc. This agency has a strong philosophical bias towards peer education, harm reduction, and client centered philosophies. As a result, it is possible that the people who volunteered for the study were already more likely to support community empowerment and “a second chance at life,” as these are values at the agency that they were recruited from. Other individuals who were not successful at Housing Works, but were successful elsewhere, did not have a voice in this study, and were not represented. Additionally, people who contracted HIV via vertical transmission (from mother to child) were not represented, and Intra-venous drug users were under represented.

However, in spite of these limitations, this study brought up some issues worth exploring further. The most important of these may be further exploration of the question, how do providers, medical and mental health assist our clients in seeking and finding self-efficacy and agency with their HIV diagnoses. As the face of HIV shifts, both demographically and in terms of health outcomes, it is the responsibility of providers to shift as well. Additionally, how can providers working with a population that is often disenfranchised across multiple spectrums help by encouraging independence, self-efficacy and confidence, rather than dependency. People who are HIV+ live with HIV with the help of others, but also and arguably more importantly because they have found insight into the value of their own lives and that being HIV+ and living do not have to be opposing ways of being.

References

- 2011 National HIV Prevention Conference. 2011. The urgency of now: Reduce incidence. improve access. promote equity.
<http://www.2011nhpc.org/arcHIVepdf/2011%20NHPC%20Final%20Program%20Book.pdf>
- Abel E., & Painter L., (2003). Factors that influence adherence to HIV medications: Perceptions of women and health care providers. *Journal of Associated Nurses AIDS Care*, 14(4):61-9.
- Altman, L. (1982, January 19). A doctor's world. *The New York Times*. Retrieved from: <http://www.nytimes.com/1982/01/19/science/the-doctor-s-world.html?scp=5&sq=kaposi%27s%20%20sarcoma&st=nyt&pagewanted=2>.
- Altman, L. (1982, May 11). New homosexual disorder worries health officials. *The New York Times*. <http://www.nytimes.com/1982/05/11/science/new-homosexual-disorder-worries-health-officials.html?scp=10&sq=gay+cancer&st=nyt>
- Altman, L. K. (1981, July 3). Rare cancer seen in 41 homosexuals. *The New York Times*. Retrieved from <http://www.nytimes.com/1981/07/03/us/rare-cancer-seen-in-41-homosexuals.html?&pagewanted=2>.
- Anonymous (1997, Dec 26). Medicaid initiative for HIV treatments shifts to states. *AIDS Policy Law*. 12(22)1, 18-9.
- Arnsten, J. Demas, P., Grant, R., Gourevitch, M. Farzadegan, H., Howard, A. & Schoenbaum, E. (2002). Impact of active drug use on antiretroviral therapy adherence

- and viral suppression in HIV-infected drug users. *Journal of General Internal Medicine*. 17, 377-381.
- Baker R. (1995, December 5) FDA approves 3TC and saquinavir. *Food and Drug Administration. BETA*, 9
- Barclay, L. (interviewer) & Hanrahan, N. (interviewee) (2008) Advanced-practice psychiatric nurse intervention for HIV and psychotropic-medication adherence: An expert interview with Nancy P. Hanrahan PhD, RN [Interview Transcript]. Retrieved from Medscape website at www.medscape.com/viewarticle/583311_print.
- Begg, J. (2001, June 3). Word for word/nameless dread: 20 years ago, the first clues to the birth of a plague. *The New York Times*. Retrieved from: <http://www.nytimes.com/2001/06/03/weekinreview/word-for-word-nameless-dread-20-years-ago-first-clues-birth-plague.html?pagewanted=all&src=pm>
- Bell, E., Mthembu, P., O'Sullivan, S., Moody, K. (2007). Sexual and reproductive health services and HIV testing: Perspectives and experiences of women and men living with HIV and aids. *Reproductive Health Matters*. 15(29) 113-135.
- Berkley-Patton, J., Goggin, K., Liston, R., Bradley-Ewing, A. & Neville, S. (2009). Adapting effective narrative-based HIV-prevention interventions to increase minorities' engagement in HIV/AIDS. *Services.Health Communication*, , 24(3), p199-209. 10.1080/10410230902804091.
- Bogart, L. M., Wagner, G. J., Galvan, F. & Klein, D. J. (2010). Longitudinal relationships between antiretroviral treatment adherence and discrimination due to HIV-Serostatus, race, and sexual orientation among African-American men with HIV. *Annals of Behavioral Medicine*, (40)2,

- Carey, M., Walther, S. RUSSELL, S. (2009). The absent but implicit: A map to support therapeutic inquiry. *Family Process*, 48(3), 319-331.
- Carr, Alan. (2010). Thematic review of family therapy journals. *Journal of Family Therapy*, 32, 409-427.
- Cha E., Erlen J. A., Kim K. H., Sereika S. M., Caruthers D. (2008). Mediating roles of medication-taking self-efficacy and depressive symptoms on self-reported medication adherence in persons with HIV: A questionnaire survey. *International Journal of Nursing Studies*. 2008 45(8), 1175-1184.
- Chesney, M. A. & Smith, A. W. (1999) Critical delays in HIV testing and care: The potential role of stigma. *American Behavioral Scientist*, 42(7), 1162-1174.
10.1177/00027649921954822
- Chesney, M., Morin, M. & Sherr, L. (2000). Adherence to HIV combination therapy. *Social Science and Medicine*, 50, 1599-1605.
- Christensen, A. J., & Johnson, J. A. (2002). Patient adherence with medical treatment regimens: An interactive approach. *Current Directions in Psychological Science*, 11(3), 94-97.
- Clay, P. G., Taylor, T. A., Glaros, A. G., McRae, M. P., Williams, C., McCandless, D & Oelklaus M. (2008) "One pill, once daily": What clinicians need to know about Atripla™. *Therapeutics and Clinical Risk Management*. April; 4(2), 291–302.
- Colodro, D., Godoy-Izquierdo & Godoy, J. (2010). Coping self-efficacy in a community based sample of women and men from the United Kingdom: The impact of sex and health status. *Behavioral Medicine*, (36) 12-23. 10.1080/0896428090352162
- Cooper, V, Buick, D, Horne, R, Lamberta, N, Gellaitrya, G, Leakeb, H & Fisher, M (2002)

- Perceptions of HAART among gay men who declined a treatment offer: preliminary results from an interview based study. *AIDS Care*, 14 (3). pp. 319-28. ISSN 0954-0121
- Cutler, D. M. & Everett, W. (2010) Thinking outside the pillbox – medication adherence as a priority for health care reform. *New England Journal of Medicine*, 362(17), 1553-1555.
- Dau, B. & Holodniy, M. (2009). Novel targets for antiretroviral therapy: Clinical progress to date. *Drugs*, 69(1) 31-50.
- Davey, M., Foster, J., Milton, K. & Duncan, T. (2009). Collaborative approaches to increasing family support for HIV+ youth. *Family Systems and Health*, 27(1), 39-52.
- Deschamps A. E., Graeve V.D., van Wijngaerden E., De Saar V., Vandamme A.M., van Vaerenbergh K. et al (2004) Prevalence and correlates of non-adherence to antiretroviral therapy in a population of HIV patients using Medication Event Monitoring System. *AIDS Patient Care and STDs*, (18)11, 644-657
- DiMatteo, Robin, M. (2004) Variations in patients' adherence to medical recommendations: A qualitative review of 50 years of research. *Medical Care*, 42(3), 200-209.
- Falvan, F. H., Davis, E. M., Banks, D. & Bing, E. G. (2008). HIV stigma and social support among African Americans. *AIDS Patient Care and STDs*, 22(5), 423-436.
10/1089/apc.2007.0169.
- Fan H., Conner R. & Villarreal, L. (1998). *AIDS: Science and society*. Boston, MA: Jones and Bartlett.
- Fawcett, D. (November/December 2011). Reclaiming emotional wellness: The challenges of HIV and mental health. *Positively Aware Magazine*, p.38-42.
- Geetanjali, C., Lau, B., & Moore, R. D. (2006) Hazardous alcohol use: A risk factor for

- non-adherence and lack of suppression in HIV infection. *Journal of Acquired Immune Deficiency Syndrome*, 43(4), 411-417.
- Glass, T., De Geest, S., Weber, R., Vernazza, P. L., Rickenback, M., Furrer, H. et al. (2006). Correlates of self-reported nonadherence to antiretroviral therapy in HIV-infected patients. *Journal of Acquired Immune Deficiency Syndrome*, 41(3). 385-392.
- Goffman, E. (1963) *Stigma: Notes on the management of spoiled identity*. New York, NY: Simon & Schuster Inc.
- Gonzalez, J. S., Penedo, F. J., Llabre, M. M., Duran, R. E., Antoni M. H., Schneiderman, N. et al (2007). Physical symptoms, beliefs about medications, negative mood, and long-term HIV medication adherence. *Annals of Behavioral Medicine*, 34(1), 46-55.
- Gottlieb, M. S., Schanker H. M., Fan P. T., Saxon, A., Weisman, J. D., Pozalski, I. (June 5, 1981). Pneumocystis pneumonia --- Los Angeles. *MMWR Weekly*. Retrieved from http://www.cdc.gov/mmwr/preview/mmwrhtml/june_5.htm.
- Haynes, B. R., McDonald, H. P., Garg, A. X. (2002) Helping patients follow prescribed treatment: Clinical applications. *Journal of the American Medical Association*. 288(22), 2881-2883.
- Hecht, F. M., Charlebois, E. D., Zolopa, A. R., Holodniy, M., Sheiner, L., Bamberger, J. D. (2000). Adherence to protease inhibitors, HIV-1 viral load and development of drug resistance in an indigent population. *AIDS*, 14(4), 357-366.
- Herek, G. (1999) AIDS and stigma. *American Behavioral Scientist*. 42, 1106-1116.
- Herek, G., & Capitanio, J. (1999). AIDS stigma and sexual prejudice. *American Behavioral Scientist*, 42, 1130-1147.
- Hill, Z. M., Kendall, C. & Fernandez, M. (2003). Patterns of adherence to antiretrovirals:

- Why adherence has no simple measure. *AIDS Patient Care and STDs* 17(10), 519-525.
- Hinkin, C. H., Barclay, T. R., Castellon, S. A., Levine, A. J., Durvasula, R. S., Marion, S. D. et al. (2007). Drug use and medication adherence among HIV-1 infected drug individuals. *AIDS and Behavior*, 11(2), 185-194.
- Hinkin, C. H., Hardy, D. J., Mason, K. I., Castellon, S. A., Durvasula, R. S., Lam, M. N. & Stefaniaka, M. (2004, January 1). Medication adherence in HIV-infected adults: Effect of patient age, cognitive status, and substance abuse. *AIDS*. 18(Suppl 1): S19–S25.
PMC2886736 /NIHMS197575
- Hinkin, C. H., Hardy, D., Mason, K. I., Castellon, S. A., Durvasula, R. S., Lam, M. N., & Stefaniaka, M. (2004). Medication adherence in HIV-infected adults: Effect of patient age, cognitive status, and substance abuse. *AIDS*, 18(1), 19–25.
- Hogben, M., Ledsy, R. Middlestadt, S., Vandevanter, N. Messeri, P Merzel, C. Bleakley, A. Malotte, C. K., Sionean, C.K., St. Lawrence, J. (2005). Psychological mediating factors in an intervention to promote adolescent health care-seeking. *Psychology, Health & Medicine*, 10(1), 64-77.
- Johnson M. O., Dilworth S. E., Taylor J. M., Neilands T. B. (2011). Improving coping skills for self-management of treatment side effects can reduce antiretroviral medication nonadherence among people living with HIV. *Annals of Behavioral Medicine*, 41(1), 83-91.
- Johnson, M. O., Chesney, M. A., Goldstein, R. B., Remien, R. H., Catz, S., Gore-Felton, C., Charlebois, E., Morin, S. F., & The NIMH Healthy Living Project Team (Ehrhardt, A. A., P. I. NY Site). (2006). Positive provider interactions, adherence self-efficacy, and

- adherence to antiretroviral medications among HIV infected adults: A mediation model. *AIDS Patient Care and STDs*, 20, 258-268.
- Johnson, M. O., Chesney, M. A., Neilands, T. B., Dilworth, S. E., Remien, R. H., Weinhardt, L. S., Wong, F. L., Morin, S. F., & NIMH Healthy Living Project Team. (2009). Disparities in reported reasons for not initiating or stopping antiretroviral treatment among a diverse sample of persons living with HIV. *Journal of General Internal Medicine*, 24, 247-251. PMC2628985.
- Johnson, M. O., Elliott, T. R., Neilands, T. B., Morin, S. F.; Chesney, M. A. (2006). A social problem-solving model of adherence to HIV medications. *Health Psychology*, 25(3), 355-363.
- Johnson, M., Dilworth, S., Taylor, J., & Neilands, T. (2011). Improving coping skills for self-management of treatment side effects can reduce antiretroviral medication non-adherence. *Annals of Behavioral Medicine*. 10.1007/s121600109230-4
- Joint United Nations Programme on HIV/AIDS. (2011) UNAIDS World AIDS Day Report 2011. Retrieved from:
http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2011/JC2216_WorldAIDSday_report_2011_en.pdf.
- Kalichman SC, Pellowski J, Kalichman MO, Cherry C, Detorio M, Caliendo AM, Schinazi RF. (2011). Food insufficiency and medication adherence among people living with HIV/AIDS in urban and peri-urban settings. *Prevention Science*, 12(3), 324-32.
- Kalichman, S. C., Cherry, C., Kalichman, M. O., Amaral, C. M., White, D., Pope, H et al. (2011) Integrated behavioral intervention to improve HIV/AIDS treatment adherence and reduce HIV transmission. *American Journal of Public Health*, 101(3), 531-538.

- Kalichman, S.C., Kalichman, M. O., Cherry, C. Swetzes, C. Amaral, C. M., White et al (2010) Brief behavioral self-regulation counseling for HIV treatment adherence delivered by cell phone: An initial test of concept trial. *AIDS Patient Care and STDs*, 25(5), 303-310. 10.1089/apc.2010.
- Kaul, R., Cohen, C., Chege, D., Yi, T. J., Tharao, W., McKinnon, L. R., Remis, R., Anzala, O. & Kimani, J. (2011). Biological factors that may contribute to regional and racial disparities in HIV prevalence. *American Journal of Reproductive Immunology*, 65(3), 317-324.
- Kolber, M., Campo, R. E. & Dickinson, Gordon M. (2004) Development of anti-retroviral resistance of HIV-1 infected individuals on therapy: Is it inevitable? *IUBMB Life*, 56(6), 301-307. 10.1080/1521-6540400000843.
- Lapinski (2010, May 1) The down low, social stigma, and risky sexual behaviors: insights from African-American men who have sex with men. *Journal of Homosexuality*, (57) (5) 610-633.
- Latkin, C.A., Vlahov, D. (1998). Socially desirable response tendency as a correlate of accuracy of self-reported HIV serostatus for HIM seropositive injection drug users. 93(8) 1191-1197.
- Leary, K. (1994). Psychoanalytic "problems" and postmodern "solutions.", *Psychoanalytic Quarterly*, 00332828, P.433-466.
- Lees, Carolyn. (2011). Measuring the patient experience. *Nurse Researcher*, 19(1), 25-28.
- Leganger A. & Kraft P. (2003). Control constructs: Do they mediate the relation between educational attainment and health behaviour? *Journal of Health Psychology*, 8(3), 361-72.

- Leonard, A. D., Markham, C. M., Bui, T., Shegog, R. & Paul M. E. (2010). Lowering the risk of secondary HIV transmission: Insights from HIV-positive youth and health care providers. *Perspectives on Sexual and Reproductive Health*. 42(4), 110-116.
- Levitt, H., Frankel, Z., Katherine, H., Ware, K., Bretz, K., Kelly, R. et al. (2004). The transformational experience of insight: A life changing event. *Journal of Constructivist Psychology*, 17, 1-26.
- Lillie-Blanton, M., Stone, V. E., Jones, A. S., Levi, J., Golub, E. T., Cohen, M.H., Hessol, N. A., Wilson, T. E. (2010). Association of race, substance abuse, and health insurance coverage with use of highly active antiretroviral therapy among HIV-infected women, 2005. *American Journal of Public Health*, Vol. 100(8), 1493-1499.
- Marantz Henig, R. (1983, February 6). AIDS, a new disease's deadly odyssey. *The New York Times*. Retrieved from: <http://www.nytimes.com/1983/02/06/magazine/aids-a-new-disease-s-deadly-odyssey.html?scp=14&sq=gay%20cancer&st=nyt&pagewanted=1>.
- Miller, L.G. & Hays, R. D. (2000, March 1) Adherence to combination antiretroviral Therapy: Synthesis of the literature and clinical implications *AIDS Reader*, 10(3). Retrieved from: <http://www.medscape.com/viewarticle/410267>.
- Morris, M., Handcock, M. S., Miller, W. C., Cohen, M. S., Ford, C. A., Schmitz, J. L., Hobbs, M. M., Harris, K. M., & Udry J. R. (2006). Prevalence of HIV infection among young adults in the United States: Results from the ADD health study. *American Journal of Public Health*, 96(6), 1091-1097.
- Moyle G. J., Nelson M. R., Hawkins D. & Gazzard B. G. (1993). The use and toxicity of didanosine (ddI) in HIV antibody-positive individuals intolerant to zidovudine (AZT). *Quarterly Journal of Medicine*, 86(3), 155-163.

- Nguyen, N., Rasch V., Bygbjerg C., Mogensen, H., (2011) Pursuing treatment and moral worth: HIV-infected women in a northern province of Vietnam living with antiretroviral therapy. *Journal of the Association of Nurses in AIDS Care*, [corrected proof] available online September 7, 2011]. 10.1016/j.jana.2011.06.006.
- No Authors Listed. (2006) Advocacy. activists to lobby congress for HIV/AIDS program funding. *AIDS Policy Law*, 21(8) 2.
- No Authors Listed. (2011) AIDS the 30 Years War [web page]. *The Advocate* Retrieved on February 12, 2012. Retrieved from: <http://www.advocate.com/AIDSThe30YearsWar/>.
- O'Leary, A., Jammott, L. S., Suarez-Al-Adam, Fernandez, I. & AlRoy C. (1993) Women and AIDS In Matteo, S. (ED.) *American women in the 1990's: Today's critical issues*. 173-192.
- Osterberg, L. & Blaschke, T. (2005). Drug therapy: Adherence to medication. *New England Journal of Medicine*. 353(5), 487-497.
- Panel on Antiretroviral Guidelines for Adults and Adolescents. Guidelines for the use of antiretroviral agents in HIV-1 infected adults and adolescents. Department of Health and Human Services. October 14, 2011, 1-167. Available at <http://www.aidsinfo.nih.gov/ContentFiles/AdultandAdolescentGL.pdf> Retrieved on 2/25/2011
- Parkes-Ratanshi R., Bufumbo L., Nyanzi-Wakholi B., Levin J., Grosskurth H., Lalloo D. G., Kamali A. (2010) Barriers to starting ART and how they can be overcome: Individual and operational factors associated with early and late start of treatment. *Tropical Medicine & International Health*, 15(11), 1347-56. 10.1111/j.1365-3156.2010.026204-190.

- Parsons, S.K., Cruise, P. L., Davenport, W. M. & Jones, V., (2006) Religious beliefs, practices and treatment adherence among individuals with HIV in the southern United States. *AIDS Patient Care and STDs*, 20(2), 97-111.
- Raffaelli, M. & Suarez-Al-Adam, M. (1998). Reconsidering the HIV/AIDS prevention needs of Latino women in the United States faculty publications, department of psychology. Paper 84. In, *Women and AIDS: Negotiating safer practices, care, and representation*. (1998) Roth, N. L. & Fuller, L. K. (ED)., New York & London: The Haworth Press. pp. 7–41. Retrieved from:
http://digitalcommons.unl.edu/cgi/viewcontent.cgi?article=1083&context=psychfacpub&sei-redir=1&referer=http%3A%2F%2Fwww.google.com%2Furl%3Fsa%3Dt%26rct%3Dj%26q%3Dleary%25201993%2520HIV%26source%3Dweb%26cd%3D3%26ved%3D0CDYQFjAC%26url%3Dhttp%253A%252F%252Fdigitalcommons.unl.edu%252Fcgi%252Fviewcontent.cgi%253Farticle%253D1083%2526context%253Dpsychfacpub%26ei%3D2VecT7S5DaTb0QH8_ZGPDw%26usg%3DAFQjCNFD_oCWn2QVWQjq7FgtBQxwu7XuLg#search=%22leary%201993%20HIV%22.
- Riley E. D., Moore K., Sorensen J. L., Tulsy J. P., Bangsberg D. R., Neilands T. B. (2011) Basic subsistence needs and overall health among human immunodeficiency virus-infected homeless and unstably housed women. *American Journal of Epidemiology*, 174(5), 515-22.
- Roberts, K.& Mann, T., (2003) Adherence to antiretroviral medications in HIV/AIDS care: A narrative exploration of one woman’s foray into intentional non-adherence. *Health Care for Women International*, 24, 552-564.

- Sankar, A., Luborsky, M., Schuman, P. & Roberts, G. (2002). Adherence discourse among African American women taking HAART. *AIDS Care*, 14(2), 203-218.
- Schilder A. J., Kennedy C., Goldstone I. L., Ogden R. D., Hogg R. S., O'Shaughnessy M. V. (2001). "Being dealt with as a whole person." Care seeking and adherence: The benefits of culturally competent care. *Social Science Medicine*, 52(11), 1643-59.
- Schmiege, S. J., Levin, M., Broaddaus, M. R. & Bryan, A. D. (2009). Randomized trial of group interventions to reduce HIV/STD risk and change theoretical mediators among detained adolescents. *Journal of Consulting and Clinical Psychology*, 77(1), 38-50.
- Shilts, R. (1988). *And the band played on: Politics, people and the AIDS epidemic*. New York, NY: St. Martin's Green.
- Simon V., Ho, D. D., & Karim, Q. A. (2006) HIV/AIDS epidemiology, pathogenesis, prevention, and treatment. *The Lancet*, 368(9534), 489–504. 10.1016/S0140-6736(06)69157-5.
- Sondik, Edward.(1996, July/August). US Public Health Report 1996. *Public Health Reports*. 3, 289-297.
- Stone, V. E., Clarke, J., Lovell, J., Steger, K., Hirschorn, L. R., Boswell, S. et al. (1998). HIV/AIDS patient's perspectives on adhering to regimens containing protease inhibitors. *Journal of General Internal Medicine*, 13, 583-593.
- The 2011 National HIV Prevention Conference: The urgency of now. August 14-17, 2011.
Retrieved from:
<http://www.2011nhpc.org/arcHIVepdf/2011%20NHPC%20Final%20Program%20Book.pdf>
- The AIDS Education & Training Centers National Resource Center, (January 2011). CD4

- and viral load monitoring: Guide for HIV/AIDS clinical care, HRSA HIV/AIDS bureau.
Retrieved from: http://www.aids-ed.org/aidsetc?page=cg-206_cd4_monitoring.
- The Centers for Disease Control and Prevention. (1996, February). HIV/AIDS trends provide evidence of success in HIV prevention and treatment AIDS deaths decline for first time [press release]. Retrieved from: <http://www.cdc.gov/media/pressrel/aids-d1.htm>
- The Centers for Disease Control and Prevention. (2011). HIV and AIDS basic statistics.
Retrieved from <http://www.cdc.gov/HIV/topics/surveillance/basic.htm#plwha>.
- The Centers for Disease Control and Prevention. Cytomegalovirus (CMV) and congenital CMV Infection. (July 28, 2010). Retrieved from
<http://www.cdc.gov/cmV/transmission.html>.
- The Henry J. Kaiser Foundation. (2001, June). The HIV epidemic in The United States. *AIDS at 20*, Publication #3029. Retrieved from <http://www.kff.org/HIVaids/upload/Fact-Sheet-The-HIV-AIDS-Epidemic-in-the-United-States.pdf>.
- The Henry J. Kaiser Foundation. (2006, October) HIV/AIDS policy fact sheet,
<http://www.kff.org/HIVaids/upload/7172-03.pdf>
- The Henry J. Kaiser Foundation. (2009, April). HIV/AIDS policy fact sheet. Retrieved from http://www.kff.org/HIVaids/upload/1584_10.pdf.
- The New York Times Editorial Staff. (1992, July 28). C.D.C. Is embarrassed by its tardy response to AIDS-like illness [from A Doctor's World]. *New York Times*. Retrieved from: <http://www.nytimes.com/1992/07/28/health/the-doctor-s-world-cdc-is-embarrassed-by-its-tardy-response-to-aids-like-illness.html?scp=35&sq=gay%20cancer&st=nyt&pagewanted=2>.
- The World Health Organization. The world health report 2004: Changing history.

Retrieved from: http://www.who.int/whr/2004/en/report04_en.pdf.

- Torti, C., Bono, L., Gargiulo, F., Uccelli, M. C., Quiros-Roldan, E., Patroni, A., Parainfo, G., Tirelli, V., Manca, N., De Francesco, M. A., Perandin, F., Carosi, G. (2004). Prevalence of drug resistance and newly recognized treatment-related substitutions in the HIV-1 reverse transcriptase and protease genes from HIV-positive patients naïve for anti-retrovirals. *Clinical Microbiology & Infection*, 10(9), 826-830. 10.1111/j.1469-0691.2004.00938.
- Turner, B. Fleishman, J. (2006) Effect of dysthymia on receipt of HAART by minority HIV-infected women. *JGIM: Journal of General Internal Medicine*, 21(12), 1235-1241.
- Turner, B. J. (2002). Adherence to antiretroviral therapy by human immunodeficiency virus-infected patients. *The Journal of Infectious Diseases*, 185(2), S143-S151.
- U.S Department of Health and Human Services (HHS), Health Resources and Services Administration HIV/AIDS Programs (HRSA). About the Ryan White HIV/AIDS legislation: Legislation. Retrieved 2012, April 28. Retrieved from: <http://hab.hrsa.gov/abouthab/legislation.html>
- U.S. Department of Health and Human Services (HHS) Panel on antiretro-viral guidelines for adults and adolescents. 2011, October 14. Guidelines for the use of antiretroviral agents in HIV-1-infected adults and adolescents. Retrieved from: <http://aidsinfo.nih.gov/guidelines/html/1/adult-and-adolescent-treatment-guidelines/0/>
- U.S. Department of Health and Human Services (HHS) Panel on Antiretro-viral Guidelines for Adults and Adolescents. (2011) *AIDS info: Fact sheet*. http://aidsinfo.nih.gov/contentfiles/HIVandItsTreatment_cbrochure_en.pdf

- Uhlmann, S., Milloy, M., Kerr, T., Zhang, R., Guillemi, S., Marsh, D., et al. (2010).
Methadone maintenance therapy promotes initiation of antiretroviral therapy among
injection drug users. *Addiction*, 105, 907-913.
- Vervoort, S., Borleffs, J., Hoepelman, A. & Grypdonck, M. (2006). Adherence in
antiretroviral therapy for HIV: A review of qualitative studies. *AIDS*, 21(3), 271-281.
- Vlahov, D., Wientge, D., Moore, J., Flynn, F., Schuman, P., Schoenbaum, E. et al. (1998).
Violence among women with or at risk for HIV infection. *AIDS and Behavior* (2)1, 53-
60.
- Waite, K. R., Paasche-Orlow, M., Rintamaki, L. S., Davis, T. C. & Wolf, M. S. (2007)
Literacy, social stigma and HIV medication adherence. *Journal of General Internal
Medicine*, 23(9), 1367-1372.
- Wallston, K. A., Osborn, C. Y., Wagner, L. J. & Hilker, K. A. (2011) The perceived medical
condition self-management scale applied to persons with HIV/AIDs. *Journal of Health
and Psychology*. 16, 109-115. 10.1177/1359105310367832.
- White, Michael. (2007). *Maps of narrative practice*. New York: W.W. Norton
- Wolf, M. S., Davis, T. C., Osborn, C. Y., Skripkauskas, S., Bennet, C. L. & Makoul, G.
(2006). Literacy self efficacy and HIV medication adherence. *Patient Education and
Counseling*, 65, 253-260. 10.1016/j.pec.2006.08/006.
- Woodward E. N., Pantalone D. W. The role of social support and negative affect in
medication adherence for HIV-infected men who have sex with men. *Journal of the
Association of Nurses in AIDS care*, Available online 29 December 2011, ISSN 1055-
3290, 10.1016/j.jana.2011.09.004.
- Woodward E. N., Pantalone D. W. (2011 Dec 29). The role of social support and negative

affect in medication adherence for HIV-infected men who have sex with men. *J Assoc Nurses AIDS Care*. Elsevier Inc. 22209470.

World Health Organization. (2011). Global HIV/AIDS response: Epidemic update and health sector progress towards universal access: Progress report 2011. Retrieved from: http://whqlibdoc.who.int/publications/2011/9789241502986_eng.pdf.

Xianhong Li, Ling Huang, Honghong Wang, Kristopher P. Fennie, Guoping He, & Ann B. Williams. (2011). Stigma mediates the relationship between self-efficacy, medication adherence, and quality of life among people living with HIV/AIDS in China. *AIDS Patient Care and STDs*, 25(11): 665-671. doi:10.1089/apc.2011.0174.

Yi T., Cocohoba J., Cohen M., Anastos K., DeHovitz J. A., Kono N., Hanna D. B., Hessol N. A. (2011). The impact of the AIDS Drug Assistance Program (ADAP) on use of highly active antiretroviral and antihypertensive therapy among HIV-infected women. *Journal of Acquired Immune Deficiency Syndrome*, 56(3), 253-262.

Young F. E. (1988). The role of the FDA in the effort against AIDS. *Public Health Reports*, 103(3), 242-245.

Zierler, S. & Krieger, N. (1997). Reframing women's risk: Social inequalities and HIV infection. *Annual Review of Public Health*, 18, 401-436.

Appendix A

Semi-Structured Interview Protocol

Did you find deciding to take your HIV medication to be a hard thing to do? Why or why not? What were some barriers to taking your medications? Explain.

Thinking back to when you first started taking your HIV medications more regularly, Was there something that happened that made you change your mind about taking medications?

Was there a person who helped you, kept you going or inspired you in deciding to take your HIV medications more regularly and in continuing to take the medication?

Was there a provider or providers who did or said something that made you think differently about taking HIV medications? What was it and why did it make you think differently?

Was there something anyone did or said that was directly not helpful in this process? What and why?

Tell me a little about your own way of thinking and how you make sense of your experience living with HIV/AIDS and choosing to take ART.

I think you are really the expert on what it is like to live with HIV, both feeling sick and feeling healthy. Is there anything else you want to share with me, about what you think is truly important/transformational about the experience of choosing to take HIV medicine?

Appendix B

Demographic Questionnaire

How old are you?
What borough do you live in?
How do you identify your race?
How do you identify your ethnicity?
How do you identify your sexual orientation?
How do you identify your gender?
Do you consider yourself religious?
Do you belong to a particular congregation or church?
If so, which one?
Does anyone live with you at home?
If yes, who lives with you?

When were you diagnosed with HIV?
Do you know how you contracted HIV?
If yes, how did you contract HIV?

THE FOLLOWING ARE QUESTIONS ABOUT POSSIBLE BARRIERS THAT MAY HAVE EFFECTED YOUR ABILITY TO TAKE ALL YOUR HIV MEDICATIONS AS DIRECTED. PLEASE CIRCLE A NUMBER THAT BEST DESCRIBES HOW TRUE EACH STATEMENT IS FOR YOU. IF THEY DO NOT APPLY TO YOU AT ALL, CIRCLE "N/A"
IT IS POSSIBLE THAT ALL OR NONE OF THESE STATEMENTS MAY APPLY TO YOU. THE INFORMATION GATHERED FROM YOUR ANSWERS WILL BE USED TO HELP THE STUDY TO BE MORE ACCURATE.
IF FOR ANY REASON, YOU DO NOT WANT TO ANSWER THESE QUESTIONS SIMPLY CIRCLE "NO ANSWER"

Now or at any time in my life using drugs or alcohol has made it difficult for me to take all doses of my HIV medications as directed by my doctor.

1	2	3	4	5	N/A	no answer
Strongly disagree	disagree	neutral	agree	strongly agree		

Now or at one time in my life, taking care of my children or others in my home made it difficult for me to take my all my HIV medications as directed by my doctor.

1	2	3	4	5	N/A	no answer
Strongly disagree	disagree	neutral	agree	strongly agree		

At any time in my life, including now, I have worried about people in my life finding out about my HIV status. I worry that friends and loved ones will judge me for being HIV + and this made or makes it hard for me to take my medication every day as directed by my doctor.

1	2	3	4	5	N/A	no answer
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Strongly disagree disagree neutral agree strongly agree

Any any time in my life, including now, My HIV medications have been a daily reminder of my HIV status and this has or does make me not want to take my HIV medications every day, as directed by my doctor.

1 2 3 4 5 N/A no answer

Strongly disagree disagree neutral agree strongly agree

At any time in my life, including now, I have disliked taking medications because I feel like they are bad for, so this has made it hard for me to take my medications every day, as directed by my doctor.

1 2 3 4 5 N/A no answer

Strongly disagree disagree neutral agree strongly agree

At any time in my life I have not trusted my doctor or been treated in a judgmental or discriminatory way and this has made it so I do/did not want to take my HIV medications as directed by my doctor.

1 2 3 4 5 N/A no answer

Strongly disagree disagree neutral agree strongly agree

At any time in my life, including now, I have been on a complicated medication cocktail and this has made it difficult for me to remember when and how to take my medications consistently.

1 2 3 4 5 N/A no answer

Strongly disagree disagree neutral agree strongly agree

At any time in my life, including now, side effects from HIV medications have seemed unbearable and have made it difficult for me to take my medications every day as directed by my doctor.

1 2 3 4 5 N/A no answer

Strongly disagree disagree neutral agree strongly agree

At any time in my life living with HIV has seemed so terrible that I didn't take my medications because I wished it would just kill me already.

1 2 3 4 5 N/A no answer

Strongly disagree disagree neutral agree strongly agree

Appendix C

Resource List

Bay Ridge Counseling Center

9435 Ridge Blvd.
Brooklyn, NY 11209

Director: Pamela Lotenberg, Ph.D.,
LCSW
Phone: (718) 238-6444
Fax: (718) 238-5165

Boro Park Counseling Center

1273 53rd Street
Brooklyn, NY 11219

Director: Faye Wilbur
Phone: (718) 435-5700
Fax: (718) 854-5495

Bronx REAL Counseling Center

55 Westchester Square
Bronx, NY 10461

Director: Rebecca Wulf, LCSW
Phone: (718) 931-4045
Fax: (718) 828-1329

Dr . Eugene D. Glynn/YCL Counseling Center

549 West 180th Street
New York, NY 10033

Director: Alicia Montero, LCSW-R
Phone: (212) 795-9888
Fax: (212) 795-9899

Gay, Lesbian, Bi-Sexual,
Transgendered and Questioning
Counseling Unit
135 West 50th Street

New York, NY 10020

Director: David Ferguson, LCSW
(Administrative Supervisor)
Phone: (212) 632-4482
Fax: (212) 632-4495

**J.W. Beatman Community
Counseling Center - Riverdale
Office**

521 West 239th Street
Bronx, NY 10463

Director: Karen L. Cwalinski, LCSW
Phone: (718) 601-2280
Fax: (718) 601-2281

**Kaplan Center for Community
Services, Rita J. and Stanley H.,
Mid-Brooklyn Office**

2020 Coney Island Avenue
Brooklyn, NY 11223

Director: Inna V. Litrovnik, Ph.D.,
LCSW
Phone: (718) 676-4210
Fax: (718) 676-4216

**On-Site Counseling at JCC in
Manhattan**

334 Amsterdam Avenue
New York, NY 10019

Director: Gloria Zicht, LCSW
Phone: (646) 505-4488

**On-Site Counseling at Washington
Heights-Inwood YM**

54 Nagle Avenue
New York, NY 10040

Director: Alicia Montero, LCSW-R
Phone: (212) 795-9888
Fax: (212) 795-9899

Pride of Judea Counseling Center

243-02 Northern Boulevard
Douglaston, NY 11362

Director: Heath Bloch, LCSW
Phone: (718) 423-6200
Fax: (718) 423-9762

**The Doris L. Rosenberg Counseling
Center/Southern Brooklyn Office**

333 Avenue X
Brooklyn, NY 11223

Director: Jeffrey Coyle, LCSW-R
Phone: (718) 339-5300
Fax: (718) 339-9082

**The Harry Blumenfeld Counseling
Center - Pelham Office**

750 Astor Avenue
Bronx, NY 10467

Director: Julie List, LCSW
Phone: (718) 882-5000
Fax: (718) 798-7633

**The Morris Black Community
Counseling Center**

2795 Richmond Avenue
Staten Island, NY 10314

Director: Valerie Mitchell-Fadil,
LCSW-R
Phone: (718) 761-9800
Fax: (718) 370-1142

Post-Graduate Center Center for Adult Psychotherapy

71 West 23rd St., 7th Floor
New York, NY 10010
212-576-4195
<http://www.pgcmh.org/>

Westside Clinic

344 West 36th St.

New York, NY 10018
212-560-6767

Brooklyn Resource Center - Counseling Center

938 Kings Highway
New York, NY 11223
718.998.3235 Ext. 314
FAX: 718.336.3040
www.fegs.org

F·E·G·S Clinic at Riverdale Manor

6355 Broadway
New York, NY 10471
718.796.4424 Ext. 219
FAX: 718.796.4138

The Harry and Jeanette Weinberg Health Related and Human Services Center

80 Vandam Street, 2nd Floor
New York, NY 10013
212.366.0066
TTY: 212.366.0066
FAX: 212.366.0050

The Harry and Jeanette Weinberg Mental Health Center

3600 Jerome Avenue
New York, NY 10467
718.881.7600 Ext. 405
FAX: 718.515.8057

The Honorable Caroline K. Simon Counseling Center · Brooklyn

Sandra P. and Frederick P. Rose Center
199 Jay Street
New York, NY 11201

The Honorable Caroline K. Simon Counseling Center · Rego Park

The Honorable Caroline K. Simon Counseling Center · Rego Park
97-45 Queens Boulevard
New York, NY 11374

Callen Lord Community Health Center

<http://www.callen-lorde.org/>
356 West 18th Street
New York, NY 10011
212-271-7206

Columbia University Center for Psychoanalytic Training

<http://www.pschoanalysis.columbia.edu/patients>

1051 Riverside Dr.

New York, NY

Holly Schneier, MD

212-927-5000

Brooklyn Center For Psychotherapy

<http://www.newdirectionsbrooklyn.com/mental-health/>

300 Flatbush Avenue

Brooklyn, NY 11217

Phone: (718) 622-2000

Fax: (718) 398-3328

Interfaith Medical Center, Inc.

Interfaith Adult Clinic

1475 Fulton Street

Brooklyn, NY 11216

Tel: (718) 613-7288

Interfaith Medical Center Mental Health Clinic

1545 Atlantic Avenue 3rd Floor

Brooklyn, NY 11213

Tel: (718) 613-4495

NYC-HHC Coney Island Hospital

Coney Island Hospital Child and Adult Outpatient Clinic Program

2601 Ocean Parkway

Brooklyn, NY 11235

Tel: (718) 616-5316

The Institute for Family Health

River Avenue Center

50-98 East 168th Street

Bronx, NY 10452

Tel: (718) 293-3900

Montefiore North Division Mental Health Clinic

4401 Bronx Boulevard

Bronx, NY 10466

Tel: (718) 304-7023

Bronx Psychiatric Center

Ginsburg Clinic

1500 Waters Place Ginsberg Building

Bronx, NY 10461 Tel: (718) 862-4574

Appendix D

Pre-screening Questions

Are you HIV+?

Are you currently prescribed anti-retroviral (ARV) medication for your HIV?

If so, are you taking your HIV medications as prescribed, every day?

Have you been taking these medications as prescribed, every day, for at least 6 months?

What is your HIV viral load?

Are you over 18?

Do you speak English fluently?

Appendix E

Informed Consent

September 20, 2011

Dear Possible Participant,

My name is Mariah Twigg. I am a clinical case manager at Housing Works. I am also a post residency graduate student at Smith College School for Social Work. I am doing a study on people who have been diagnosed with HIV. The study will look at people who have at one time not taken medications for their HIV as directed by their doctor at least 9 days out of every 10 days, but who are now taking their medications at least every 9/10 days, or 90% of the time. People in the study will also have maintained an undetectable viral load for at least 6 months.

In the study I will explore the following areas:

- How people identify their barriers to taking medications most of the time.
- Important ideas, people and events that have helped people decide to start and continue to take HIV medications consistently
- Beliefs about the ability to succeed at taking HIV medications regularly
- How those beliefs may (or may not) have changed over the course of life, while living with HIV/AIDS

Data obtained in this study will be used for Masters level thesis and possible future presentations and publications.

You are being asked to be in this study because you: are HIV+ and:

- Are taking your HIV medications at least 90% of the time meaning that you are taking all doses as directed by your doctor, at least 9 days out of every 10 days. This means you are only missing a day of taking medication 3 days out of the every month or less.
- You have had an undetectable (<78) HIV viral load for at least 6 months.
- You are over the age of 18 and speak English fluently.
- It is also important that you are doing well right now and are not in the midst of housing, mental health or family related crisis. I want you to be feeling pretty stable in your life right now because I do not want to put more stress on anyone already who is already in crisis.

All interviews will be about 1 hour long. Interviews will be recorded with a digital audio recorder.

Participation in this study may cause you to remember some difficult times and experiences. Some of the questions may remind you of things that are not pleasant to think about. In case you need to talk more about some feelings that may have come up during the study, I will provide you with a list of local counselors and community center resources. You may also gain good

things by being in this study. First of all, you will know that your story of healing may help others. Your story may help people who have HIV and their doctors, case managers and social workers to understand what helps to take and keep taking HIV medications. You may also feel a sense of success, because you have improved your own health, in spite of challenging barriers. You will also be given \$20 cash. This compensation is meant to thank you for your time and effort towards this interview. You will receive these items even if you feel that you cannot complete the interview, or if you decide later that you do not want your information in the study. Your participation in this study is confidential and voluntary. This means that I will not use your real name (first or last) in my writing of the final report. I will also disguise any other identifying information. No one except for me, possibly a transcriptionist and my research advisor will see any of the interview data before your identifying information is disguised. I will follow federal guidelines to keep your information safe. This means I will lock all written material and audio tapes in a secure place for three years. At the end of three years, all interview recordings and transcripts will be destroyed.

You may refuse to answer any of the interview questions. Also, even after you do the interview, you may still decide that you do not want your information to be in the study. There will be no penalty for removing your information from the study. You must simply state in writing that you no longer want to participate before April 1, 2012 – the date when the final results will be written.

If you have any questions, you may contact me at [REDACTED] or [REDACTED].

If you have any concerns about your rights related to this study, you may also contact the Smith College School for Social Work Human Subjects Review Committee chair at (413) 585-7974.

Please keep a copy of this form for your own records.

YOUR SIGNATURE INDICATES THAT YOU HAVE READ AND UNDERSTAND THE ABOVE INFORMATION AND THAT YOU HAVE HAD THE OPPORTUNITY TO ASK QUESTIONS ABOUT THE STUDY, YOUR PARTICIPATION, AND YOUR RIGHTS AND THAT YOU AGREE TO PARTICIPATE IN THE STUDY.

Participant's Signature: _____ Date: _____

Researcher's Signature: _____ Date: _____

Appendix F



School for Social Work
Smith College
Northampton, Massachusetts 01063
T (413) 585-7950 F (413) 585-7994

December 7, 2011

Mariah Twigg

Dear Mariah,

I have reviewed your revisions and proposal and they are now approved.

Please note the following requirements:

Consent Forms: All subjects should be given a copy of the consent form.

Maintaining Data: You must retain all data and other documents for at least three (3) years past completion of the research activity.

In addition, these requirements may also be applicable:

Amendments: If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

Renewal: You are required to apply for renewal of approval every year for as long as the study is active.

Completion: You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished).

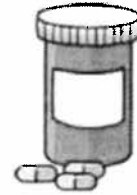
Sincerely,

A handwritten signature in black ink, appearing to read 'David L. Burton', with a long horizontal line extending from the end of the signature.

David L. Burton, M.S.W., Ph.D.
Chair, Human Subjects Review Committee

CC: Jean LaTerz, Research Advisor

ATTENTION!



Are you HIV+?
Do you take HIV medications every day?
Is your viral load undetectable (<78)?

You may be eligible to participate in a study about why people choose to take HIV medications. The interview will be conducted in person and will be about 45 minutes long.

If you are interested in participating in this study, please contact me for more information:



or



\$20 CASH FOR PARTICIPATION!